The Cusp of Capacity

Empowering and protecting people in decisions about treatment and care

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Abstract

The law's cliff-edge approach to mental capacity denies those who lack capacity any right to determine what will happen to them. Consequently, the test for capacity (contained in section 3 of the Mental Capacity Act 2005) must accurately distinguish between those who can and cannot make autonomous decisions.

However, the test relies on too narrow a conception of autonomy, preventing it from capturing impairments in the content of the person's beliefs or values, rather than their decision-making processes. Moreover, whether a decision is autonomous is rarely as clear-cut as the threshold approach presupposes, and there is substantial ambiguity on the cusp of capacity, exacerbated by the realities of assessing capacity in practice. Faced with this uncertainty, decision-makers have sought to manipulate the test through straining the 'use or weigh' criterion in section 3, and more readily rebutting the presumption of capacity where the person wishes to do something that will harm them. This thesis therefore advocates introducing a new authenticity limb to the test that asks whether the person's values or beliefs are the product of an illness or disorder, as well as greater guidance to enhance the consistency with which the test is applied.

Even so, as no test can infallibly distinguish autonomous from non-autonomous decisions, the law's cliff-edge approach needs softening. To address concerns that the best interests provisions currently facilitate risk aversion and paternalism, a new framework is proposed to encourage decision-makers to prioritise the wishes of the individual, through a rebuttable presumption that their wishes be determinative of their best interests *unless* giving effect to them would expose the person to a serious risk of significant harm. If this is rebutted, the weight accorded to the person's wishes ought to be proportionate to the strength of those wishes when determining what is in their best interests.

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Table of Contents

Table of Cases

Case Law from England and Wales

Re SA (vulnerable adult with capacity: marriage) [2006] 1 FLR 867.	31, 77
Re MM (an adult) [2007] EWHC 2003 (Fam)	157
Re S and S (Protected Persons) [2009] WTLR 315.	118
Re P [2009] EWHC 163 (Ch)	118-119
Re M (Statutory Will), ITW v Z and Others [2009] EWHC 2525 (Fam).	29, 116, 119-120, 270
G v E [2010] EWHC 621 (Fam)	147
A Local Authority v A [2010] EWHC 1549 (Fam).	96-97
VAC v JAD and Others [2010] EWHC 2159 (Ch)	120
PH v A Local Authority and Others [2011] EWHC 1704 (Fam).	107
W v M and others [2011] EWHC 2443 (Fam)	127-128
Hillingdon LBC v Neary [2011] EWHC 1377 (COP)	147, 253, 278
Re D [2012] EWHC 885 (COP)	266-267
DL v A Local Authority [2012] EWCA 253	30
Re SA (vulnerable adult with capacity: marriage) [2012] EWCA 253	31, 77
ZH v Commissioner of Police for the Metropolis [2012] EWHC 604 (QB)	288
A Local Authority v E [2012] EWCOP 1639 (COP).	28, 69, 72, 136-140, 153, 170, 176, 184, 187, 199-200, 204, 206, 243, 259, 268, 278
XCC v AA and others [2012] EWHC 2183 (COP).	31-32
Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67	26, 120-122, 125, 127, 129-133, 135, 140
PC & NC v City of York Council [2013] EWCA 478 (Civ).	195
Re SB (A patient; capacity to consent to termination) [2013] EWHC 1417 (COP)	92, 98, 205-209, 216
Re M (Best Interests: Deprivation of Liberty) [2013] EWHC 3456 (COP), [2013] MHLO 97.	122-123
An NHS Trust v Dr A [2013] EWHC 2442 (COP), [2013] MHLO 4	35
NT v FS and another [2013] EWHC 684	120
Re P (Abortion) 2013 [EWHC] 50 (COP)	260
NHS v VT and another [2013] EWHC B26 (Fam)	252
IM v LM [2014] EWCA Civ 37	167-168
RB v Brighton and Hove CC [2014] EWCA Civ 561, [2014] MHLO 25	135-136, 247

An NHS Trust and others (Respondents) v Y (by his litigation friend) [2018] UKSC 46	131
Bawa-Garba v General Medical Council [2018] EWCA Civ 1879.	240

European Court of Human Rights Case Law

Case	**Pages referenced**
Dudgeon v United Kingdom 7525/76 (1983) 5 EHRR 573	153, 259
X and Y v. Netherlands (1986) 8 E.H.R.R. 235	27, 72
Al-Nashif v Bulgaria (2003) 36 EHRR 655	73-4
Y.F. v Turkey (2004) 39 EHRR 34	27, 72
Tysiac v Poland (2007) 45 EHRR 42	73
Shtukaturov v Russia 44009/05 [2008] ECHR 223	126
X and Y v Croatia 5193/09 [2011] ECHR 1835	126
Ivinović v Croatia 13006/13 [2014] ECHR.	126

Table of Statutes

Legislation from England and Wales

Legislation	Pages referenced
Abortion Act 1967	255
Mental Health Act 1983 (as amended by Mental Health Act 2007)	27, 30, 33-36, 92, 222-3, 229-230
Children Act 1989	215, 257-8
Human Rights Act 1998	27-28.
Mental Capacity Act 2005	12, 16, 19, 22, 24, 30-33, 36, 47, 55-56, 60-64, 68, 70, 74, 84, 86, 88-89, 94, 104, 109-10, 113, 115, 117, 120, 136, 141-3, 148-9,155-6, 160-1, 164-8, 172, 183, 192, 198, 202, 210, 215-16, 218, 220-1, 223-4, 241, 244-5, 276, 281, 284, 290, 292-3, 295, 300, 305, 310-11.
Defamation Act 2013	275
Care Act 2014	233
The Court of Protection (Amendment) Rules 2015	120

Legislation from other Jurisdictions

Legislation	Jurisdiction	Pages referenced
Civil Code of Quebec (C.C.Q.), S.Q. 1991, c. 64, Art. 291.	Quebec, Canada	290
Representation Agreement Act, British Columbia 1996	British Columbia, Canada	290
The Adult Guardianship and Co-decision-making Act, Saskatchewan 2000	Saskatchewan, Canada	290
Adult Guardianship and Trusteeship Act, Alberta 2008	Alberta, Canada	290
Assisted Decision-Making (Ireland) Act 2015	Republic of Ireland	231, 258, 289

Mental Capacity Act (Northern Ireland) 2016	Northern Ireland	230, 257, 280 4, 288

Introduction

> It is a terrible thing to be assessed as lacking capacity when you do not – to have others make decisions on your behalf and set aside your own wishes based on what they think is in your best interests. You lose control over your life. You are no longer in charge of your destiny.
>
> It is a terrible thing to be said to have capacity when you do not – to be left to cause yourself and those you love great harm on the basis that you know what you are doing and you are making your own choices, when in fact your decisions are not really yours. To have others harm you and to be told no protection is offered because you have chosen this harm, even though it is against your deepest values, is horrific.[1]
>
> *Jonathan Herring and Jesse Wall*

The legal consequences of finding someone to have or to lack mental capacity are immense. This is true in many ways, but nowhere more so than in the arena of medical treatment and care. For those who have capacity, the values of autonomy and self-determination dominate: consent must be sought for any care decision or medical treatment, and their right to bodily integrity permits them to refuse any treatment, even where that refusal will result in their death.[2] But for those who are found not to have capacity, their decisions about treatment and care do not carry legal authority. The Mental Capacity Act (MCA) requires that decisions be made on their behalf, in their 'best interests'[3]. Determining what these interests may be requires the wishes of the

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[1] J Herring and J Wall, 'Autonomy, capacity and vulnerable adults: filling the gaps in the Mental Capacity Act' (2015) 35 Legal Studies 698, 1.

[2] *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All England Reports 449.

[3] Mental Capacity Act 2005, ss1(5) and (4).

incapacitated person to be taken into account – but this is only one among many factors that the decision maker must have regard to.

The effect of the law adopting this ‘cliff-edge’[4] approach to capacity is to place substantial pressure on the test for capacity as the means of reliably distinguishing those who are capable of making autonomous choices, from those who are not. Unfortunately, this is weight it cannot bear. The conception of autonomy it adopts is too narrow to capture the full range of ways in which a person’s decision-making may be impaired, focussing only on their decision-making processes and not on the substance or origins of the beliefs or values underpinning their decisions. Even were a more demanding understanding of autonomy to be embraced however, decision-making is rarely as clear-cut as the threshold approach pre-supposes. Autonomy admits of degrees: people are capable of being impaired to different extents, and in very different ways. There will inevitably be a ‘grey area’ on the cusp of the capacity threshold in which capacity is unclear — a problem exacerbated by the clinical realities of making capacity assessments, which often leaves the decision-maker without the information they need to make robust assessments.

The decision-maker in this position — be that a doctor or a care-worker — is faced with an unenviable choice in situations where their views collide with those of the patient.[5] If they resolve this ambiguity in favour of capacity, the patient has complete freedom to act as they choose, even to do something that may be profoundly

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[4] E. Jackson, ‘From ‘Doctor Knows Best’ to Dignity: Placing Adults Who Lack Capacity at the Centre of Decisions About Their Medical Treatment’ (2018) 81(2) MLR 247–281, 247.

[5] Generally the term ‘patient’ will be used where the person is in a medical context, while ‘person’ will be used for all decisions being taken outside of the medical context. Occasionally however, as in this paragraph, ‘patient’ will be used to refer to both the medical or care context, where it would otherwise create confusion.

harmful to themselves. If, however, they find the person to lack capacity, they will be able to prevent this harm and to act in a way which they regard as best for the patient.

It is no surprise, then, that many doctors have sought to mitigate this problem by manipulating the test for capacity in the Act, so as to tip their patients ‘over the cliff’ into incapacity. They do so primarily when the consequences are grave. By responding in this way however, they expose themselves to legal liability; their actions collectively undermine the conceptual clarity and consistency of the test for capacity; and they together leave the person’s right to autonomy vulnerable to the idiosyncrasies of the decision-maker called upon to assess them. The aim of this thesis is therefore to set out a new legal framework which provides a better way of addressing these problems.

The effect of the ambiguity on the cusp of the capacity threshold is that there may be reasonable disagreement over whether or not a person has capacity. This makes the cliff-edge approach to capacity — permitting a substantial degree of interference with those found to lack capacity — hard to justify. Yet, the way the best interests test is currently framed in the MCA provides doctors and care-workers with very little support should they wish to make a decision that carries an element of risk to the person, even if it accords with the person’s strongly and deeply-held wishes, values and beliefs. A high-handed (if well-intentioned) paternalism and aversion to risk have become the default position, with the result that people who lack capacity frequently find themselves profoundly disempowered. A new approach to best interests is therefore necessary if decision-makers are to feel able to prioritise the wishes of the individual, even where that will put the person at risk of harm.

While this thesis will focus on decisions made in the treatment and care context, the MCA covers all manner of decisions, including financial and administrative decisions. It applies not only to doctors and care or social-workers, but to everyone working with or caring for adults who may lack capacity. The conclusions thus have wider implications for the use of the concept of capacity in law, not only in respect of issues covered by the MCA, but also to questions of testamentary capacity, the voidability of contracts and the availability of defences in criminal law. But perhaps the most urgent need to revisit concepts of capacity and best interests lies in the challenge of caring for an ageing population, among whom ever increasing numbers are suffering from dementia. By 2021 it is expected that there will be over 850,000 people in the UK living with some form of dementia,[6] placing ever greater pressures on an already over-burdened health and social care system. It is therefore essential that our legal framework for making capacity and best interests decisions for this population strikes an ethically acceptable balance between empowering individuals in decisions of profound importance to them, and protecting them from unintended harm. This cannot be achieved without addressing the very complex issues involved in making such decisions, and recognising the many factors external to the patient (such as resource and time pressures, and the fear of litigation) that are currently influencing the way in which doctors and carers approach such decisions in practice.

It is useful at the outset to be mindful of the terminology being employed. The test for capacity is intended to determine whether a person is capable of making an autonomous decision or not (see Section IV below). The law thereby treats capacity and autonomy as synonymous: if a person has capacity, they are deemed to be acting autonomously; if they do not, they are thought to be non-autonomous. However, as this

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[6] Alzheimer's Society, 'Statistics', available at: <www.alzheimers.org.uk/statistics>accessed 11th November 2018.

thesis will explore, while someone who lacks capacity will undoubtedly have impaired autonomy, capacity and autonomy are not in fact one and the same. A person may have capacity even if their autonomy is impaired; or they may lack capacity but retain important aspects of their autonomy. Where reference is made in this thesis to a person's 'capacity', therefore, this will indicate capacity in a legal sense. Where, however, a person's 'autonomy' is discussed, this is not intended to refer only to their legal capacity, but to the wider philosophical concept of autonomy.

I Outline of thesis

In chapters 1 and 2, the problems with the current legal framework are outlined. This begins in chapter 1, by identifying three different ways in which the test for capacity is unable to reliably distinguish those who have capacity from those who do not. The first problem lies with the inadequate conception of autonomy relied upon in the MCA, which addresses only the *processes* required for an autonomous decision, and therefore fails to take into account the effects of mental illness on the substance of a person's values and beliefs, which may impair their autonomy.

The second problem is that the 'all-or-nothing' threshold approach fails to recognise that in reality, autonomy admits of degrees, with the result that there is always an uncertain 'grey area' on the cusp of capacity. This has resulted in the test being applied inconsistently between different decision-makers, leading to disagreements over whether the person has capacity or not. Exacerbated by the difficulties of making such assessments in practice, this casts further doubts over the reliability of the test.

Notwithstanding this uncertainty, doctors and care-workers are obliged to make a decision, with stark legal and ethical consequences if they get it wrong. The third problem is thus that the need to avoid some unwelcome repercussions encourages decision-makers to tip patients 'over the cliff' into incapacity, especially where the consequences of the decision are grave. Where assessments of capacity are being influenced by a desire to avoid outcomes which doctors regard as undesirable, this exacerbates concerns about the consistency with which the test is being applied, and the vulnerable position in which patients are left, their rights subject to the idiosyncracies of the individual decision-maker.

Given these concerns about the reliability of the capacity test, a cliff-edge approach to capacity which sanctions wholesale paternalistic interference once a person is found to lack capacity, cannot be justified. If autonomy is not all-or-nothing, but rather admits of degrees, a mere failure to meet one of the criteria for the capacity test should not be regarded as an 'off-switch' for the person's rights and freedoms.[7] Moreover, if one accepts that there is a second dimension to autonomy (relating to the authenticity of the person's values and beliefs) which operates independently of the person's ability to reason in accordance with those beliefs, it follows that there will be a number of people who, while their reasoning may be impaired, nonetheless retain strongly and deeply held beliefs or values, which warrant respect. It is important, therefore, that these are given substantial weight in any determination of what is in a person's best interests.

Chapter 2 examines best interests decision-making and the implications of the concerns outlined in the previous chapter for this. It will be argued that the way that the law is currently framed — according to which the person's wishes and feelings are just one factor among many that the decision-maker must take into account — fails to

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[7] *Wye Valley NHS Trust v B* [2015] EWCOP 60, [11].

provide any guidance for those called upon to make these decisions, about how to weigh these various factors. Nor does it offer any kind of support should they take a decision which prioritises the wishes of the individual even in the face of harm. This makes decision-makers reluctant to do so with the result that risk-aversion and medical paternalism dominate.

Chapters 3, 4 and 5 therefore consider different solutions to these problems. Chapter 3 examines what measures might help improve the accuracy with which the test for capacity assesses whether a person can make an autonomous choice. One way this might be achieved is through introducing a new limb to the capacity test that deals with the question of whether the values and beliefs underpinning the decision are authentic to the person. However, if the law is to capture impairments to authenticity, it must have a clear conception of what is means to be ‘authentic’. Different theories of authenticity are therefore considered, and a model of authenticity is then adopted, based on the origins of the person’s values and whether they are the product of a mental illness or disorder.

Chapter 4 considers ways to enhance the consistency of capacity assessments. The inherent subjectivity in the test for capacity and the discretion that must necessarily be left in the hands of the decision-maker mean that some inconsistency is unavoidable, the law being too blunt an instrument for such finely nuanced judgements. It is nonetheless argued that greater (and more specific) guidance is needed to enhance the consistency with which decision-makers exercise their discretion under the Act.

Both of these solutions will limit the discretion available to the doctor to manipulate the test for capacity. Neither, however, comprehensively tackles the most intractable problem — that in order to prevent a harmful outcome, the doctor *must* find the person to lack capacity. This chapter ends by briefly touching on whether the law can be amended to remove the current incentives for doctors to find their patients to lack capacity, but concludes that only very limited changes are possible without substantially eroding the protections against illegitimate state interference.

Although these changes might successfully introduce a conception of autonomy that better accounts for the complexities of decision-making, they will do little to soften the effects of the capacity 'cliff-edge'. In order to address this, the law must be amended so as to give decision-makers more leeway to make decisions which prioritise a person's strongly held wishes, even where these pose serious risks to the person. Chapter 5 considers how this might be achieved, suggesting that there ought to be a presumption that the person's wishes and feelings will be understood to be what is in their best interests, except where giving effect to them will expose the person to a serious risk of significant harm. Even where the harms are significant, there will still be occasions where the person's wishes and feelings should nonetheless take precedence, specifically where to do otherwise would involve frustrating their deeply and authentically held beliefs, values or commitments. It will therefore be suggested that the weight accorded to the person's wishes in the best interests assessment ought to reflect the strength of these views. This will be supported by a non-exhaustive list of factors which will help the decision-maker to assess the relative strength, consistency, and depth of the person's wishes.

This will be supported by an amendment to section 5 of the MCA, to narrow the defence to battery contained in it so that it applies only where the intervention was necessary to prevent the patient suffering serious harm. In doing so, the law will strike a better balance between empowering people to make decisions which reflect and promote their interests and values, and protecting them from making harmful decisions which they cannot understand and would not ultimately wish for themselves.

II Methodology

This thesis is founded on a combination of theoretical and empirical research. The purpose of the empirical research was to gain a better understanding of how the provisions in the MCA are being understood and applied in practice. This is important for two reasons. Firstly, as will be explored further in Chapter 1, both the provisions on testing for capacity and on assessing best interests are broadly framed, according decision-makers a large margin of discretion when it comes to applying them. Given this, it is important to understand how these provisions are being applied, what factors are affecting the way that these assessments are being conducted and whether or not the application of them is consistent. Secondly, while some information about how the provisions are being applied can be gleaned from the case law, very few cases ever make it to court, and those that do, are frequently those which are especially challenging or controversial. The case law does not therefore give an accurate representation of how most decisions are being taken on the ground. Moreover the circumstances in which most decisions are being made are very different to those present in the majority of Court of Protection cases. While some judgments are made *ex tempore*, judges are generally not subject to the same time and resource pressures that doctors and care workers commonly face, which may, as explained below, affect the robustness of both capacity and best interests assessments. Consequently, a series of semi-structured interviews were conducted with medical consultants from a range of specialisms, in order to explore how they conducted capacity and best interest assessments. This section explains the methodology employed for these interviews, and how the data that was acquired was then used.

In accordance with the terms of the ethics approval received (Appendix E),[8] named participants were approached by email, having been identified using lists of consultants working in three different NHS trusts: Oxford University Hospitals NHS Foundation Trust; Oxford Health NHS Foundation Trust and Barts Health NHS Trust (London). In each instance, every consultant working in the given specialism in that trust was emailed, and every person who volunteered to take part in the study and was subsequently available to do so was interviewed (see Appendix C for further details of the participants who took part in the study). Consequently, the specialisms included in this study are:

1. Liaison Psychiatry (4 participants)
2. Old Age Psychiatry (3 participants)
3. Psychiatry – emergency medicine (1 participant)
4. Psychiatry – general (1 participant)
5. Emergency Medicine (3 participants)
6. Geriatric Medicine (3 participants)
7. Intensive Care (1 participant)
8. General Practice (1 participant)

While far greater numbers of participants were approached than agreed to take part in the research, in at least some specialisms (liason psychiatry, geriatrics and emergency medicine), there was a high degree of what has been termed by Benjamin Saunders *et al* 'inductive thematic saturation',[9] with later interviews generating very few new codes

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[8] Research Ethics Approval (CUREC 1A), Ref No: R39750/RE001.

[9] B. Saunders et al, 'Saturation in qualitative research: exploring its conceptualization and operationalization' (2018) 52(4), 1893–1907, 1896.

or themes. Each interview followed the same format, which began with a series of general questions (Appendix A), asking participants what they thought they were testing for when assessing whether a person has capacity; whether they often came across hard or borderline cases and what it was that made those cases difficult, and what factors they weighed up when deciding what was in the best interests of someone who lacked capacity. They were also asked for their provisional thoughts on recent proposals put forward by the Law Commission.

The participants were then presented with a number of short vignettes in which someone with questionable or uncertain capacity required treatment (Appendix B). The participants were asked to decide in relation to each of the scenarios whether or not they thought the person in question had capacity; what factors or pieces of information were important when making that assessment, and whether there was any other information they would have needed or wanted in order to make that assessment. They were subsequently asked whether, if the person was found to lack capacity, the treatment in question would be in the best interests of the patient, as well as what factors were important when making this assessment, and why they were weighing the factors in that particular way. Depending on the nature of the specialism, some vignettes were omitted from particular interviews. For example, the scenarios of Lucy and Becky, which related to the contraceptive or birthing decisions of young women, were not shown to those specialising in geriatrics. But some specialisms, such as Liaison Psychiatry, were asked to comment on all the vignettes.

The interviews lasted between 40 minutes and 1.5 hours, depending on the number of vignettes considered and the fullness of the answers given. They usually took place at the doctor's place of work, although two were conducted at Merton College, University of Oxford. These were recorded and transcribed, and the transcripts analysed using qualitative analysis software NVivo 10 to classify and organise the data. A thematic analysis was then conducted —a method commonly used in the social sciences for analysing qualitative data, which focuses on identifying common themes or patterns of meaning that emerge from a number of different sources.[10] This analysis involved coding the transcripts to identify common themes arising in the interviews responses, in particular in relation to two key questions: how doctors understood the test for capacity embedded in the MCA, and what factors were influencing their application of this. These were conceived inductively, using the method set out by Virginia Braun and Victoria Clarke:[11] a line by line analysis of the transcripts was conducted picking out key words, phrases or points. These were then reviewed, to further refine the codes and check for any duplication (where the same or similar content was placed under different codes), and from this overarching themes or factors were extrapolated. These themes are detailed in Appendix D.

Quotes taken directly from these interviews are used throughout this thesis. In accordance with the terms of my ethics approval (Appendix E) and the information sheets I provided to participants before they agreed to take part (Appendix F), these have been completely anonymised. Given that a number of the participants work in close proximity with one another (including the use of shared offices and shared diarising), the exact dates and locations of the interviews have not been included in citations, so as to preserve anonymity. For the same reason, the thesis does not use pseudonyms for participants. As Angelica Orb et al note, although the use of pseudonyms is ordinarily recommended, ‘this strategy may not be sufficient if the

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[10] V. Braun and V. Clarke, ‘Using Thematic Analysis in Psychology’ (2006) 3(2) Qual Res Psychol 77.

[11] ibid, 86-93.

study is conducted in a small community where participants could be easily recognised',[12] where 'quotations… even though anonymous, could reveal their identity.'[13] Given the closeness of the group of participants interviewed in this thesis, the use of pseudonyms would therefore be inappropriate as there are a number of instances where multiple quotes (sometimes substantial in length) have been taken from the same participant, which, if attributed to one individual, might enable them to identified.

This research is qualitative and not quantitative. Given the relatively small sample size (17 participants were interviewed in total) the results of this study cannot be extrapolated to the medical body at large, as robust evidence about the way in which capacity assessments are made in general. Moreover, those who took part in the study volunteered to do so, most likely because they regarded the topic as interesting or important in some way, which may have altered both the way they responded to the questions and their level of engagement with the topic. This may also account for the much higher turn-out among some specialisms (in particular psychiatry and geriatrics, who tended to regard capacity as a more pressing issue) than others. For example, across four GP surgeries, only one GP responded.

Nonetheless, the evidence does demonstrate some common themes or factors which appear to be influencing the decisions of doctors, and some shared concerns amongst the medical profession about the difficulties inherent in making these assessments and the consequences of doing so. It also highlights that even within the relatively small numbers of participants interviewed, there were clear differences of

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[12] Orb et al, 'Ethics in Qualitative Research' (2000) Journal of Nursing Scholarship 33(1):93-96, 95.

[13] ibid.

opinion when it came to interpreting and applying the test. Once these themes had been identified, these were then considered in conjunction with the case law and other research that had been conducted into how the provisions of the MCA were being applied (for example, the results of the House of Lord post-legislative scrutiny of the MCA[14] and the Law Commission's Consultation Analysis[15]) to ascertain whether the issues or patterns raised by doctors in the empirical research had also been identified as operating more broadly. Sometimes, this evidence of how the provisions were being applied in practice provided support for the existence of problems that had already been identified at a theoretical level in the legal or ethical literature (for example, the broad discretion afforded to decision-makers under the best interests provisions, or the lack of attention given to concerns about the authenticity of the person's beliefs). In other places, it unearthed new concerns which had not previously been identified, such as the challenges that circumstances in which decisions must be made present to making robust assessments of capacity.

While the results of this empirical research will be explored in greater detail in Chapter 14, it should be noted that there are different ways in which the results of this research might be used to critique the legal framework. Firstly, if there is evidence that assessments are being influenced by factors which do not appear in the statute, and that the provisions are being applied inconsistently (with different doctors accommodating factors in different ways), then this might lend support for the idea that the way that the law is currently framed enables it to be applied in a way that lacks consistency and

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[14] House of Lords Select Committee on the Mental Capacity Act 2005, '*Mental Capacity Act 2005: post-legislative scrut*iny' (HL Paper 139, *13/3/14*),

[15] Law Commission, 'Mental Capacity and Deprivation of Liberty – Consultation Analysis available at < https://s3-eu-west-2.amazonaws.com/lawcom-prod-storage-11jsxou24uy7q/uploads/2017/03/cp222_mental_capacity_responses_analysis.pdf> accessed 25/09/18.

transparency, and therefore changes need to be made either to the legal framework, or to the accompanying guidance, to accord decision-makers less discretion when it comes to applying the law. Secondly, if evidence suggests that doctors frequently experience a tension between adhering to the strict letter of the law and what they regarded as morally right or clinically appropriate, then this might suggest that the law is not framed in the way that best facilitates ethically desirable decisions. Finally, the findings might give cause to doubt whether the legal framework accounts sufficiently for the realities of clinical decision-making.

However as well as forming the basis for critiquing the current law, the empirical research was also useful when formulating proposals for reform of the law. Once again, the research was used in different ways. Some proposals for reform (such as those advocating for more clinical guidance to enhance consistency) originated in the empirical research, either being based on a suggestion that was put forward in interviews, or being a direct response to a particular concern raised by participants. In other instances, the empirical research was used to test reform proposals that had been proposed by others, such as the Law Commission. Interviewees were therefore questioned about possible reforms, and this evidence was then used to evaluate the utility of proposals. Finally, the empirical evidence was relied on to help 'flesh out' ideas for law reform that had been previously raised in the literature, in order to develop more precise proposals for reform. For example, while many commentators have suggested the need to reform the law so as to better ensure that the wishes of the individual are prioritised, there are many different ways that this could be implemented in practice. Having a better understanding of the reasons doctors and care workers have for *not* prioritising the wishes of people therefore helped to formulate a response to this problem, which centrered around the need to provide a strong symbolic statement that the person's wishes take precedence, and greater protection from impunity when making empowering decisions.

III The cliff-edge approach to capacity

When a person is found to have the capacity to make a decision (or, more accurately, where they are not found to lack it, since the law's starting point is that people are presumed to have capacity), that decision is guided by their autonomous choices: consent must be sought for any treatment or care intervention, and their right to bodily integrity permits them to refuse any treatment, regardless of whether the reasons are 'rational, irrational, unknown or even non-existent',[16] and even where the refusal will result in their death.[17] This accords people extensive powers to govern their lives according to their own values and priorities, qualified only by the courts' powers under two jurisdictions (considered below): the Inherent Jurisdiction, and the Mental Health Act 1983 (MHA).

This is supported by a number of legal ramifications, if a person is treated (or otherwise interfered with) without their consent. Firstly, this will amount to a battery. Defined as 'the direct imposition of any unwanted physical contact on another person',[18] this is a form of the tort of trespass to the person which is committed whenever a person intentionally and directly inflicts force (that is, any physical

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[16] *Re T (Adult: Refusal of Medical Treatment)* [1992] 4 All ER 649, 664.

[17] *Re B* (n2).

[18] Clerk and Lindsell on Torts (22nd Edition), 15-09.

touching) on another. Consent operates as a defence to battery,[19] providing the person has the capacity to give their consent. However, if a person with capacity is treated *without* their consent, the doctor will have no defence.[20]

This could also constitute a breach of Article 8 of the European Convention on Human Rights (ECHR), in accordance with which public bodies, including public hospitals and courts, are obliged to act.[21] This protects a person's right to 'private and family life' and has been held to encompass both 'the physical and psychological integrity' of an individual.[22] The right is qualified, and subject to restrictions made 'in accordance with law' where 'necessary in a democratic society... for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others'.[23] However in the absence of a person's consent, any interference would not be in accordance with the law, and so it could not be justified by Article 8(2). It would therefore amount to a breach of Article 8. It could also amount to a breach of Article 3 ECHR, if the treatment could be shown to be inhuman or degrading. This has been recognised in the case of forcible feeding, for example.[24]

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[19] *F v West Berkshire HA* [1990] 2 A.C. 1.

[20] This is subject to section 5 MCA, which provides a defence to battery where a decision-maker 'reasonably believe' that the person lacks capacity and that they are acting in accordance with their best interests (MCA, s5(1)(a)-(b)). This will be discussed in more detail below.

[21] Human Rights Act 1998, section 6.

[22] *X and Y v. Netherlands* (1986) 8 E.H.R.R. 235, [22]; *Y.F. v Turkey* (2004) 39 EHRR 34, [33].

[23] Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention on Human Rights, as amended) (ECHR) art 8(2).

[24] *A Local Authority v E* [2012] EWCOP 1639, [126].

Meanwhile, for those who are found to lack capacity, their decisions are not treated as legally authoritative, and a decision must instead be made on the basis of what is in their 'best interests'.[25] Although 'best interests' is not defined in the Act, the case law is clear that it captures 'welfare in the widest sense, not just medical but social and psychological'.[26] The Act sets out a number of relevant factors that must (or must not) be taken into account by the decision-maker when making this assessment. The decision cannot be made merely on the basis of the age or appearance of the person;[27] the likelihood of the person regaining capacity must be considered[28] and the decision-maker is required to 'permit and encourage the person to participate' in the decision.[29] They must take into account, 'if it is practicable and appropriate to consult them', the views of others engaged in the care of the person, or interested in their welfare.[30] Importantly, the decision-maker must also, 'so far as is reasonably ascertainable', consider:

> a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by [them\ when [they] had capacity),
> b) the beliefs and values that would be likely to influence [their] decision if [they] had capacity, and
> c) the other factors that [they] would be likely to consider if [they] were able to do so.[31]

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[25] MCA ss1(5) and (4).

[26] *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [39] per Lady Hale.

[27] MCA s4(1).

[28] ibid, s4(3).

[29] ibid, s4(4).

[30] ibid, s4(7).

[31] ibid, s4(6),

Finally, the decision-maker must also never be motivated by a desire to bring about death.[32]

Crucially, the framing of section 4 makes clear that none of factors it outlines is to take priority in the best interest assessment.[33] It is thus left to each individual decision-maker to decide on the weight to be accorded to each, with the result that an individual's wishes and feelings may frequently be outweighed by other factors, where the perceived need to protect them (or a fear of the legal consequences if the decision-makers fail to do so) is thought to take precedence over the desire to empower them. While the way in which the provisions are being applied will be considered in Chapter 2, suffice for now to say that the way the provision in section 4 is framed, gives doctors very little incentive to make empowering decisions.

It is clear then that the law adopts a cliff-edge approach to capacity: for those safely on the cliff-top, autonomy and self-determination dominate; but those who fall over the edge are powerless: someone else's view of what is 'best' for them is imposed upon them. The provisions in s4(6) are one means by which the law has sought to mitigate some of the harshness of this – though as noted above, save for the decision-maker being mandated to 'take account' of the person's wishes and feelings, there is no duty on clinicians to follow, or even to give significant weight to the wishes of their patients. The other means by which the law has attempted to soften the cliff-edge is by placing some limits on the actions of those who are found to have capacity, through the Inherent Jurisdiction, and the Mental Health Act 1983. As these are important to

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[32] ibid, s4(5).

[33] See for example, *Re M* [2009] EWHC 2525 (Fam), [32], per Mr Justice Munby.

understanding how the law strikes the balance between empowering and protecting people, each is considered below. However, while both do soften the capacity cliff-edge to some extent, neither allows the provisions of the MCA to be circumvented.

(a) Vulnerable Adults: The Inherent Jurisdiction

The MCA applies only where a person's inability to make a decision is caused by 'an impairment of, or a disturbance in the functioning of, the mind or brain.'[34] There are a number of other reasons why a person's decision-making might be impaired however. The inherent jurisdiction thus plugs this 'gap' in the legal powers available to courts to offer protection to adults not falling within the remit of the MCA:

> Where, on a strict mental health appraisal, such an individual does not lack capacity in the terms of the MCA 2005 and therefore falls outside the statutory scheme, but other factors, for example coercion and undue influence, may combine with his borderline capacity to remove his autonomy to make an important decision, why, one may ask, should that individual not be able to access the protection now afforded to adults whose mental capacity puts them on the other side of that borderline?[35]

Although Munby J felt it would be 'unwise, and indeed inappropriate'[36] to attempt to define *all* those who might fall under the jurisdiction, he has indicated that it would include

> a vulnerable adult who, even if not incapacitated by mental disorder or mental illness, is, or is reasonably believed to be, either (i) under constraint or (ii) subject to coercion or undue influence or (iii) for some other reason deprived of the capacity to make the relevant decision, or disabled from making a free choice, or incapacitated or disabled from giving or expressing a real and genuine consent.[37]

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[34] MCA, s2(1).

[35] *DL v A Local Authority* [2012] EWCA 253, [65].

[36] *Re SA (vulnerable adult with capacity: marriage)* [2006] 1 FLR 867, [77].

[37] ibid, [79].

The jurisdiction thus captures situations in which the person's autonomy has been undermined as a result of the pressure or influence of others, rather than by a mental illness or impairment. However, Munby J later suggested that it might extend beyond these situations to include circumstances where the person's understanding and reasoning may be undermined by factors such as 'physical disability, illness, weakness (physical, mental or moral), tiredness, shock, fatigue, depression, pain or drugs'.[38] Subsequently, it has also been held to capture people who lack capacity under the terms of the MCA, providing that they do *not* have a remedy available under the Act. In *XCC v AA* for example,[39] concerning whether or not to recognise the marriage in Bangaldesh of a woman with severe learning disabilities, Justice Parker made clear that:

> The protection or intervention of the inherent jurisdiction of the High Court is available to those lacking capacity within the meaning of the MCA 2005 as it is to capacitous but vulnerable adults who have had their will overborne, and on the same basis, where the remedy sought does not fall within the repertoire of remedies provided for in the MCA 2005. It would be unjustifiable and discriminatory not to grant the same relief to incapacitated adults who cannot consent as to capacitous adults whose will has been overborne.[40]

A finding of capacity does not, therefore, accord the person unlimited rights to self-determination; rather it is subject to the court maintaining an inherent jurisdiction to override that decision where it is deemed necessary to protect a vulnerable adult.

Despite this, the reach of the inherent jurisdiction is not such that it can be used to circumvent the requirements of the MCA wherever a doctor regards the person's decision as unwise. It can only apply where the person's ability to make a decision had

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[38] ibid.

[39] [2012] EWHC 2183 (COP).

[40] ibid, [54].

been compromised by something which was *not* covered by the MCA, or where the Act does *not* provide any remedy for the person.[41] For example, where the person's autonomy is interfered with by the overbearing influenced of others, or where the remedy sought is a declaration of non-recognition of a marriage (as in *XCC v AA*[42]). This means that in the cases considered for most of this thesis — namely, where the person is in need of medical care and the doctor considers them to have capacity — this jurisdiction provides no basis for overriding their refusal.[43] Moreover, as the jurisdiction resides in the court, the doctor cannot simply invoke the inherent jurisdiction to justify his or her own decision to treat. This limits its application in certain contexts, such as emergencies. Hence while the court has broad powers under the inherent jurisdiction, these do not allow doctors to circumvent the MCA by providing a legal justification for treating an otherwise capacitous patient. This is however provided for by the MHA.

(b) The Mental Health Act

The Mental Health Act (MHA) covers the detention, care and treatment of those with a mental disorder. Although in many cases both the MCA and the MHA will apply, if the person has a mental disorder of sufficient severity to fall within the jurisdiction of the MHA, the doctor is at liberty to treat the person under the MHA instead, which includes more far-reaching powers, not limited by the person's capacity to consent. A

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[41] ibid, [66].

[42] ibid.

[43] The one exception might be where the person is not affected by a condition of the mind of brain but is subject to undue influence or pressure from, for example, a family member, as in the vignette of Becky.

mental disorder is broadly defined as ‘any disorder or disability of the mind’.[44] The Act does little to elaborate on this definition, except that it does not include dependence on alcohol or drugs;[45] and while learning disabilities could constitute a mental disorder, this is only deemed to be the case where that learning disability is associated with ‘abnormally aggressive or seriously irresponsible conduct’.[46] Many of the cases discussed in this thesis do fall within the remit of the Act, which in addition to psychotic illness, eating disorders and depressive illnesses, also covers a range of neurocognitive conditions such as Alzheimer’s disease, Lewy Body dementia and vascular disease, all of which can be found in the DSM-5.[47] However not every case will: it would not apply to those who have a learning disability (except where it falls within the aggressive behaviour exception above), a brain injury, or those whose incapacity has been caused by contextual factors (alcohol, drugs, medication, pain or shock etc).

The MHA permits the detention of a person for 28 days for assessment, if it can be shown that they are suffering from a ‘mental disorder of a nature or degree’ which warrants detention[48] and that detention is necessary for the person’s own safety or the

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[44] Mental Health Act as amended by Mental Health Act 2007, s1(2).

[45] ibid, s1(3).

[46] ibid, s1(2A).

[47] American Psychiatric Association, ‘Diagnostic and Statistical Manual of Mental Disorders’ (2013, 5th Edition).

[48] ibid, s2(2)(a).

safety of others.[49] If treatment cannot be provided unless he is detained,[50] the period of detention may be extended. These provisions apply *irrespective* of whether the person has capacity to consent or not: even if they have capacity and they refuse detention or treatment, their wishes can be overridden. While detained, the person may be treated for his mental disorder, or for any symptom or manifestation of this. For the first three months, the consent of the patient to this treatment is not required.[51] After this, the administration of medicine can occur only if either the patient has capacity and consents to it, or if they lack capacity but a second opinion confirms that continued treatment it is appropriate. Other forms of treatment, including psychotherapy, and even force-feeding, can continue regardless of their consent.

While a large proportion of people falling within the remit of the MHA will lack capacity, this is not invariably the case. Evidence from Gareth Owen *et al* suggests that around 86% of people detained under the MHA in general adult acute inpatient units lack capacity to make decisions about their treatment (the figure is around 60% for those on an acute psychiatric ward who are not detained under the MHA).[52] There will be some people detained under the Act then, who do have the capacity to consent to treatment — or, of course, to refuse it — yet they may be treated regardless.

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[49] ibid, s2(2)(b).

[50] ibid, s3.

[51] MHA, s63. There are two exceptions to this. Where the treatment is Electric Convulsive Therapy, if the person has capacity, they must consent to the treatment. If they do not have capacity, a second opinion must be provided by a registered medical practitioner that the treatment is appropriate (s58A). Where the treatment is psychosurgery, the person must both consent to the treatment, and a second opinion must be provided by a registered medical practitioner that the treatment is appropriate (s57).

[52] ibid.

While this would seem to be a substantial interference with rights and freedoms of at least some people with capacity, a number of points must be borne in mind. Firstly, as noted above, the MHA only applies to those with mental illness, not learning disabilities, brain injuries or other forms of impairment. Secondly, the MHA can only be used to justify treatments for the person's mental disorder, or for symptoms or manifestations of that disorder. While this has been broadly interpreted to include treatment for a physical disorder where this might affect the person's mental health,[53] the doctor must be able to show it is necessary for the treatment of their mental illness. In *A NHS Trust v Dr A*[54] for example, a person went on hunger strike in an attempt to force the UK Border Agency to return his passport, which had been confiscated following a failed claim for asylum. Force-feeding was found not to be treatment for his mental disorder, but only for his physical condition (the effects of starvation and dehydration).[55] His physical condition was in part a *consequence* of his mental disorder, but it was not a *manifestation or symptom* of it.[56]

Therefore while the effects of the MCA are to some extent mitigated by the existence of the inherent jurisdiction and the MHA, there are still many situations in which neither jurisdiction will apply: namely where the person is incapacitated by anything other than a mental disorder and is refusing medical treatment, or where they

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[53] For example in *Tameside and Glossip Acute Services Trust v CH* [1996] 1 FLR 762 (QBD), this provision was relied upon to authorise the caesarean section of a pregnant woman suffering from schizophrenia, on the basis that a stillbirth would cause a deterioration in her mental state and interrupt the treatment of her schizophrenia.

[54] [2013] EWHC 2442 (COP).

[55] ibid, [79].

[56] ibid.

do suffer from a mental disorder but the treatment is for a physical illness or condition which is not a symptom or manifestation of that mental disorder. In neither of these situations, then, is a doctor able to override a person's decision — even if that decision is a profoundly harmful one. Given the stark legal position, the theoretical basis must be considered for preventing any such interference with the decisions of those found to have capacity, yet permitting such substantial interference for those without.

IV The theoretical basis for operating a threshold

Generally, the law is thought to subscribe to a Millian conception of liberty,[57] in which considerable justification is required before the state may interfere with the autonomous choices of its citizens.[58] To understand how John Stuart Mill's conception of liberty operates, it is necessary to put it in the context of his wider philosophy. In his view, 'happiness is desirable, and the only thing desirable, as an end, all other things being desired as a means to an end.'[59] As a proponent of utilitarianism, Mill adheres to the belief that actions are right if they result in producing the greatest sum of human happiness. It is not therefore that people have a 'right' to liberty, but rather that respecting it will result in the best outcome for society and its citizens, 'utility in the

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[57] J. S. Mill, *On Liberty* (Cosimo Classicz (2005 [1859])); for a more detailed discussion of this see J. Feinberg, Harm to Self (Oxford: Oxford University Press, 1986).

[58] As Coggon and Miola note ('Autonomy, Liberty, and Medical Decision-Making' (2011) 70(3) CLJ 523–43), there are many other theories in political philosophy which state that a person should be free to act autonomously 'provided they do not breach well-grounded external laws which legitimately limit their actions.' (p528) While Mill's harm principle represents the simplest, and most widely accepted basis for these laws, other examples cited by them include 'positive obligations derived directly from the receipt of benefits inherent in membership of a stable political system, and in being part of a system of civic republicanism' (p528).

[59] J.S. Mill, *Utilitarianism* (Oxford Philosophical Text Series edn, Oxford: Oxford University Press 1998), 81.

largest sense, grounded on the permanent interests of man as a progressive being'.[60] Achieving happiness demands that a person be free to pursue '[their] own good in [their] own way',[61] providing this does not interfere with the interests of others. As Mill asserts:

> In the part which merely concerns himself, his independence is, of right, absolute. Over himself, over his own body and mind, the individual is sovereign.[62]

For Mill, a sphere of independence from state intervention was essential for human individuality to develop. It was also necessary if people were to have the freedom to pursue those things which they enjoyed, or deemed morally appropriate, and thus was an essential part of ensuring the happiness and morality of individuals.[63] Other commentators have similarly seen respecting autonomy as important because it leads to greater welfare – although often this is intended to apply to individual 'welfare' rather than collective 'happiness' in the Millian sense. As Molyneux observes, there are two ways in which this might occur: instrumentally and intrinsically.[64] Regarding the former, it is argued that respecting autonomous choice is the best way of determining what is best for the individual: as Mill explains it, individuals are best placed to make choices that are good for them.[65] There is also the point, as Herring and Wall observe,

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[60] Mill, *On Liberty* (n57), 70.

[61] Mill, *Utilitarianism* (n59), 142.

[62] Mill, *On Liberty* (n57), 14.

[63] ibid, 75-76.

[64] D. Molyneux, 'Should healthcare professionals respect autonomy just because it promotes welfare?' [2009] JME 245.

[65] Mill, *On Liberty* (n57).

that often people are not very good at assessing what may be in someone else's interests.[66] As Kim Atkins puts it:

> Respect for autonomy is an acknowledgment of the limitations of our knowledge of other people and a willingness to incorporate that understanding into our world-views. When we respect autonomy we do not simply observe another's freedom from a distance, as it were; we accede to our fundamental fallibility and epistemological humility. It is in recognition of the fact that we cannot experience from another's perspective that we normally refrain from judging what will make another's life good for them.[67]

Often then, individuals will be best placed to make decisions for themselves, as others inevitably face limitations when deciding for others. Herring and Wall see further value in the way that respecting autonomy 'encourages people, in their interactions with others, to seek to engage with them, accepting their values.'[68] In the medical context, autonomy prompts caregivers to put themselves in the position of the patient to try to understand the illness and treatment options from their perspective.[69]

But it may also be the case that autonomy is a fundamental (or intrinsic) part of welfare. As Ronald Dworkin explains, it is essential for our fulfilment that we lead our life by our own beliefs:

> Autonomy makes each of us responsible for shaping his own life according to some coherent and distinctive sense of character, conviction, and interest. It allows us to lead our own lives rather than be led along by them, so that each of us can be, to the extent such a scheme of rights can make this possible, what he has made himself.[70]

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[66] Herring and Wall (n1), 702.

[67] K. Atkins 'Autonomy and the subjective character of experience' (2000) 17 J Appl Phil 71, 75.

[68] Herring and Wall (n1), 702.

[69] C. Mackenzie 'Relational autonomy, normative authority and perfectionism' (2008) 39 J Soc Phil 512, 516.

[70] R. Dworkin, 'Autonomy and the Demented Self' *The Millbank Quarterly* 4, 5.

In a similar vein, Will Kymlicka argues that an authentic life is one that is lived from the inside, pursuing values and objectives that the *individual* considers important;[71] while Joseph Raz notes that an autonomous person's well-being consists in 'the successful pursuit of *self-chosen* goals and relationships.'[72]

John Stuart Mill further observes that the capacity to choose, and the exercise of this choice, is in itself fulfilling, enabling us to use our 'human faculties of perception, judgment, discriminative feeling, mental activity, and even moral preference' to come to a reasoned decision.[73] As Julian Savulescu succinctly puts it, choices 'are independently valuable when they are expressions about active decisions and deliberations about one's life and how to live. There is a value in just deciding to be'.[74]

Finally, some philosophers view autonomy as having normative value, independent of its contribution to welfare. As Molyneux argues, there is a 'strong intuition' that 'part of being human involves deciding how one should live, and this should be respected even when individuals make decisions that will reduce their welfare'.[75] Molyneux draws on Darwall's theory of demand autonomy, which involves an essentially Kantian argument that there is something fundamentally important about

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[71] W. Kymlicka, Liberalism, Community, and Culture (Clarendon Press, 1991), 12.

[72] J. Raz, *The Morality of Freedom* (Clarendon Paperbacks, 1988).

[73] Mill, *On Liberty* (n57), 122.

[74] J. Savulescu, 'Autonomy, the good life, and controversial choices'. In: Rhodes R, Francis LP, Silvers A, eds. *The Blackwell guide to medical ethics* (Oxford: Blackwell, 2006) 17–37.

[75] Molyneux (n64), 247.

being a person that demands our respect for the person's autonomous choices,[76] 'not because the choices are respect-inducing in themselves, but because respect for choices is what one person can reasonably demand of another person.'[77] In other words, respect for a person demands that we respect their autonomy, even when to do so would not necessarily promote their individual welfare. It is not the fact of personhood that warrants this respect, but rather, as Simon Lee suggests,[78] that people have the capacity to make decisions that are reasoned and reflect their true desires.

Given the normative importance that is attached to people being free to make autonomous choices, it is clear, as Mill suggests, that this sphere of independence should not be too readily interfered with by the state. One circumstance in which most accept that the state has jurisdiction to intervene, is where in exercising their autonomy, a person causes (or is likely to cause) harm to another, thereby interfering with that person's autonomy. Many legislative interventions may be seen as having this as their aim. Mill captured it thus: 'the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is *to prevent harm to others*.'[79] Of course this must be subject to qualifications. Mill himself set out a number: he differentiated harm (an action that was injurious or set back important interests of others) from 'mere offence' (which did not warrant protection);[80] excluded

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[76] S. Darwall, 'The Value of Autonomy and Autonomy of the Will' (2006) 116(2) Ethics, 263.

[77] Molyneux (n64), 248.

[78] S. Lee, *Law and Morals: Warnock, Gillick, and Beyond* (Oxford University Press, 1986), 64.

[79] Mill, *On Liberty* (n57), 68.

[80] Mill, *Utilitarianism* (n59), 141. This distinction was reiterated by Joseph Feinberg, who likewise distinguishes hurt and offence — which while undesirable, does not thwart our interests — from harm, which he defines as a setback to interests (see J. Feinberg, Harm to Others: The Moral Limits of the

consensual harms;[81] and reiterated that harm prevention should be seen as a necessary, but not a sufficient condition for restricting individual liberties (which will depend on a utilitarian calculation of whether the benefits of regulation outweigh the disadvantages of doing so[82]). While it is not necessary to examine these in detail for the purposes of this discussion, it is clear that the law has a legitimate utilitarian goal of promoting the welfare of its citizens, such that when a person's welfare is infringed by another, the law is sometimes justified in encroaching on the liberty of the infringer in order to prevent this from occurring. Preventing harm being caused to others is thus a legitimate basis on which to interfere with a person's autonomy.

Much more contentious, however, is the role of the state in protecting its citizens from *themselves*. Mill adopted a robust stance against paternalism: paternalistic interference of the state is not deemed acceptable where a person understands the decision they are making and is capable of freely exercising their autonomy. However, later liberal philosophers have been less vociferous in their objections to paternalism with Raz arguing that the state can intervene to prevent harm to oneself in certain circumstances. Central to Raz's theory is the idea that the government has a positive duty to protect and promote the autonomy of its citizens. The use of coercion thus violates their autonomy:

> First, it violates the condition of independence and expresses a relation of domination and an attitude of disrespect for the coerced individual. Second, coercion by criminal penalties is a global and indiscriminate invasion of autonomy.[83]

Criminal Law Volume 1 (Oxford Scholarship Online, November 2003), 45-51). For a more in depth discussion of the nature of 'harm' see n661.

[81] ibid, 142.

[82] Mill, *Utilitarianism* (n51), 70.

[83] Raz (n72) 418.

It ‘thus defeats the purpose of promoting [autonomy]’,[84] and is a way of causing harm to the person, depriving them of opportunities, or of the ability to use them, which they would otherwise have.[85] Where coercive power is necessary to prevent one’s actions diminishing the autonomy of others however, or ‘even of that person himself in the future’,[86] it may be justified. Accordingly, Raz accepts some level of paternalistic interference where it is necessary to protect the person from making decisions which severely limit their future autonomy. While he does not set out in detail when these circumstances will be, he notes in particular that

> paternalism affecting matters which are regarded by all as of merely instrumental value does not interfere with autonomy if its effect is to improve safety, thus making the activities affected more likely to realize their aim.[87]

Regulations directed at the safety and efficacy of products or mandating the use of seat belts in cars may therefore be justifiable: they do not greatly violate the person’s autonomy, since the behaviour which they constrain is not a central purpose of the person’s reason for acting. He draws a distinction between this, and a risky sport, ‘where the risk is part of the point of the activity or *an inevitable by‐product of its point and purpose*.’[88] It is the latter, which aligns more closely with the sorts of decisions being contemplated in this thesis — albeit that it may depend to an extent on

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[84] ibid, 419.

[85] ibid, 413.

[86] ibid.

[87] ibid, 422.

[88] ibid, 422.

the precise decision and context in question. Where a person makes a decision to either have or to refuse a treatment or care decision, usually they are deliberately seeking a certain outcome, or at the very least, they are aware that certain risks are an inevitable consequence of making the choice that they have. The risks are therefore rarely unforeseeable or inadvertently taken — rather the person has weighed up the advantages and disadvantages of different courses of action, and made a value-judgement about which they would rather pursue. When a person decides to refuse chemotherapy for example, this will generally be a deliberate wish to prioritise the quality of their life over its longevity. Likewise when a Jehovah's Witness refuses a blood transfusion, their very reason for deciding as they have is to prevent blood entering their body, as they consider adhering to religious doctrine to be more important than the risk of premature death. Where such decisions involve a person making an informed value-judgement about which outcome they wish to pursue, preventing them from acting in accordance with their own reasons and values would constitute a very large invasion of their autonomy. This is especially so given that unlike for health and safety regulations or the mandatory wearing of seatbelts, such interventions do not entail the removal of 'bad' options at a legislative level, but rather involve an individual doctor or carer taking a view of what is best for the specific person in the future and overriding individual choices accordingly. The nature of this interference is also arguably more substantial. Overriding a person's treatment or care decision in a way that protects their future autonomy will usually involve imposing treatment or protective care measures on them, which will infringe either their bodily integrity or their liberty. So while forcing somewhere to wear a seatbelt or abide by safety standards does interfere with a person's autonomy by removing some of the choices that are available to them, it is to a much lesser degree that forcing drugs or an operation on someone who is resisting, and is far less likely to produce psychological or emotional harm. This issue will be discussed further in Chapters 4 and 5. Suffice to say however, that overriding a person's considered treatment decision, especially in such a coercive manner, would not seem to be the kinds of interferences being contemplated by Raz, nor do his views substantially undermine the importance attached to people being able to exercise their autonomy in decisions about their treatment and care. Indeed elsewhere, when discussing legitimate authority, he is clear that:

> Decisions about the safety of pharmaceutical products are not the sort of personal decisions regarding which I should decide for myself rather than follow authority. They do not require me to use any drugs, etc., and in that they are unlike decisions about undergoing a course of medication or treatment where we may well feel that I should decide for myself, rather than be dictated to by authority.[89]

There may, however, be circumstances where a person is deemed sufficiently 'vulnerable' to need especial protection on the part of the state; as when they are unable to exercise the powers of understanding, reasoning and deliberation required to make a truly autonomous choice which protects their rights or interests. Interventions on such grounds have been termed by some 'soft paternalism'.[90] Mill gives the example of someone about to cross a bridge that is unsafe. If there is not time to warn him, then it is acceptable to grab him and pull him back, as this does not interfere with his liberty, as liberty is only the freedom to do what one desires, and in this instance, he does not desire to fall into the river below. If, however, he determines, with knowledge of the risk, to proceed over the bridge, we must accept his autonomous choice.[91] While

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[89] J. Raz, 'The Problem of Authority: Revisiting the Service Conception' (2005) 90 Minn. L. Rev. 1003.

[90] J. Feinberg, *Harm to Self* (Oxford: Oxford University Press 1986).

[91] Mill, *On Liberty* (n57), Ch 5.

in this instance the lack of autonomy is attributable to a lack of information rather than an inherent vulnerability caused by an impairment or illness, it still demonstrates that in Mill's view, a degree of paternalistic interference is deemed acceptable where it does not interfere with the *autonomous* choices of people.

Mill is clear that libertarianism does not extend to those who cannot make autonomous decisions. Immediately following the harm principle, he notes, 'it is perhaps hardly necessary to say that this doctrine is meant to apply only to human beings *in the maturity of their faculties*... Those who are still in a state to require being taken care of by others must be protected against their own action as well as against external injury'.[92] Later this is made even more explicit: the principle of liberty has no application to people incapable of 'free and equal discussion',[93] those without an 'ordinary amount of understanding',[94] or to someone who is 'a child, or delirious, or in some state of excitement or absorption incompatible with the full use of the reflecting faculty'.[95] H.L.A Hart similarly argues that paternalism can be justified if a person's capacity to make free and informed choices is diminished by factors such as 'inner psychological compulsion' or 'pressure from others', or where they have an inadequate appreciation of the consequences of their choices.[96]

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[92] ibid, 69.

[93] ibid.

[94] ibid, 142.

[95] ibid, 166.

[96] H.L.A Hart, Law, Liberty and Morality (Oxford University Press, 1963), 32-33.

It would seem then, that if a person's autonomy is severely impaired, the moral imperative to refrain from interference no longer applies. Intervention by the state, contrary to the norm for those who are autonomous, no longer constitutes the same infringement of a person's autonomy and liberty. According to Kant, it is their capacity for rational action that distinguishes humans from other animals, and makes them worthy of respect.[97] As Simon Lee suggests, respect for autonomy thus rests on an assumption: that people are rational beings, capable of assessing the information and weighing the options available to them.[98] The value in recognising people as rational agents capable of making choices, is therefore deemed less pertinent for people who lack that decision-making ability. Geoffrey Scarre makes this point in relation to children (albeit he perhaps underestimates their ability to form 'systems of purpose'):

> the reason why we cannot carry the alcoholic away for a fortnight's forcible cure, even though his drinking is harmful and is not sanctioned by his reason, is that by doing so we should insult him by imposing our plans for his life on him when, as an adult, he has plans and policies of his own…. Children do not have such systems of purpose of their own so it does not infringe their rights to intervene in their behalf when their irrationality threatens their well-being.[99]

The same may be said of those whose autonomy is impaired in others ways, and who are (to a greater or lesser extent) unable to form a coherent vision of their own lives and values. As Herring observes, enabling people to flourish 'may be possible with little intervention by the state' for some people, but for others, some degree of intervention may be necessary 'to enable a person (or group of people) to live their

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[97] E. Kant, *Groundwork of the Metaphysics of Morals* (Cambridge Texts in the History of Philosophy ed, 2 edn, Cambridge University Press 2012).

[98] Lee (n78).

[99] G. Scarre, Children and Paternalism (1980) *Philosophy* Volume 55, Issue 211:117-124, 123-124.

lives fully.'[100] Generally, the decisions people make will reflect their values and desires, enabling them to live according to their own conception of the good life. Those who are incapable of making autonomous decisions, however, may not be able to make decisions which reflect and further their priorities and interests. It may even be that they are influenced, dominated or coerced by others. In these cases, then, the law is justified in intervening to ensure that the decision that is made is one which promotes the person's interests, and to prevent them from harming themselves through making decisions, the consequences of which they do not fully appreciate. While people with autonomy ought then to have the liberty to make decisions free from state interference, for those who are incapable of autonomy, the law has a legitimate role in intervening to ensure that the decision made best reflects the person's values and beliefs, and protects their interests. The capacity threshold thus plays an important role in defining the limits of legitimate state intervention.

It is imperative therefore, that the law can distinguish those who are capable of making autonomous choices from those who are not. This is the role of capacity in law. As Jonathan Herring and Jesse Wall note (above), legal capacity 'typically seeks to determine the minimum necessary for autonomy and treats the person as autonomous once they cross that threshold.'[101] Capacity is therefore generally understood as a condition for the exercise of autonomy: if a person has capacity, then absent other ways in which their autonomy may be being undermined (such as the coercion or undue influence of others), they are deemed to be capable of acting autonomously. If they do not, they are thought to be non-autonomous. Given the consequences of a finding that

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[100] Herring, *Caring and the Law* (n74), 304.

[101] Herring and Wall (n1).

the person either has, or lacks capacity, it is crucial that the test for capacity in the MCA should be able to delineate these conditions reliably.

Although the MCA imposes a presumption in favour of a person having capacity,[102] whether they are deemed capable of making a decision depends on whether they meet the test for capacity set out in sections 2 and 3 of the MCA. Under section 2(1) MCA, ‘a person lacks capacity in relation to a matter if at the material time [they are] unable to make a decision for [themselves] in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.’ Section 3(1) further explains that 'for the purposes of section 2’, a person is ‘unable to make a decision’ if they are unable’-

> (a) to understand the information relevant to the decision,
> (b) to retain that information,
> (c) to use or weigh that information as part of the process of making the decision, or
> (d) to communicate [their] decision (whether by talking, using sign language or any other means).

A key question that will be considered in this thesis is therefore whether or not this capacity test is sufficient to reliably distinguish those who are capable of making autonomous decisions from those who are not.

Autonomy and paternalism in the medical context

When considering the role of capacity in demarcating the appropriate limits of state intervention, it is important to note how the medical context may differ from other contexts in which the state is interfering with the autonomous decisions of its citizens. In the medical sphere, decisions are generally made after something has gone wrong: a person has been injured or harmed and a decision has to be made about how best to

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[102] MCA, s1(2).

help them. This decision is based *not* on a generalised assumption about what is 'good' for people (as in some other instances of state paternalism), but on a doctor's detailed assessment of the individual patient – their circumstances, values, priorities.[103] Moreover, unlike in some other contexts, the doctor in these cases may *legitimately* claim that they are well-placed to have a view on what is best for the person, and what the effect of deciding differently may be on them, based not only on their superior medical expertise, but also on their accumulated experience of dealing with similar cases.

These differences may alter the way we think about the balance between autonomy and paternalism in the realm of medical decisions. Ordinarily, we assume that people know best what is good for them, and decide accordingly. Respecting their autonomy is thus an essential component of ensuring their welfare. While this will often be true in medical decisions too, the context in which decisions must be made – frequently in conditions of pain, enormous stress and heightened emotion – may distort the person's reasoning abilities, and raise doubts over whether they are *always* best placed to know what decision will be best for them. In addition, the specialist nature of therapeutic interventions may well necessitate a degree of technical knowledge and understanding that the layman cannot reasonably be expected to possess, such that they may often not understand all the implications of their decision; or how the decision might affect the opportunities available to them in the future.

Many commentators have pointed to the deficiencies that attach to decision-making in a medical context. Katz, for example, cites 'ignorance, misconceptions, exaggerated fears, and magical hopes about tests and therapeutic interventions' as

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[103] The importance of engaging with the values, priorities and commitments of the individual patient was stressed in *Montgomery v Lanarkshire Health Board* [2015] UKSC 11, discussed in more detail below.

influences that can distort the thinking even of those who have capacity;[104] and certainly when it comes to decision-making about others, there are multiple examples of parents withholding medical treatment from their children in the belief that God may intervene or a miracle cure will be found.[105]

Levy, meanwhile, relying on literature from psychology, has found that humans typically discount the future, over-estimate the effects of events and changes in circumstances on their level of well-being, and under-appreciate their ability to adapt to new circumstances. They are often unreliable at predicting how future events will make them feel, just as they tend to forget exactly how past events felt at the time.[106] There is also ample evidence that people are not always very good at understanding statistical information, or applying it to themselves.[107] While these weaknesses will have some bearing on decisions of every kind, they are particularly pertinent to the medical context, where even relatively minor decisions can have extensive and long-lasting consequences, and where statistics play a major role. This may result in people making decisions that do not accurately reflect their values, or in people being unable to see how different treatment decisions may continue to allow for these values and goals to be achieved even in circumstances they had not previously envisaged.

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[104] J. Katz, 'Can principles survive in situations of critical care?' in J. Moskop and L. Kopelman (eds), *Can Principles Survive in Situations of Critical Care?* (D Reidel and Kluwer Academic, 1985), 41, 55.

[105] see J Brierley et al, 'Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children?' *J Med Ethics*, doi:10.1136/medethics-2011-100104, accessible at < http://jme.bmj.com/content/early/2012/03/08/medethics-2011-100104.full>.

[106] N. Levy, 'Forced to be free? Increasing patient autonomy by constraining it' (2014) 40 JME 293.

[107] Which may depend on factors such as the patient's educational background: see M. Galesic et al, 'Statistical Numeracy for Health: A Cross-cultural Comparison With Probabilistic National Samples' (2010) 170(5) *Arch Intern Med* 462–468.

Against this background, the presence of a beneficent expert who can bring both objectivity and experience to bear is important. That is not to say that the doctor's opinion is infallible, or that their view of what is best, if in conflict with that of the patient, will necessarily always be the 'better' one. But it does mean that within this context there is another actor whose training and experience makes them particularly well placed to anticipate how the decision might affect the patient in the future, in a way that a patient without experience of the treatment or condition may not. The doctor and the patient may then both legitimately have different perspectives on what is best for the patient, or about how to achieve the outcome that they both consider to be desirable.

The role of the doctor in these situations may then be to help the patient come to a decision that will not just help them therapeutically, but will better reflect their essential values, through testing the patient's understanding, engaging in discussion of why they have chosen as they have, offering counselling, and giving the patient the opportunity to reflect on their decisions. The 'state actor' in this scenario is not therefore intervening merely to frustrate a person's wishes and impose a decision upon them that they do not want, but rather is essential to them reaching an autonomous decision in the first place, providing them with the conditions necessary for them to make an autonomous choice.

The existence of the benevolent expert is important not just because it alters the relationship between autonomy and paternalism, but also because it involves another individual in the decision-making process — an individual who may have entirely different value-systems. In the interviews conducted with doctors for example, underpinning a lot of the responses was a perceived conflict between their duty to respect autonomy, and an ethical imperative to prevent harm, and to promote what they regard as in the patient's interests. This reflects the four key principles proposed by Tom Beauchamp and James Childress that ought to guide decision-making in the medical context:[108] respect for autonomy; non-maleficence; beneficence and justice. In many of the cases that will be considered below, in which the patient wishes to act in a way which the doctor considers to be harmful to them, these principles may pull in different directions: where the patient's autonomy is respected, the other principles are subjugated to it. Respecting the patient's autonomy must therefore be balanced against these other principles, most especially that of not causing harm to the patient. It becomes clear that there are different, overlapping ethical frameworks involved in such decisions.

Indeed one of the key problems with the way these decisions are made in practice is that the decision-maker may adhere to (or be influenced by) a number of other values which are not accounted for in the law. The law is premised on autonomy being the foundational value which determines the legitimacy of legal interventions. In practice, however, as will become apparent throughout chapters 1 and 2, the doctor might have all manner of values and commitments guiding their decision-making. So when a doctor overrides a patient's decision, it may be less because a person is not capable of deciding autonomously than because that decision conflicts with profoundly held values on the part of the doctor. And this of course distorts the way that the capacity threshold operates in practice, and the clear line drawn by the law between those with autonomy and those without.

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[108] T. L. Beauchamp and J. F. Childress, *The Principles of Biomedical Ethics* (4 ed, Oxford University Press, 1994).

I Problems with a cliff-edge approach to capacity

As the discussion above highlighted, the consequence of the law adopting a cliff-edge approach to capacity is to place a great deal of pressure on the capacity threshold as a means of accurately distinguishing those who are capable of autonomous decision-making from those who are not. The question explored in Chapter 1 is therefore whether the capacity threshold is capable of bearing the weight placed on it, given that the realities of decision-making are somewhat more complex than the law supposes.

It will be suggested that the law as it currently stands falls short in three ways. Firstly, the test for capacity adopts too narrow a conception of autonomy, which fails to account for situations in which the substance or content of the person's values have become disordered, with the result that someone might, on the face of the statute, have capacity, yet nonetheless be incapable of autonomous choice.

Secondly, the current law does not account for the fact that autonomy is not all-or-nothing, but admits of degrees: autonomy may be impaired to different extents and in qualitatively different ways. Consequently, there will inevitably be a 'grey area' on the cusp of capacity, where a person's autonomy is uncertain — a problem exacerbated by the realities of decision-making in the clinical or social care context, and the paucity of time and information generally available to decision-makers when making capacity assessments. The effect is that disagreements are arising over whether or not a person has capacity, both among doctors, and between doctors and judges, leading to the test being applied inconsistently as between decision-makers.

This inherent uncertainty, when combined with the fact that the capacity test fails to impairments in the person's values, and the cliff-edge approach taken in the law, which means that the consequences of finding a person to have or to lack capacity are stark, has led to the third problem: a predisposition among doctors to tip their patients 'over the cliff' into incapacity to allow them to make best interests decisions on the patient's behalf, particularly where the consequences of the decision are grave. This means that the way in which capacity test is applied can vary significantly, as some doctors (very understandably) are taking into account the outcome they wish to achieve when determining what 'level' of capacity the person must exhibit.

In failing to account for the complexities of decision-making, the test for capacity does not inspire sufficient confidence in those who must apply it, that it can reliably distinguish between those who should be considered capable of making an autonomous decision and those who should not. In this sense, it might be criticised for being both under and over-inclusive. While the wording of the Act (and the lack of provision for assessing the substance of a person's values) might lead to people being found to have capacity when they cannot make autonomous decisions, the practical implementation of the statute by doctors and other decision-makers — contrary to the provisions on the face of the statute — has resulted in people being too readily found to lack capacity when they may in fact be able to make autonomous decisions.

I Too narrow a conception of autonomy

The test for capacity, as currently employed, reflects a restricted conception of autonomy, which does not seek to determine whether the person's decision reflects values and beliefs that are authentic to them. The result is that a person could be found to have capacity even though their decision rests on beliefs and values that are disordered. In order to address this problem, both doctors and the courts have relied on a strained interpretation of whether the person can 'use and weigh' the information relevant to their decision, to encompass these concerns. This, however, has been at the expense of clarity, consistency and transparency.

(a) What account does the MCA adopt?

Innumerable competing conceptions of autonomy have been advanced in both moral and political philosophy, which emphasise different aspects as essential to the concept. As Gerald Dworkin writes:

> It is used sometimes as an equivalent of liberty (positive or negative in Berlin's terminology), sometimes as equivalent to self-rule or sovereignty, sometimes as identical with freedom of the will. It is equated with dignity, integrity, individuality, independence, responsibility, and self-knowledge. It is identified with qualities of self-assertion, with critical reflection, with freedom from obligation, with absence of external causation, with knowledge of one's own interests. It is even equated by some economists with the impossibility of interpersonal comparisons. It is related to actions, to beliefs, to reasons for acting, to rules, to the will of other persons, to thoughts, and to principles. About the only features held constant from one author to another are that autonomy is a feature of persons and that it is a desirable quality to have.[109]

Given this multitude of ways in which autonomy can be understood, it is important to be clear at the outset that for the present discussion, we are concerned with autonomy only in the sense of a quality, trait or characteristic that individuals can exhibit throughout their lives, not in a Kantian sense[110] (which concerns the person's capacity to impose moral law on themselves), or as a source of political legitimacy.[111] Even with this in mind however, there are a number of different understandings of the concept,

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[109] G. Dworkin, *The Theory and Practice of Autonomy* (New York: Cambridge University Press 1988), 6.

[110] Kant (n97).

[111] According to this use, political power and authority can only be justified if it is acceptable to all of the citizens who are bound by it (see for example, J. Rawls, *Political Liberalism* (1993, New York: Columbia University Press),144-150).

which vary both in their substantive demands, and in what capabilities they regard as being essential to the exercise of autonomy.

John Coggon provides a useful taxonomy of the three main understandings of autonomy.[112] These are:

1. Ideal desire autonomy — Leads to an action decided upon because it reflects what a person *should* want, measured by reference to some purportedly universal or objective standard of values.
2. Best desire autonomy — Leads to an action decided upon because it reflects a person's overall desire given his own values, even if this runs contrary to his immediate desire.
3. Current desire autonomy — Leads to an action decided upon because it reflects a person's immediate inclinations, i.e. what he thinks he wants in a given moment without further reflection.[113]

On the face of it, the MCA appears to adopt the least demanding of these three understandings in its test for capacity: current desire autonomy. The test set out in section 3 MCA focuses only on the person's decision-making *process* — whether they can understand the information pertinent to their decision, retain that information, and reason about it. But there is nothing at all in the Act which explicitly addresses whether or not the decision reflects the person's underlying values and beliefs. This approach allows the law to adopt a form of 'value-agnosticism':[114] whether a person has capacity in relation to a decision may be judged by reference to the person's reasoning alone, without having to engage with the substance or content of their values. Indeed, as Lord Donaldson set out in *Re T,* a person is entitled to refuse treatment or care interventions

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[112] J. Coggon, 'Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?' (2007) 15 Health Care Analysis 235, 240.

[113] ibid.

[114] J. Coggon and J. Miola, 'Autonomy, Liberty, and Medical Decision-Making' (2011) 70 (3) CLJ 523–43, 528.

whether the reasons are 'rational, irrational, unknown or even non-existent'.[115] This, as Coggon notes, would seem to suggest that 'as long as the patient's thought processes are not in doubt, his underlying reasons are not open to question'.[116]

While this approach may have the benefit of value-neutrality (important in a society committed to pluralism and tolerance), the following section will highlight why such an account of autonomy is deficient, given its potential to allow people to make profoundly harmful decisions on the basis of beliefs which are clearly disordered. Where this is the case, and decisions are motivated by inauthentic values or reasons, it is doubtful whether the same normative importance attaches to respecting them.

The effect of a failure to scrutinise the content of the values underpinning a person's decision is vividly illustrated by the case of *The NHS Trust v Mrs T*.[117] Mrs T suffered from borderline personality disorder. She had, on a number of occasions, self-harmed through blood-letting, with the result that her haemoglobin level was life-threateningly low, and she required a blood transfusion. Despite understanding that the consequence of refusing it were that she would die, she was nonetheless resistant to a transfusion, and accordingly wrote an advance directive setting out her intentions, and giving the grounds for her decision:

> I believe my blood is evil, carrying evil around my body. Although the blood given in transfusions is perfectly healthy/clean, once given to me it mixes with my own and also becomes evil. Contaminated by my own. Therefore, the volume of evil blood in my body will have increased and likewise the danger of my committing acts of evil.[118]

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[115] *Re T* (n16), 664.

[116] Coggon (n112), 239.

[117] [2004] EWHC 1279 (Fam).

[118] ibid, [9].

The difficulty in this case lies not in Mrs T's reasoning process, but in her disordered belief about her blood. If one accepts her premise — that any blood entering her body will become evil and cause her to commit evil acts — to refuse a blood transfusion is an entirely logical, indeed honourable, decision. As Coggon and Miola note, 'here, the rationality of the patient's decision-making is not to be doubted; it is the rationality of her *starting point* that is questionable.'[119] An approach which focuses only on process and not on substance ought to permit Mrs T to make this decision. It is doubtful, however, given her clearly disordered belief, that most people would regard this as a genuinely 'autonomous decision', still less one which the law ought to uphold, given the profound harm this would cause for Mrs T. It is no surprise that the judge in this case found her to lack capacity on the basis that her belief (which he described as a 'misconception of reality' evidencing a 'disorder of the mind'[120]) meant she was 'unable to use and weigh the relevant information'.[121]

While *Mrs T* may seem an extreme case, there are many instances of mental illness affecting a person's values and beliefs. One example of this is in anorexia nervosa, where the desire to 'be thin', even at the expense of physical health and well-being, may be thought to stem not from the authentic desires of the person, but from

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[119] Coggon and Miola (n114).

[120] *Mrs T* (n117), [61].

[121] ibid, [62].

their illness.[122] In Tan *et al*'s study of young women with anorexia,[123] it was found that the women rationally understood and accepted information about their weight and the consequences of a failure to take in further calories. So, their decision to refuse food was not based on an inability to understand or reason; rather the values that influenced their decisions — an overwhelming desire not to put on weight, and a deprioritising of death — were distorted by their condition. Likewise, in a recent study of adults, only 34.3% of the 70 patients with anorexia were clinically assessed to have diminished capacity to consent to treatment.[124]

The effect of mental illness on a person's value systems is equally pronounced in cases of severe depression. Jesse Wall for example, observes that 'individuals with major depression may employ a reflective attitude that is informed by a sense of worthlessness or excessive pessimism',[125] as depression tends to impair their 'concern for self and appreciation of future possibilities'.[126] Matthew Ratcliffe describes the depressive as undergoing 'existential change'[127] in which 'she gradually loses the sense

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[122] For a full discussion see T. Hope et al, 'Anorexia Nervosa and the Language of Authenticity' (2011) 40 Hastings Center Report 19.

[123] J. Tan et al, 'Competence to refuse treatment in anorexia nervosa' Int J Law Psychiatry 2003; 26: 697–707.

[124] F. Isis et al, 'Mental capacity to consent to treatment in anorexia nervosa: explorative study' British Journal of Psychiatry Open Mar 2016, 2 (2) 147-153.

[125] J. Wall, 'Being Yourself: Authentic Decision-making and Depression' in C. Foster and J. Herring (eds), *Depression: Law and Ethics,* 134-144, 139.

[126] ibid, 134.

[127] M Ratcliffe, *Experiences of Depression: A Study in Phenomenology* (Oxford University Press, 2015), 14.

that the world could offer happiness; she ceases to experience its possibility'.[128] The effect is that the person loses their sense of agency, and in losing any conviction that they may be able to alter their circumstances, they lose the will to do so. As Mary explains:

> In decisions about treatment for the depressive condition, if there is no possibility of improvement/recovery, then treatment is either a hopeless, or where the person experiences existential guilt, a wrongful waste. A similar issue arises with treatment for other illnesses or conditions. Although such conditions may have other biological bases, the interlinkage between bodily feelings and existential feelings, means that the experience of a loss of possibility of recovery may well extend to these. Thus, in both respects, a person may have a perfectly accurate cognitive understanding of the proposed treatment, its side-effects, risks and benefits, but may be unable to conceive that the treatment would succeed. It is not simply that s/he does not believe that the treatment will be effective in his or her case; rather, the scope of his or her 'possibility space' is so reduced that such a possibility does not even arise.[129]

Donnelly draws further on evidence from Owen *et al,* which suggests that depression has an effect on what they termed the person's 'temporal agility'.[130] Part of that includes the person's ability to see their future as open and to recognise the impact of their choices on that future, or to conceive of different possible futures.[131] For people with severe depression,

> the future was not experienced as open or as able to be shaped by their actions. Alternatively, some seemed to be able to see a future but not a future that made a difference or one which was normatively differentiated. For people in this situation,

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[128] ibid, 66.

[129] M. Donnelly, 'Depression and Consent to Treatment: The Limits of a Capacity-based Approach' in C. Foster and J. Herring (eds), *Depression: Law and Ethics,* 200-210*,* p205.

[130] G. Owen et al, 'Temporal Inabilities and Decision-making Capacity in Depression' (2015) 14 *Phenomenology and the Cognitive Sciences* 163, 165.

[131] ibid, 170.

> decisions lack significance; they make no difference and offer no possibility for the future.[132]

Despite the very high incidence of depression among the general population (evidence suggests as many as one in five people suffer from depression at some point in their adult life[133]), there is currently 'very little jurisprudence regarding the operation of the MCA standard in the context of a depressive condition'.[134] One reason Donnelly gives for this is that the very nature of the condition means that those suffering from it are 'less inclined to engage in the legal process to dispute a finding of incapacity'.[135] Empirical evidence suggests however that people with severe depression may be more likely to be wrongly assessed as lacking capacity (according to the terms of the MCA), when they ought not to be. Owen *et al* for example, found that while 31% of patients admitted onto a psychiatric ward with depression did lack the capacity to make treatment decisions (proportionately far fewer than patients on the ward generally),[136] the tests did not measure the person's insight into their own condition as effectively in non-psychotic disorders such as depression, resulting in more people wrongly being found to lack capacity.[137] While greater empirical evidence is needed before any

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[132] Donnelly, 'Depression' (n129), 206.

[133] In 2014 for example, 19.7% of people in the UK aged 16 and over showed symptoms of anxiety or depression: J. Evans et al, Measuring national wellbeing: Life in the UK (2016) ONS. Available at < https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/measuringnationalwellbeing/2016#how-good-is-our-health.>.

[134] Donnelly, 'Depression' (n129)*,* 202.

[135] ibid.

[136] G. Owen et al, 'Mental Capacity to Make Decisions on Treatment in People admitted to Psychiatric Hospitals: A Cross-sectional Study' (2008) 337(7660) *British Medical Journal* 40.

[137] ibid.

definitive conclusions can be drawn in relation to the prevalence of these false negatives, this evidence does suggest that there is reason to question whether the MCA as it is currently framed is able to capture the complex ways in which a person's decision-making ability might be adversely affected by depression.

Both anorexia nervosa and depression involve situations in which a person's reasoning processes may be intact, and yet they may still reach a decision that does not reflect their beliefs or values, since the values underpinning that decision are themselves distorted or impaired by illness. Herring and Wall are rightly critical of the MCA's failure to provide any mechanism for evaluating the *content* of the person's values in such cases: providing a person can understand and use the information, it is not necessary for decision-makers to consider whether the person is being true to themselves in their expressed beliefs, desires and preferences.[138] Rigid adherence to the MCA would thus enable someone to make harmful, even life-ending decisions, in this situations.

It was suggested above that our fulfilment in life depends on our ability to pursue those priorities and commitments that matter to us, to lead our lives in accordance with our own values and beliefs. If, however, the person is not acting on authentic beliefs and values — because their decision is being dictated by a mental illness — then respecting that decision will not help the person to flourish or develop their individuality, indeed the decision they make may even be antithetical to their objectives and priorities more generally in life. By focussing only on the person's immediate inclinations then, current desire autonomy cannot distinguish between those decisions made in pursuance of values and objectives which are important to the

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[138] Herring and Wall (n1), 709.

person, and those which are driven purely by illness or phobia. Where, in addition, the decision made also undermines the person's welfare (as where it involves the refusal of treatment or food), then there would seem no good reason to respect it: if the value in respecting a person's choices is that doing so is most likely to enhance their welfare, then a decision that neither promotes their welfare, nor is driven by values that are important to them, would not seem to demand that same respect. If the normative importance of autonomy is to be realised, enabling people to live our life according to values and priorities that are important to them, it must therefore be more demanding than current desire autonomy would suggest.

(b) How have decision-makers responded to this minimalist account of autonomy?

The effect of the MCA adopting such a minimalist account of when a decision ought to be treated as autonomous (and thus capacitous) is to leave decision-makers (be they doctors, care workers or judges) in a difficult position in circumstances where the person's reasoning appears to be intact, but the substance of their values is disordered. As one psychiatrist interviewed for this thesis summed it up:

> The legal test is built for people with cognitive impairment. When people have a mental impairment that is affecting their values and their desires and their wishes, that's when it becomes tricky - because their decision-making processes often seem intact. Because it is their values - and therefore their ability to weigh up when it comes to their values - that is affected, not their ability to understand something or retain it.[139]

A clinician called upon to make an assessment of capacity in such a case ought, if applying the statute properly, to find the person to be capacitous (they can understand the information, retain it, and weigh it up) and would therefore be required to allow the patient to refuse medical treatment if desired, even though it may be harmful — or, as

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[139] Interview [anonymised] (Oxford, May 2017).

in the case of *Mrs T*[140] or an anorexic patient refusing food, certain to end in death. However, in many such cases, both doctors and judges have demonstrated an understandable and no doubt well-intentioned reluctance to accept such decisions as autonomous, and to permit the person to make a deeply harmful decision on account of it.

St George's Healthcare NHS Trust v S[141] provides a clear example of doctors attempting to capture concerns about the content of the person's values. (Although the case was brought before the passing of the MCA, the requirement that the person was able to 'weigh' the information was also included in the common law test for capacity pre-MCA[142]). This case concerned a woman who at 36 weeks pregnant was diagnosed with pre-eclampsia. Despite being told that both her own life and that of her unborn child were at risk, she refused treatment for the condition, saying that she believed that nature should take its course. When asked to explain her reasons for refusing treatment, S did so with extreme clarity and articulacy, writing:

> At the request of Dr. Jeffreys, senior registrar, I am writing in an effort to clarify my views, and my reasons for upholding them so strongly, with regard to medical or surgical intervention in the case of illness (specifically at this time; pre-eclampsia). (i) I am a qualified veterinary nurse, and am therefore quite able to comprehend the medical terminology used, and feel happy to ask for clarification if an unfamiliar term is used. (ii) I fully understand that pre-eclampsia is a potentially life-threatening condition, i.e. that the raised blood pressure may lead to haemorrhage, shock and, if untreated, death; or alternatively death due to total organ failure resulting from inability to compensate. (iii) I have always held very strong views with regard to medical and surgical treatments for myself, and particularly wish to allow nature to 'take its course,' without intervention. I fully understand that, in certain circumstances this may endanger my life. I see death as a natural and inevitable end point to certain conditions, and that natural events should not be interfered with. It is not a belief

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[140] *Mrs T* (n117).

[141] [1998] 3 All ER 673.

[142] *Re C (Adult: Refusal of Treatment)* [1994] 1 WLR 290, 292.

> attached to the fact of my being pregnant, but would apply equally to any condition arising.[143]

Taken at face value, this reasoning does not appear non-autonomous. On the contrary, it suggests a well-thought-out decision which reflects long-standing and deeply held beliefs about not interfering with nature — beliefs which, while unusual, are no more obviously irrational than letting God determine one's fate. This is supported by the fact that S chose not to attend any antenatal classes until 36 weeks pregnant, consistent with her stated desire to minimise medical involvement. The view of the treating clinicians, however, was that S was severely depressed, having experienced a number of recent difficulties with 'relationships, housing, changing jobs and indeed being pregnant with a child that she says she doesn't want and would give to the father as soon as it is born.'[144] The treating clinician, Dr Jeffreys explained that:

> She appears to be significantly depressed with low self-esteem and a profound indifference to the consequences of refusing treatment for her serious physical condition. She is pregnant and her behaviour is putting her own life and the life of her unborn baby at risk.[145]

At times she appeared 'tearful', and said that she 'would not be bothered if she dies and it would be better for the baby to be dead'.[146] When it was suggested to her that the baby might die (in response to her request to give birth to the baby in a barn in Wales), she responded that she was not interested in the pregnancy or the baby,[147] and

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[143] *St George* (n141), 681 [E-G].

[144] ibid, 678 [J].

[145] ibid, 679 [J].

[146] ibid, 680 [B].

[147] ibid, [G].

demonstrated complete indifference to ‘the fact that she could die or be severely brain damaged if the pre-eclampsia is not treated’.[148] Dr Jeffreys found she could not adequately explain why she cared so little about what happened to her, but merely reasserted her belief that pregnancy was ‘a natural process and any intervention was to be avoided’.[149] The doctors then took the view that her severe depression had resulted in her no longer attaching the same value to her life, or that of her foetus, as she would have done if she had not been suffering from the illness. Her decision was thus not autonomous, as it had been distorted by her illness.

Notwithstanding the concerns of the doctors, the judge in this case found S to have had capacity. The medical team then, in treating her without her consent, had committed a battery for which they were accountable; yet there would have been no mechanism within the test to account for the real problem in this case: that the values on which she based her decision had been affected by her mental illness to the point that she was no longer able to attribute importance to her continue life (or that of her child) in the same way. While we can never know for sure whether the doctors were correct in their assumptions, the fact that S originally sought to give the child up for adoption but later changed her mind, lends some weight to their argument that her decision was the direct result of an acute depressive episode. Certainly, her fatalistic attitude was consistent with the evidence collected by Owen *et al*, which suggested that people with depression often experience their situation as something they are powerless to change.[150]

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[148] ibid, 681 [B].

[149] ibid, 681 [C].

[150] Owen et al, ‘Depression’ (n130), 165.

Other decisions also suggest that doctors are incorporating assessments of the person's values into their capacity assessments — even if not explicitly. One vignette presented to doctors in this study related to Cara, a 26 year old woman with chronic anorexia nervosa, who had taken an overdose of paracetamol and was refusing treatment on the basis that she could not get better and no longer gained any pleasure from her life.[151] When considering whether or not to uphold Cara's decision, one consultant said that the crucial factor when determining her capacity was to establish 'whether her desire to be dead is being influenced by a mental illness as opposed to being a capacitous choice in consequence of a life of suffering that she's endured.'[152] The doctor was clearly anxious to understand whether her wish to die was a true reflection of her values and priorities, given that she had suffered a difficult life, or whether is it was a product or consequence of her illness.

Similar concerns were raised over the delusional beliefs of those with schizophrenia. In response to the vignette of Max,[153] a schizophrenic who believed that his bladder stone was God's punishment for the sins he had committed throughout his life, one doctor suggested that a 'huge focus of the assessment' would be 'the boundary

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[151] Cara is 26. She has suffered from anorexia nervosa since she was 14, and has been detained under the Mental Health Act a number of times in those years. She is admitted to hospital after taking an overdose of paracetamol. She says that she doesn't want to receive any treatment. She explains that her life has, for over 10 years, been plagued by her anorexia, and despite trying everything, she cannot get better. She says that she gains no pleasure from her life anymore, and wants to be left to die.

[152] Interview [anonymised] (Oxford, May 2017).

[153] Max suffers from schizophrenia, and experiences persecutory delusions. He has a kidney stone, which is causing him some abdominal pain, and he requires an operation to remove it. He understands the medical evidence in favour of having the operation, and the consequences of not having it, because he believes the pain is God's punishment for the sins he has committed during his life. He thinks doctors should not interfere with the actions of God, and that it is only God that will decide his fate. As a devout Christian throughout his life, he believes God will not let him die.

around his Christian beliefs and his psychosis'.[154] Another suggested that 'you'd have to explore whether you felt this view about God was a part of his psychotic illness at the moment, or whether that is consistent with his previous belief system',[155] a view supported by other doctors who questioned 'whether or not as a devout Christian, his beliefs were actually a reflection of his persecutory delusions'.[156] In *Wye Valley,* meanwhile,[157] a case in some ways similar to that of *Mrs T,* a man with schizoaffective disorder had persistent auditory hallucinations in which he heard the voices of angels and of the Virgin Mary, which told him to refuse a leg amputation. Here Peter Jackson J was clear that the patient lacked capacity due to 'a clear inability to weigh the relevant medical evidence as part of the process of reaching his decision.'[158]

Further uncertainties occur in the context of dementia, as explored in the vignette of Isobel,[159] a 70-year-old woman in the early stages of dementia, who was refusing a hip replacement because of her fear of anaesthesia. Here, one doctor stated:

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[154] Interview [anonymised] (Oxford, July 2017).

[155] Interview [anonymised] (Oxford, March 2017).

[156] Interview [anonymised] (Oxford, July 2017).

[157] *Wye Valley* (n7).

[158] ibid, [35].

[159] Isobel is 70 and has been diagnosed as suffering early stage dementia. She has a problem with her hip, which, due to stiffness and pain, makes it hard for her to get up the stairs to her bedroom and bathroom. Her family and doctors think it is advisable that she has a hip replacement however Isobel strongly objects to this. Although she understands the medical evidence in favour of having the replacement, she is scared of having an anaesthetic. Despite being in otherwise good health, and a low anaesthetic risk, she fears she will never wake up again. The doctors are concerned that if she does not have the hip replacement, Isobel will soon become unable to live in her home, and may have to move to a care home. Isobel is deeply opposed to moving from her home, but continues to refuse the operation.

> I want to know if this was pathological or not, for want of a better word — is this an anxiety related disorder or is it an understandable subjective value-laden judgment about the worry of an anaesthetic?[160]

Other clinicians showed a similar concern over whether her refusal stemmed from a long-held belief, or was merely a product of her dementia. Dementia raises particular challenges precisely because the person is not going to ‘recover’ and regain their ‘usual’ values or beliefs, making the decision to override a decision on this basis harder to justify.

Despite the fact that the MCA does not explicitly capture concerns about the content of a person’s values therefore, it is clear that assessments about the origins or substance of a person’s values or beliefs, and the extent to which they are disordered, *are* in practice influencing assessments of capacity under the MCA. When asked how such problems were usually dealt with by doctors, one psychiatrist suggested: ‘usually, just shove it under ‘weighing up’ because that's the broadest, most nebulous aspect of the test.’ Other interviews also revealed how doctors tended in such situations to reduce the problem of the substance of a person’s values to a feature of the ‘use and weigh’ criterion. For example, if Max ‘genuinely believes that the pain is God's punishment for the sins he's committed during his life and not just the pain presumably, but the fact of the stone itself, then he is not weighing up [the information properly].’[161]

Evidence suggests that the courts have taken a similar approach, as demonstrated by *Mrs T,*[162] where despite one of the psychiatrists raising doubts over

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[160] Interview [anonymised] (Oxford, April 2017).

[161] Interview [anonymised] (Oxford, April 2017).

[162] *Mrs T* (n117).

whether the situation could rightly be captured by the law on capacity,[163] the judge nonetheless held that her beliefs demonstrated a failure to 'use or weigh' the information, without providing any explanation for why this might be the case. As *A Local Authority v E,*[164] and *Wye Valley*[165] demonstrate, cases involving anorexia nervosa and schizophrenia have both been regarded as instances of failure to 'use or weigh' salient information. Indeed, in all of the cases given above except *St George*,[166] the individual involved was found to lack capacity because of that very inability to 'use or weigh' information.

(c) Conclusions

It is clear that in many cases, both doctors and judges feel they must manipulate the test for capacity to protect a person whom they consider is not making a genuinely autonomous decision (owing to an impairment in the values or beliefs underpinning that decision), but whose impairment is not directly captured by the MCA. For a doctor, the legal consequences of acting in this way could be grave. As noted above, to treat a person who has legal capacity without their consent amounts to a battery at common law. While section 5 MCA provides a defence for the doctor where they 'reasonably believe' that the person lacks capacity,[167] the doctor is nonetheless exposed

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[163] Ibid, [56].

[164] *E* (n24).

[165] *Mrs T* (n117).

[166] *St George* (n141).

[167] MCA, s5(1)(b), (i) and (ii).

to the risk that their decision will be challenged, and if so, they will have to justify precisely why they believed the person to lack capacity, given that it involves a strained interpretation of the words of the Act. On the other hand, the patients in such cases are protected from causing sometimes irreversible harm to themselves *only* if the doctor is willing to take such a risk.

While stretching the 'use and weigh' criterion to include instances where the person's values are disordered might be necessary if the test for capacity in the MCA is to reflect the different ways in which a person's autonomy may be impaired, doing so is not without its problems. The effect is to conflate two different types of inquiry. One focuses on *process*: given the values and beliefs that the person holds, can they be using and weighing the information correctly if they have come to the decision that they have? The other relates to the *content* of the values themselves, and the extent to which they may have been altered or distorted by disease. By treating both of these different types of impairment as instances of a failure to 'use and weigh' the information, this creates a lack of transparency over exactly what the nature of the impairment is in any given case. Rather than pin-pointing any particular impairment, it could apply to any number of different issues — even those which do not fall within the natural meaning of the words 'use and weigh'. As a patient does not know exactly what it is that the doctor has concerns about, it is markedly harder to challenge the decision, or to adduce evidence to dispute it.

Moreover, the effect of encompassing concerns both about the person's decision-making process, *and* about the content of their values within 'use and weigh', is to permit a number of value-judgements to be made by the decision-maker, which are not open to interrogation. Whenever doctors make an assessment of the person's values and whether or not they are the product of a mental illness, this inevitably involves them making a number of judgements about whether these values are sufficiently 'outside of the norm' that they should not be regarded as simply unusual or eccentric, but as 'disordered'. While most people would agree that the belief that blood is evil is 'delusional', other beliefs are less clear-cut. The religious hallucinations of Max or Mr B demonstrate some of the difficulty in distinguishing unusual and idiosyncratic religious beliefs from those that stem from a mental disorder. They also show the inherently value-based assessment these entail: we accept the refusal of blood transfusions by Jehovah's Witnesses to be a legitimate religious belief which ought to be respected; while a person who says they experience God speaking to them and telling them to refuse medical treatment is deemed to be suffering from auditory hallucinations symptomatic of a psychotic illness. Similarly, while refusing treatment on the basis that one ought not to interfere with God's plan might be regarded as unusual, but not disordered, S's belief in *St George*[168] that nature should be allowed to 'take its course' was considered to be symptomatic of depression, causing S to feel powerless to change or control her own life.

Given this ambiguity, there is a real concern that the way the current law is framed allows these judgements to be made opaquely, concealed within the broad terminology of 'use and weigh', which insulates them from scrutiny or challenge, while maintaining the fiction that capacity assessments are objective and value-neutral. If a person's values are deemed to be disordered (leading the doctor to regard the decision as non-autonomous), this ought to be said explicitly, so that the person can dispute this if they wish, and provide evidence that the values or beliefs — while unusual — are consistent with their (perhaps eccentric) life view. This is particularly so

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[168] *St George* (n141).

given that judgements of this nature are at risk of favouring those who hold values or beliefs which are ‘understandable’ or ‘acceptable’ to the decision-maker, such as established religious beliefs, at the expense of those who hold more unusual (and non-religious) value systems. Some degree of bias (albeit unconscious) in the way that decision-makers evaluate the values of others is perhaps unavoidable. But in a democracy committed to plurality of values, religious freedom and tolerance, it is imperative that we do not simply disregard the wishes of people because they reflect beliefs or priorities which might seem unusual, ill-advised, or even reprehensible.

That such assessments should be capable of scrutiny and challenge is not just ethically desirable, but may even be legally mandated for public bodies. Article 8 ECHR protects a right to respect for ‘private and family life’, which has been held to encompass both ‘the physical and psychological integrity’ of the individual,[169] including their right to exercise their autonomy freely in treatment and care decisions. Any determination that someone lacks capacity thus denies the person this right, invoking the protections of Article 8. The right is qualified, where ‘necessary in a democratic society’ for ‘the protection of health or morals, or for the protection of the rights and freedoms of others’.[170] While this may justify the decision to find someone to lack capacity, it does not justify maintaining a capacity test which is not open to challenge. The European Court of Human Rights in *Tysiac v Poland*[171] held that:

> the Convention is intended to guarantee not rights that are theoretical or illusory but rights that are practical and effective. Whilst Art.8 contains no explicit procedural requirements, it is important for the effective enjoyment of the rights guaranteed by

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[169] *X and Y v. Netherlands* (1986) 8 E.H.R.R. 235, [22]; *Y.F. v Turkey* (2004) 39 EHRR 34, [33].

[170] *E* (n24), Art 8(2).

[171] (2007) 45 EHRR 42.

> this provision that the relevant decision-making process is fair and such as to afford due respect to the interests safeguarded by it.[172]

This was applied in *Tracey*,[173] where it was found that the failure of doctors to consult with their patient before placing a Do Not Resuscitate order in place was sufficient to breach the 'Article 8 procedural obligation' to consult with her.[174] While neither case directly concerns the right to challenge decisions which impinge upon one's autonomy, it may be argued that enabling doctors to assess a person to lack capacity on the basis of a judgement that is not made explicit (and is therefore not open to challenge), is neither 'fair' nor affords 'due respect' to the person's interests in autonomy.[175] Certainly, in other contexts, such as deportation proceedings, policies which have made it harder to challenge decisions (such as not being able to give evidence in person[176]) have been held to be in breach of the procedural requirements of Article 8. In *Al-Nashif v Bulgaria*[177] for example, it was held that:

> The concept of lawfulness and the rule of law in a democratic society require that measures affecting fundamental human rights must be subject to some form of adversarial proceedings before an independent body competent to review the reasons for the decision and relevant evidence.[178]

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[172] ibid, [115].

[173] *Tracey v Cambridge University Hospitals NHS Foundation Trust & Ors* [2014] EWCA Civ 822.

[174] ibid, [59].

[175] It may even be argued that a failure to disclose the real basis on which a decision is being made against a person could be in breach of their right to a fair hearing in civil matters under Article 6(1).

[176] See for example, *R (Kiarie) v Secretary of State for the Home Department* [2017] UKSC 42.

[177] (2003) 36 EHRR 655.

[178] ibid, [123].

To ensure the effective protection of a person's Article 8 rights, in decisions which deprive them of their ability to exercise their autonomy, they must therefore be sufficiently transparent to be able to be scrutinised and challenged if necessary.

II Teetering on the edge of the cliff

The previous section demonstrates some of the problems with the law adopting an insufficiently nuanced understanding of autonomy in the test for capacity. Even were the law to adopt a more demanding conception of autonomy in the MCA however (such as best desire autonomy referred to above[179]), a further difficulty afflicts the way that capacity operates in practice. Capacity is, in law, a threshold: either a person has legal capacity, or they do not. The realities of decision-making are however, substantially more complex: a person's capacity for autonomous decision-making is not an all-or-nothing concept, but rather admits of degrees. Indeed, autonomy may be impaired not only to different degrees but in qualitatively different ways. As a result, the question of whether a person's decision is 'sufficiently' autonomous to be regarded as capacitious will not always be certain. This is exacerbated by the fact that in the medical (and to a lesser extent social care) context, decision-makers often do not have the information available to them to be able to make a detailed assessment of the person's capacity — be that because of time and resources pressures, or because of the person's reluctance to engage with the assessment process. The result is that the test for capacity is being inconsistently applied by different decision-makers, with substantial disagreement arising among doctors and judges over whether or not a particular person has capacity in relation to a decision or not. This both compounds the harshness of the

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[179] Coggon (n112).

cliff-edge approach to capacity, and cast doubts over the reliability with which the test is being applied.

(a) Capacity on a spectrum

While the law draws a sharp line between those who have and those who lack capacity, the realities of decision-making are somewhat more complex. As Emily Jackson captures:

> The reality of the psychological ability to exercise choice is not binary... In addition to the rather obvious fact that a person's capacity will fluctuate over the course of her lifetime, the ability to make decisions, with or without others' help, exists on a spectrum. At one end, there might be someone in a permanent vegetative state, who cannot express a view, while at the other end, someone may appear to be able to take decisions without others' support.[180]

The extent to which a person can be said to capable of autonomous decision-making depends both on the extent to which a person possesses any particular component (or attribute) of autonomy (for example understanding, reasoning etc), *and* on the number or combination of these different attributes or components. Autonomy operates not only on a two-dimensional linear spectrum where it can be impaired to a greater or lesser extent therefore (as Jackson, or Michael Gunn have depicted it[181]); but the ways in which it may be impaired may also be qualitatively distinct.

This does not necessarily sit at odds with the idea of operating a capacity threshold at law. It is possible, at least at a theoretical level, to accept that people may be more or less capable of making autonomous decisions while also acknowledging that the law must select a 'minimum' point at which a decision can be said to be non-

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[180] Jackson (n4), 248.

[181] M. Gunn, 'The Meaning of Incapacity' (1994) 2 *MedLRev* 8, 9.

autonomous and put the capacity threshold at that point. In other words, one must reach a certain point for their decision to be described as autonomous at all, but beyond that point, there will remain decisions which are more or less autonomous. Given, however, that there are many different components or capabilities that a person must demonstrate in order to be deemed legally capacitous (understanding, retention, reasoning), and that each of these admit of degrees (a person may understand more or less for example), ascertaining when a person reaches a 'sufficient' level of any of these will be difficult. The result is that a person may then exist on the cusp or borderline of capacity, making their capacity uncertain.

Any significant medical decision comes with a cargo of more or less complicated information. And the consequences that may flow from it can be various and uncertain. People are rarely, if ever, able to understand *everything* in respect of a particular decision, or able to weigh the information they have been given against salient information to the contrary. Even the most basic treatment decisions involve volumes of potential risks, and while a patient may be able to understand the most substantial or serious of these, they are rarely expected to weigh up each and every risk that could flow from any given treatment; nor to understand the precise biological basis for a treatment and how it works. It is accepted that different people will understand more or less of the information, and at different levels of complexity. An intelligent adult's understanding, for instance, would be greater than that of a child, and that of a trained doctor greater still. However, the level and nature of understanding is not contingent only on the individual's intelligence and expertise. As Munby J points out, there are

> many other circumstances that may so reduce a vulnerable adult's understanding and reasoning powers as to prevent him forming or expressing a real and genuine consent, for example, the effects of deception, misinformation, physical disability, illness,

> weakness (physical, mental or moral), tiredness, shock, fatigue, depression, pain or drugs. No doubt there are others.[182]

Once we accept that all these factors can affect how much information a person is able to take in and process, it is clear that the capacity to understand sits on a spectrum, and is vulnerable to impairment by a wide range of factors, both internal and external.

The same considerations apply to the retention of information: for a person to make a decision, it is of course vital that they can remember the information for long enough to decide how to act on it. Given that people will retain information for different periods of time and at different levels of complexity, it is clear that those able to retain only partial information, or who cannot hold information for any length of time, will be less able to make autonomous decisions than those able to retain all the salient information. This will be a particular problem for the elderly who may suffer from memory loss. In *Westminster CC v Sykes* for example, despite being described as 'intelligent, articulate and knowledgeable', Manuela Sykes was nonetheless found to lack capacity as her inability to retain information for more than one minute meant she could not weigh the information in order to make decisions about her care. [183]

A person's ability to reason logically and to evaluate a course of action in the light of their commitments and values can of course also be undermined in many different ways and to many different degrees. Quoting from Freyenhagen and O'Shea,[184] Herring and Wall cite anxiety disorders, schizophrenia, anorexia nervosa, personality disorders and phobias as conditions known to impair evaluative judgment.

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[182] *Re SA* (n36).

[183] *Westminster City Council v Sykes* [2014] EWCOP B9.

[184] F. Freyenhagen and T. O'Shea, 'Hidden substance: mental disorder as a challenge to normatively neutral accounts of autonomy ' (2013) 9 *Int'l J L Contex*t 53

In such cases, although the individual may be perfectly able to understand the relevant information, the decision is overwhelmed by affective attitudes so powerful that they impair the person's ability to evaluate the consequences of their decision, and to decide accordingly.

While someone living with severe mental illness may well have their reasoning impaired to a large degree by that disorder, it is not necessary to be suffering from an illness for a person's reasoning to be impaired: the effects of pain, exhaustion or heightened emotional states also commonly afflict decision-making in the medical sphere. Pain relief will also have an effect on capacity, especially in settings where powerful drugs such as morphine are in use. When asked what conditions commonly led to a finding of incapacity, a consultant in intensive care responded:

> it's the drugs or the side effects of a lot of different illnesses. So, an awful lot of them have hallucinations and delirium and that is a mixture of drugs, just the general upset to your system from being very unwell, the fact that they haven't slept properly, that there is no daylight cycle, and it's noisy.[185]

At the other end of the spectrum, a GP observed that for an elderly woman receiving 'even small amounts of codeine… might knock them off'.[186]

Adding to the physical effects of injury, illness, and pain was the emotional trauma undergone by patients:

> Somebody might get up, kiss their husband, wife goodbye, go to work, be hit by a bus, fracture their pelvis and come in here in pain they never knew or could even imagine; have a drug they've never had (like morphine); be greeted by a group of strangers who cut their clothes off them (because we have to for trauma to assess them); go and have a series of tests they've never had, and are then told they've got life-threatening injuries. I don't believe that person has any capacity to make any rational judgment yet under the Capacity Act, they would have capacity to refuse an operation if they wanted

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[185] Interview [anonymised] (Oxford, March 2017).

[186] ibid.

> to…. how much capacity do any of us have to make a decision under those deeply emotionally disturbing circumstances?[187]

Even for those not suffering from debilitating conditions, there may be variations between people's ability to reason. It is a trite observation that a person with an extremely low IQ might be less able to absorb complex information and might demonstrate less well-developed reasoning abilities than a professor of philosophy. If that professor, however, is given to panic at times of stress, that situation might be entirely reversed. While capable of understanding the information, he might find himself unable to process it in a timely manner.

This discussion suggests that there are a number of different attributes contained in the test for capacity, that contribute to a person's ability to make a decision, which could be impaired to different degrees (such as understanding different levels of information), but which might also be impaired in qualitatively different ways (such that a person could understand the information, for example, but not reason in respect of it). A person's aptitude for autonomous decision-making (reflected in the assessment of whether they have capacity) is not therefore an all-or -nothing 'quality', but rather the abilities that inform it admit of degrees: a person can have more or less of all of them, or any one of them to a greater or lesser extent. This not only true at a theoretical level, but also reflects the way in which doctors experience the process of testing for capacity. In the words of a consultant in intensive care, they 'have a spectrum from fully competent/completely with it/could do the Times crossword to

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[187] Interview [anonymised] (London, July 2017).

completely unconscious/ unable to interact in any way; and then there is a grey area in the middle.'[188] He gave the following analogy to explain this:

> What we deal with is a spectrum like being drunk. You could have someone who is stone cold sober. And you could have someone who is unconscious. And then you have degrees of inebriation in between. And most of ours are degrees of inebriation in between.[189]

Likewise, another consultant in psychiatry described a spectrum extending 'between somebody who's unconscious and clearly lacks capacity and somebody who is making a poor decision but has capacity, and we have everything in between.'[190] Capacity, he continued,

> is a very simple concept but it is one of those things that is so difficult to operationalize in practice. And it is one of those things that is so easy to measure at the extremes… but most people don't exist in either one of the extremes. And most patients' ability to judge changes all of the time.[191]

This doctor's experience was that the nature of his patients' impairment could also vary in many different ways. For some — those with learning disabilities, or someone who has suffered a stroke or brain injury — their capacity would be impaired in a relatively stable way. For others — those in acute pain, suffering from a mental illness, or confusion following an illness or accident — their capacity to make autonomous decisions might fluctuate, with intermittent periods of lucidity. This is a particular problem among elderly patients, whose capacity may fluctuate both within and between days. As one doctor put it, 'they have good days and bad days, and so sometimes you see them and you think, "Yes, I think they have capacity," and then the

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[188] Interview [anonymised] (Oxford, April 2017).

[189] ibid.

[190] Interview [anonymised] (Oxford, August 2017).

[191] ibid.

next day you feel as if they don't.'[192] This is especially so if they are suffering from certain conditions or diseases, for example Lewy Body Dementia, which causes the person's capacity to deviate considerably. Even over the course of a single day however, many elderly patients could exhibit widely differing capabilities. It is common for the elderly to be taking some form of medication or pain relief which can cause them be drowsy, especially in the morning. Similarly, they often become less attentive and able to interact meaningfully towards the end of the day — colloquially termed 'sundown'. A person's capacity may thus be impaired to different degrees, in different ways and at different times.

That there is a spectrum of capacity means that there will always be some people who exist on the cusp of the capacity threshold, whose decision-making ability is unclear. This was recognised by Mr Justice Macdonald in *Kings College Hospital NHS Foundation Trust v C & V*,[193] who regarded the fact that he had disagreed with 'two very experienced psychiatrists' over the question of C's capacity as

> in large part a product of this being a finely balanced case in which a number of reasonable interpretations of the information available are possible.[194]

Different doctors pointed to different reasons why someone might, in relation to a decision, fall into this grey area. Some focussed on people who could retain some, but not all of the information or risks pertaining to the decision. Others focussed on the person's reasoning ability: 'where understanding and retention is intact, and

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[192] Interview [anonymised] (Oxford, July 2017).

[193] [2015] EWCOP 80.

[194] ibid, [94].

articulation is intact, so they seem superficially plausible, but the ‘weighing up’ or reasoning apparatus is damaged.’[195] Yet others had a different view:

> Well, it's not really the rationality. One of the areas where borderline capacity can come into play is if I know somebody's got a memory impairment and they’re making their decision where it's important that they are able to retain enough information to be able to weigh it up and then come to a decision. If the material the patient needs to be able to remember is too complex, too large in its scope for somebody to remember, then that can lead to a borderline situation where I'm not quite sure how much the patient is remembering… that can be a tricky judgment to make.[196]

Clearly there are numerous cases in which there is a degree of uncertainty over whether the person has capacity or not.

(b) The realities of decision-making in practice

These uncertainties are exacerbated by the contexts in which capacity assessments are frequently made. It was suggested in the interviews that in order to reliably assess the person’s capacity (especially where they are on the borderline), it is often necessary to have some collateral information about the patient’s pre-morbid self; their personality, beliefs and ordinary reasoning processes. This may be more or less difficult to achieve depending on the setting, with evidence suggesting that in certain specialisms, and in respect of certain patients, the combined effects of limited resources, time pressure and lack of patient engagement can make gaining this information extremely difficult.

To marshal this information, so as to more accurately determine the effect of their illness on their cognition, requires a significant input of time with both the patient and their family or carers. This may be all but impossible in certain specialisms, given the large numbers of patients and low staffing levels. And this, of course, is particularly

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[195] Interview [anonymised] (Oxford, July 2017).

[196] Interview [anonymised] (Oxfordshire, July 2017).

true in specialisms which see high numbers of older patients with cognitive difficulties. One geriatrician estimated that in acute medicine, over half of the patients aged over 75 have significant cognitive problems, yet fewer than half of these have a formal diagnosis of dementia. This is borne out in statistics from NHS England, which suggest that in April, 86.1% of patients over 75 who were admitted for more than 72 hours as an emergency, were initially thought to have dementia.[197] Figures from Department of Health suggested that around 25% of hospital beds at any one time are occupied by someone with dementia[198] — with others suggesting this is a 'gross underestimate, with some hospitals stating that 40 — 50% of their patients have dementia.'[199] These pressures were compounded by staff shortages, which often resulted in rota gaps. As one geriatrician stated: 'given the numbers of patients we are dealing with and the pressures we're under, that presents significant challenges when assessing capacity.[200]

It should not be assumed that this is a problem only within the medical sphere. The ageing population has led to ever-increasing numbers in need of social care, while Skills for Care estimate that there are as many as 110,000 vacancies in adult social care

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[197] NHS England, 'Dementia Assessment and Referral data collection – April 2018', available at < https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2018/07/Dementia-Press-Notice-April-2018-PDF-195KB.pdf> accessed 9th July 2019.

[198] Response to a Parliamentary Question (November 2014). Available at < https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2014-11-05/213473> accessed 9th July 2019.

[199] Alzheimer's Society, *Fix Dementia Care: Hospitals* (January 2016), available at < https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/fix_dementia_care_-_hospitals.pdf> accessed 9th July 2018. For further evidence see L. Lakey, 'Counting the cost: caring for people with dementia in hospital wards' (2009) *Alzheimer's Society,* available at < https://www.alzheimers.org.uk/sites/default/files/2018-05/Counting_the_cost_report.pdf>, 8.

[199] Interview [anonymised] (Oxford, March 2017).

[200] Interview [anonymised] (Oxford, March 2017).

at any given time — 8% of the total roles in this sector.[201] In its scrutiny of the MCA, the House of Lords explicitly picked up on this problem. Evidence was provided that capacity assessments are best administered by people who know the patient and are experienced in communicating with people with disabilities. Yet one consequence of these challenges was that assessments were often conducted by professionals who 'are not closely involved with the care of the person affected.'[202] As one contributor noted:

> the assessor needs a solid understanding of how P communicates and that takes time and commitment that isn't often available. Certainly, in my experience, the time and commitment doing the assessment nowhere near matches the seriousness of the issues at stake for P.[203]

Time pressures (whether occasioned by workload or by the urgency of the decision) mean there may simply not be the hours available for decision-makers to go through the whole interactive process that the capacity test demands, and to develop an understanding of the patient from their family or GP, so as to have a full picture of their capacity. One consultant in emergency medicine, for example, suggested that 'real capacity' demands that you 'weigh up, assess, discuss and feedback whatever it is you're discussing…there isn't time for that.'[204] A geriatrician, meanwhile, estimated that they probably get 'three or four cases a week' in which a person's capacity is uncertain because they are in pain or have been given morphine, noting: 'it's not the

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[201] Skills for Care, The state of the adult social care sector in England, 2018 (Leeds, 2018), available at < https://www.skillsforcare.org.uk/NMDS-SC-intelligence/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/The-state-of-the-adult-social-care-sector-and-workforce-2018.pdf> accessed 1st November 2018.

[202] House of Lords Select Committee on the Mental Capacity Act 2005, '*Mental Capacity Act 2005: post-legislative scrut*iny' (HL Paper 139, *13/3/14*), [70].

[203] Steven Neary, ibid, [69].

[204] Interview [anonymised] (London, July 2017).

best time really to decide, but you have to decide there and then.'[205] In light of this, one psychiatrist observed that

> there can be elements that can look as if they're subjective, as you're making a best estimate on the basis of the best information you gather in a short period of time, particularly if you haven't got many informants. You may have to make a decision not really knowing what somebody's previous decision-making processes would have looked like or sounded like.[206]

These pressures were exacerbated in certain specialisms by an unwillingness on the part of the patient to engage with the assessment. Capacity assessments are inherently participatory, requiring the patient to respond to questions and demonstrate their understanding and reasoning abilities: where they decline to do so, it is very difficult for the doctor accurately to assess their capacity. This issue was raised repeatedly in the context of Emergency Medicine, where patients are often intoxicated, may be suffering from a psychiatric illness and are frequently in a state of shock or extreme distress — all of which may render them less willing to submit to capacity assessments. As one consultant put it, 'the tool requires engagement and it requires honesty. Many of the patients are not honest, play games with us and don't engage.'[207]

Even where patients co-operate willingly, the test demands a level of communication which can be difficult for some patients, such as those suffering speech problems following a stroke. It is a recurrent problem with elderly patients with hearing loss, where it can be difficult to be sure 'whether they can understand what you're saying and can weigh up and reason, but can't communicate successfully back;

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[205] Interview [anonymised] (Oxfordshire, March 2017).

[206] Interview [anonymised] (Oxford, April 2017).

[207] Interview [anonymised] (London, July 2017).

or whether they are not in fact understanding completely what you're saying to them.'[208] Here there is a real risk that lack of engagement by the person because of an inability, for example, to hear well, might be mistaken for a cognitive deficit.

There are, of course, ways to support such patients, such as giving information in written form, or calling in a speech therapist. But in practice, the level of such support differs widely depending on the resources and time available. One of the guiding principles of the MCA is that a 'person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.'[209] What is 'practicable' however, is context- and resource-dependent. In their submission to the House of Lords scrutiny, the charity Mind highlighted this problem:

> To assess, engage and empower a person who may lack capacity can be resource intensive. It may require help from speech therapists or occupational therapists or for more time to be devoted to that person by the care staff or clinical team supporting them. There is a risk that in a time of austerity when resources are scarce there will be a temptation to cut corners and to fail to properly give effect to the requirements of the Act.[210]

The problem is that it is those very specialisms in which these impairments afflict patients most significantly, that are also those in which doctors lack the time to provide this support – namely those which see the highest numbers of older patients with cognitive or communication difficulties. In evidence gathered by the Alzheimer's Society for example, only 12% of people with dementia surveyed felt that professionals always supported them to make their own decisions, while 28% felt they were either

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[208] Interview [anonymised] (Oxford, July 2017).

[209] MCA, s1(3).

[210] House of Lords (n12), [81].

never or rarely supported to do so.[211]

(c) A range of impairments

A particular problem raised by the doctors in interview, is that they are sometimes unsure about how different disorders or illnesses might impair a patient's capacity. Does it, for example, affect the person's understanding, their recall, their reasoning ability, or the content of their values? This is most acute in specialisms such as emergency medicine and general practice, where doctors encounter patients with a wide range of cognitive impairments, mental illnesses and learning disabilities, and so understanding exactly how each might affect the person's decision-making can be difficult. Similarly, the House of Lords enquiry uncovered serious concerns over the accuracy of capacity assessments in adults with Down's syndrome, autism and brain injury.[212] In their consultation, the Down's Syndrome Association questioned the ability of many social workers to assess the capacity of young people with the condition, noting that the latter 'often have quite good language skills and so they come across as being more able than they actually are because they have learnt lots of different social cues to use.'[213] Similar issues were raised by the National Autistic Society who suggested there was a lack of understanding about autism amongst assessors.[214] Outside of the context of learning disabilities, a number of submissions raised concerns about assessments of those with brain injuries being conducted by

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[211] ibid, [80].

[212] ibid, [71].

[213] ibid, [71], quoting from Q84.

[214] ibid.

people without experience in this field.[215] The report quoted from the British Association of Brain Injury Case Managers, who set out the key problem:

> Clients who have a good residual intellect, who present plausibly and articulate their thoughts well, are very likely to be considered to have capacity to manage their own affairs, even despite a lengthy history of impulsivity, lack of social judgement, tangential thought processes, problems with attention and a lack of insight into how their cognitive deficits affect their decision making.[216]

Clearly it was hard for people who did not understand this cohort well to be able to give an accurate assessment of their capacity. Similar issues arise in assessing people with certain mental illnesses, such as personality disorders, where patients are often both high-functioning and extremely plausible, making it difficult for non-specialists to understand how their capacity is impaired. Yet there are many situations in which doctors or care workers are nonetheless required to do so, raising doubts over the accuracy of their assessments in these circumstances.

Even if the decision-maker understands how the impairment is affecting the person however, they may be unsure how this is captured by the MCA. Evidence suggests that there can be uncertainty and disagreement over whether the person's impairment falls within the definition of, 'an impairment of, or a disturbance in the functioning of, the mind or brain',[217] which must, under the MCA, be the cause of the person's inability to make a decision. This was the case where the impairment was caused by factors such as medication, pain, confusion, shock or extreme emotion – none of which fall clearly within the definition. This will be considered in more detail

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[215] ibid, [72].

[216] British Association of Brain Injury Case Managers; Brain Injury Rehabilitation Trust; Head First, quoted by the House of Lords report, at [72].

[217] MCA, s2(1).

in Chapter 3 — suffice to say however, that these impairments were not always accommodated in the same way by doctors.

(d) Disagreements on the 'cusp' of capacity

From the preceding discussion it becomes evident that there will be many cases in which the person's capacity to decide is uncertain — where they sit on the cusp of capacity and where doctors lack the information to be able to assess reliably whether they fall just above or below the threshold. Doctors must however make a decision one way or the other: there is no 'grey area' in the MCA. As a result, disagreements frequently arise between doctors over whether or not a person has capacity. This example given by a consultant in emergency medicine shows just how wide the scope is for disagreement:

> I had a young woman that… had a history of self-harm. She slashed her hand. She had a tendon injury and she got drunk. There was no doubt when she got drunk she did not have capacity. When she sobered up, my junior colleague thought she didn't have capacity, the psychiatry junior colleague thought she did, the psychiatry senior colleague thought she didn't, and I was asked to come in and give an opinion. Really as the senior doctor, I thought she had capacity and I let her go, but she used her capacity to turn down repair of something that was repairable. But some weeks later when she regretted her decision, it was not properly repairable.[218]

One area which has given rise to particular disagreement in the case law is in respect of those who indisputably have some mental illness — but it is not clear how, if at all, this is affecting their understanding and awareness of the situation and the decision at hand. One example is where a person suffers from delusions — a situation which amply illustrates some of the difficulties at the margins of capacity. While the person might appear to understand the relevant facts perfectly well, their decision may be subject to influence by a 'false' or delusional belief and the assessor must therefore determine

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[218] Interview [anonymised] (Oxford, March 2017).

how far this false belief is undermining their understanding of the situation and the decision that is being made.

Re C (Adult: Refusal of Treatment)[219] for example, concerned whether a 68-year-old man with paranoid schizophrenia had the capacity to refuse the amputation of his gangrenous foot, without which there was an 85% chance he would die. C, who suffered from persecutory delusions that any treatment was intended to destroy his body, along with delusions of grandeur that he had enjoyed a distinguished career as a doctor and had never lost a patient, opposed the treatment. Despite understanding his prognosis, he expressed complete confidence that he would survive his current condition, aided by God, the doctors and the nurses. While aspects of his reasoning were thus clearly irrational, others were perfectly rational. He was clear for example, that he 'would rather die with two feet than live with one' — an understandable decision for an elderly man detained in a secure hospital, who did not want to have to adapt to using a prosthetic limb. Below the knee amputation also carried a 15% risk of death, and while he rejected the surgery proposed, he agreed to more conservative surgery (subject to not having a more localised spinal injection because of the risk of paralysis).

The medical professionals in the case could not reach agreement over the extent to which his delusions were affecting his ability to make such a decision. In the view of one psychiatrist, Dr Eastman, although C's capacity was 'plainly' reduced by his mental illness, 'whether it is sufficiently reduced remains marginal in the absence of any direct link between the persecutory delusions and his present condition.'[220] Dr Gall

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[219] *Re C* (n142).

[220] ibid, 292 G.

reached a similar conclusion, with both doctors attaching considerable weight to the ‘rational’ reasons he gave for his refusal. Dr Ghosh meanwhile, described this as a case that ‘far from being on the borderline’, was ‘very clear cut’. While she acknowledged that his capacity was ‘not absent’ she found it to be ‘very seriously reduced’ by his persecutory and grandiose delusions. It was Dr Eastman and Dr Gall’s evidence that ultimately found favour with Thorpe J, who did not find sufficient evidence of the link between C’s refusal and his persecutory delusions. This was in part because Dr Ghosh was found not to have known the full consequences of C refusing treatment at the time, and that the amputation operation carried its own mortality risk – information which Thorpe LJ considered would have ‘influenced her appraisal of the critical equation and of C's approach to it.’[221] He concluded that:

> Although his general capacity is impaired by schizophrenia, it has not been established that he does not sufficiently understand the nature, purpose and effects of the treatment he refuses. Indeed, I am satisfied that he has understood and retained the relevant treatment information, that in his own way he believes it, and that in the same fashion he has arrived at clear choice.[222]

Heart of England NHS Foundation Trust v JB[223] involved very similar issues (she was also refusing an amputation on the basis of delusional beliefs), which once again gave rise to a disagreement between JB’s community psychiatrist (who felt her ability to weigh the information was ‘compromised by her tendency to minimise and disbelieve what the doctors are telling her’[224]), and an independent psychiatrist who found her to

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[221] ibid, 294 B.

[222] ibid 295.

[223] *Heart of England NHS Foundation Trust v JB* [2014] EWHC 342 (COP), per Peter Jackson J at [28].

[224] ibid, [30].

be ‘consistent in her views and reasoning process’.[225] The latter view was supported by the surgeon and later the judge, who was unsatisfied that a link between JB’s mental illness and alleged incapacity had been established.[226]

Even where there is agreement between doctors however, a judge might disagree with the medical consensus. *Re SB (A patient; capacity to consent to termination)* for example,[227] concerned whether a woman suffering from bipolar disorder had the capacity to consent to terminate her pregnancy at 23 weeks. During the early weeks of her pregnancy, all the evidence suggested she wanted the baby, and she conscientiously attended scans and other antenatal appointments. But after four months, she stopped taking the medication prescribed for her bipolar disorder, after which she started to exhibit symptoms of being unwell. She now made appointments for a termination, not once but twice, but on neither occasion went ahead with it. The first time she claimed to have insufficient funds to travel to the clinic,[228] while the second time she professed a dislike of the type of procedure proposed.[229] At this time SB was compulsorily detained under the Mental Health Act. Despite her requests for a termination, the hospital did not consider her to have the capacity to make this decision. Although she understood the relevant information,[230] her consultant

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[225] ibid, [33].

[226] ibid, [40].

[227] *Re SB (A patient; capacity to consent to termination)* [2013] EWHC 1417 (COP).

[228] ibid, [21].

[229] ibid, [22].

[230] ibid, [23]; [34].

psychiatrist was ‘100% clear that she does not have capacity to take the decision’,[231] a view supported by the independently instructed psychiatrist.[232] Her reasons were based ‘upon flawed evidence and paranoid beliefs’,[233] namely that her husband and mother would not support her if she had a baby (a view strongly disputed by them, and contrary to the opinion of the treating psychiatrist who observed her husband to be attentive and caring). Both psychiatrists considered these to be paranoid beliefs, a view corroborated by the strong correlation between the time when she stopped taking her medication, and the commencement of these beliefs.[234] This view was however rejected by Holman J, who found her to have capacity. Even though she had ‘some skewed thoughts and paranoid or delusions views with regard to her husband’,[235] she also gave many other reasons for requesting a termination.[236] These included the fact that she did not want to have a child while compulsorily detained under the MHA;[237] that she was worried about her ability to bring up a child;[238] and that she felt suicidal at the prospect of having to carry the child to term, and might well attempt to kill herself if denied a termination. Justice Holman concluded that:

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[231] ibid, [32].

[232] ibid, [33].

[233] ibid, [34].

[234] ibid.

[235] ibid, [41].

[236] ibid

[237] ibid, [42].

[238] ibid.

> It seems to me, therefore, that even if aspects of the decision-making are influenced by paranoid thoughts in relation to her husband and her mother, she is nevertheless able to describe, and genuinely holds, a range of rational reasons for her decision.[239]

Where rational and irrational beliefs are held simultaneously, this clearly places a greater burden on the assessor seeking to establish capacity, and these cases demonstrate how expert opinion can differ widely in making that judgement.

This is not to suppose that *all* capacity assessments give rise to uncertainty and disagreement. In fact Raymont *et al,*[240] found a high degree of consistency in the capacity assessments of 'experienced psychiatrists and psychologists'.[241] Notably however, they also found that:

> those thought unanimously to have capacity were more cognitively intact, more likely to be living independently and performed consistently better on all subtests of the two capacity tools, compared with those who were unanimously thought not to have capacity. The group in whom there was disagreement fell in between.[242]

This suggests that even if there is a high level of agreement at the extremes, disagreement remains at the margins: in fact, they found disagreement in 22.5% of these 'in between' cases. It is also worth noting that this study only examined the reliability among 'experienced psychiatrists and psychologists'[243] — not among medical and social care staff more broadly — and the doctors in these cases had none

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[239] ibid, [44].

[240] V. Raymont et al, 'The inter-rater reliability of mental capacity assessments' (2007) 30 *International Journal of Law and Psychiatry,* 112–117.

[241] ibid, 114.

[242] ibid, 112.

[243] ibid, 116.

of the time pressures, or awareness of the outcome of their assessments, which usually afflicts assessments (since the study relied on transcripts of interviews and vignettes).

(e) Subjectivity in the test for capacity

The propensity for professionals to disagree over capacity is compounded by the subjectivity inherent in capacity assessments. Although a presumption exists in favour of finding capacity,[244] the MCA does not set out prescriptively in advance what degree of each 'ability' (understanding, retaining, weighing) the person must exhibit to be found to be capacitous — perhaps more germane, to what extent each ability must be *impaired* in order to rebut the presumption of capacity. This instead is left to the individual assessor to determine. While the person is required to understand the nature and consequences of the decision, it is for the assessor to determine exactly *what* consequences they must understand, and in what level of complexity, in order for the decision to be deemed sufficiently autonomous as to warrant respect. The effect is that doctors have a substantial degree of discretion when determining of whether or not someone has capacity, which then becomes contingent on what information or facets of the decision they consider to be most important.

This can be most clearly seen in respect of the 'understanding' limb of the capacity test. For any given decision there will, as noted above, be a number of consequences that will flow from it. The extent to which a failure to understand any of these consequences renders a person incompetent will thus depend on how important (or not) the capacity assessor considers that piece of information to be. Gunn *et al*, for example, found that even in relation to a relatively simple decision over whether to undergo a blood test, it was very difficult to reach consensus over what information

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[244] MCA, s1.

was necessary for the person to understand,[245] while in a study into how capacity assessments were being made for people with dementia over decisions about discharge,[246] Emmett *et al* concluded:

> assessment practices were largely idiosyncratic in their approach and varied considerably between cases. Professionals were left to determine which information they considered material or relevant to the decision and how much information was to be imparted to the patient during the assessment process. This had an important influence on the outcome of any assessment since it tended to yield subjective and unpredictable outcomes.[247]

This difficulty also acknowledged by doctors:

> When you take consent from somebody to something, what does understand mean? Do they understand everything? What does everything mean? If you're trying to explain a new procedure, does that mean they have to know exactly what the research is showing on one side versus the other side etc? The level of understanding again is completely subjective to the person doing the test as to how much information they feel is sufficient understanding…I think it's entirely manipulable, this entire test.[248]

This is a problem that also afflicts decisions in the social care context. Anna Murrell and Leona McCalla, for example, found that across four adult health and social care teams, 'the information that was identified as relevant to the decision for which capacity was being assessed was inconsistent.'[249]

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[245] M. Gunn and others, 'Decision-Making Capacity' (1998) *MedLRev* 7: 269-306, 278.

[246] C. Emmett et al, 'Homeward bound or bound for a home? Assessing the capacity of dementia patients to make decisions about hospital discharge: Comparing practice with legal standards' (2013) 36(1) *International Journal of Law and Psychiatry* 73-82.

[247] ibid, 80.

[248] Interview [anonymised] (Oxford, April 2017).

[249] A. Murrell and L. McCalla 'Assessing Decision-making Capacity: The Interpretation and Implementation of the Mental Capacity Act 2005 Amongst Social Care Professionals' (2016) 28:1 Practice: Social Work in Action, 21-36, 28.

However this is not just a problem that affects the decisions being made on the ground. Judges similarly appeared to attach differing levels of importance to different pieces of information when testing for capacity. In *A Local Authority v Mrs A and Mr A,*[250] for example, it was held that Mrs A needed to understand only the 'proximate medical issues'[251] to have the capacity to refuse contraception. These included the reasons for contraception (including the likelihood of pregnancy if not used); the types of contraception available and how each is used; the advantages and disadvantages of each type; the possible side-effects of each; how easily each type could be changed; and the general effectiveness of each.[252] She was not, however, expected to comprehend what bringing up a child would be like in practice, whether she would be able to do so, or whether any child would be likely to be removed from her care.[253] In *The Mental Health Trust/ The Acute Trust & The Council v DD and VC (Number 2)*[254] by contrast, Cobb J went significantly further than this, accepting that in order for DD to have capacity to refuse contraception, she would need to understand not only the list of factors given above*,* but also any additional risks which were specific to her. These included: the risk of a thromboembolic disease during any future pregnancy; the risk of delivering a pre-term infant; the impact on DD's mental and emotional health of any further pregnancy; the risk of placenta accrete; and the considerable risks to her life

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[250] *A Local Authority v Mrs A and Mr A* [2010] EWHC 1549 (Fam).

[251] ibid, [64].

[252] ibid, [64].

[253] ibid.

[254] *The Mental Health Trust/ The Acute Trust & The Council v DD and VC (Number 2)* [2014] EWCOP 13.

posed by delivery of any child.[255] This clearly demanded a much higher degree of understanding than that required in the previous case,[256] and it is no surprise that as a result, DD was found to lack capacity to make the decision.

Clearly then, there is substantial variation in the level of understanding deemed ‘sufficient’. However, it is not just this limb which is susceptible to variable treatment. In *Kings College Hospital NHS Foundation Trust v C & V*,[257] having accepted that ‘use or weigh’ was the ‘most difficult’ limb of the capacity test because of ‘the degree of subjective judgement involved’,[258] Justice Macdonald went on to express

> some concern that Dr R in particular set the test for capacity too high in this case in looking for C to demonstrate significant using and weighing of information demonstratively ending with a balanced, nuanced, used and weighed position.[259]

In *Re C*[260] and *Re SB*[261] meanwhile, each psychiatrist attached importance to the different reasons given by C or SB for wanting or refusing the treatment in question. Those who favoured a finding of capacity emphasised the ‘rational’ reason given, while those preferring a finding of incapacity focussed on the delusional or paranoid reasons given. Similarly, in finding SB to have capacity, Holman J clearly attached

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[255] ibid, [17].

[256] *Mrs and Mrs A* (n250).

[257] *C & V* (n193).

[258] ibid, [42].

[259] ibid, [94].

[260] *Re C* (n142).

[261] *Re SB* (n227).

great weight to the perceived rationality of the reasons SB gave for her decision.[262] Her desire not to have a child while detained under the MHA was characterised as 'perfectly understandable',[263] while both her fear of having to give up the child into care, and her wish to terminate the pregnancy so as not to have suicidal thoughts, were said to be 'entirely rational.'[264]

Capacity assessments are also subjective in a different way. As assessors cannot know exactly how the person processed specific information (they cannot, after all, see into the mind of the decision-maker), assessing whether they can 'use or weigh' information becomes inherently value-laden. As Natalie Banner has persuasively argued, when we say that a person has 'used or weighed' the information, what we are actually saying is that he used or weighed the information in the way that *he ought*, reaching a conclusion which is within a range of those that we would consider to be reasonable.[265] If the person fails to reach an outcome which we would consider reasonable or rational, this will be thought to result either from assigning unreasonable or irrational weight to a particular factor, or from a failure to assign sufficient weight to a piece of information that we regard as relevant. The Mental Capacity Act Code of Practice cites the familiar example of a person suffering from anorexia nervosa,[266] for

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[262] ibid.

[263] ibid, [42].

[264] ibid, [42] and [43].

[265] N. Banner, 'Unreasonable reasons: normative judgements in the assessment of mental capacity' J Eval Clin Pract 2012 Oct; 18(5): 1038–1044.

[266] Department for Constitutional Affairs, Mental Capacity Act 2005 Code of Practice (London: TSO, 2007), 4.22.

whom their compulsion not to eat outweighs all other considerations. This is instructive. In saying that their decision to refuse food is due to an inability to use and weigh the information correctly, we are in fact making a normative assessment that the risk to a person's health *ought* to have had a sufficiently large impact on the decision-making process as to override the desire to be thin. That the sufferer reached a different conclusion indicates that either insufficient weight was attached to the desire to avoid death, or that disproportionate weight was attached to the perceived need to be thin.

This kind of thinking also emerged in interviews for this study. One consultant, for example, explained his response to needle phobias:

> Sometimes they'll say they don't want a cannula because they're needle phobic for example, but they're dying of blood loss. The emotional context to them is, "I hate needles. I'm scared of them." The emotional context to me is, "If I don't get a needle in you and give you some blood, you might die." Both those positions are valid. Now of course, the patient's position is very valid to them in terms of fear, but it's not valid to them in terms of where they're going to be in a year.[267]

The doctor is clearly subjecting the patient's views to some sort of 'reasonableness test', in which their views will not be regarded as 'valid' if they strike an inappropriate balance, or if they involve an 'unreasonable' weighting of concerns. This inevitably makes the assessment of whether a person can 'use and weigh' the relevant information heavily dependent on what seems reasonable to the individual assessor, and what they regard as an acceptable range of responses. Indeed, one clinician suggested that this limb of the test for capacity was therefore 'entirely subjective'[268] – further undermining the consistency with which the test for capacity is applied.

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[267] Interview [anonymised] (Oxford, July 2017).

[268] Interview [anonymised] (Oxford, July 2017).

(f) Conclusions

If we accept the nature of capacity as admitting of degrees, this means there will always be a ‘grey area’ on the cusp of the threshold where capacity cannot be gauged with any certainty. This, when combined with the realities of health and social care which mean that decision-makers often do not have all the information they need to robustly assess a person’s capacity, and with the subjectivity inherent in elements of the assessment process, has led to inconsistency in the way in which the test for capacity is being applied. This is problematic. As Emmett et al observe,

> the legitimacy of our current legal model relies heavily on health and social care professionals making accurate and reliable ‘neat, clean, dyadic (either/or) distinctions between decisional capacity and incapacity’. In reality, capacity is rarely seen in such black and white terms and operates at the margins in varying shades of grey.[269]

If the determination of whether a person has capacity is dependent on what the decision-maker considers to be important, however, then maintaining the capacity cliff-edge becomes harder to justify, as it leaves a person’s right to autonomy contingent on the idiosyncrasies of another person. The cliff-edge approach to capacity is also undesirable for doctors, who must tread a difficult path knowing that if they wrongly find the person to *lack* capacity, and treat them on this basis, they may be guilty of a battery and a breach of Article 8; while mistakenly regarding the person to have capacity and allowing them to refuse treatment may give rise to a risk of a negligence suit, or even gross-negligence manslaughter.

These concerns are heightened by an awareness that if the test is not being applied consistently by doctors, the courts are likely to prove equally inconsistent. As one doctor admitted:

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[269] Emmett et al (n246), 80.

> what frightens me is, I know I could go to court and I could be found guilty by one court with one set of lawyers and not guilty with another. I've got no faith that there is enough reproducibility in the current legal position to give me a robust defence.[270]

This raises fundamental concerns for a legal system in which values of legal certainty and consistency are paramount. Though conceptions of the rule of law differ hugely,[271] both formal and substantive conceptions subscribe to the idea that there are certain formal values to which all legal systems should adhere, including that laws should be prospective, open, certain and capable of guiding human conduct. As Joseph Raz explains, these values are designed to prevent the danger that 'the law may be unstable, obscure, retrospective, etc., and thus infringe people's freedom and dignity.'[272] Certainty and consistency in the application of the law is essential if people are to be able to plan their lives accordingly, and not have their freedom arbitrarily interfered with. Albert Venn Dicey commented similarly in his seminal works on the UK constitution, that the rule of law 'excludes the existence of arbitrariness, of prerogative, or even of wide discretionary authority on the part of the government.'[273] A law that is open to widely divergent application (as well to a number of different interpretations, as was seen above in the way that doctors were applying 'use or weigh'), clearly fails to adhere to the value of the rule of law. The uncertainty created by the current legal approach is thus problematic for doctors, for patients, and for the normative integrity of the law.

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[270] Interview [anonymised] (London, July 2017).

[271] For a discussion of different conceptions of the rule of law, see P. Craig, 'Formal and substantive conceptions of the rule of law: an analytical framework' [1997] PL 467.

[272] J. Raz, 'The Rule of Law and its Virtue' [1977] 93 LQR 195.

[273] A. V. Dicey, *An Introduction to the Study of the Law of the Constitution* (Liberty Classics Edition, 1982), p120.

III Pushing the patient over the edge

Given the inevitable uncertainty afflicting capacity assessments on the cusp of capacity, *and* that fact that the test for capacity fails to accommodate an important dimension of autonomy, decision-makers are left in an impossible situation. If they resolve this uncertainty in favour of capacity, the person will be permitted to do something profoundly harmful to themselves; whereas if they find them to lack capacity, they will be able to prevent this harm and act in a way which they regard as best for the patient. So, the decision-maker must either risk frustrating the patient's autonomy (which brings with it the potential for legal liability for committing a battery, and potentially for a breach of their rights under Articles 3 and 8 ECHR); or they must allow someone to cause themselves irreparable and avoidable harm which they may not have really wanted, and will later regret. In the face of this uncomfortable choice, it is not surprising that doctors feel conflicted:

> The vast majority of people feel that the law is unworkable and go back to the first principles of above all, do no harm. Be as restrictive in your care as you can (i.e. do the minimum), but always act to save life. I think the failings of the Act see many doctors and nurses trying to apply it, but in the end, going back to the basic principle of, "I'm here to relieve suffering in my fellow humans."[274]

This implies that at best, many doctors are left feeling unsupported by the law; and at worst it acts as an impediment to them doing their job. One way of resolving this dilemma is to demand greater evidence of capacity, where the person wishes to make a harmful decision. This, as Herring suggests, would mean 'the strength of the presumption [of capacity] may vary depending on the gravity of the issue at hand: the more harmful the effect of the decision the weaker the presumption and indeed more is

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[274] Interview [anonymised] (London, July 2017).

needed to establish capacity'.[275] There was substantial evidence in the interviews that the known consequences of a capacity assessment might affect the way in which it is conducted. One clinician, for example, said:

> the thing that isn't in the test but which I think will be the overriding thing in clinicians' mind is the pragmatic end results of this. If I say they lack capacity, it means I can do this, and this, and this. If I say they have capacity, then this and this and this is the likely outcome. And actually, which is the outcome I want? Which is the least harmful? Which is the best for the patient? So I think all of those things are going through your mind as you're making that judgement and I think it's the harm or the outcome of the test which actually probably predominates.[276]

Another consultant from Liaison psychiatry suggested:

> I think the nature of the decision that the caregivers are going to make or an imagined best interest decision affects the capacity here… Even if it shouldn't, of course it affects the capacity. So if somebody is making a decision – terribly unwise – even if they have a right to do that, if they have also got dementia and they're saying, "I want to sunbathe in the roof," then it makes it easier to say that they lack capacity.[277]

When discussing the vignette of Cara meanwhile (the 26-year-old with anorexia nervosa who had taken a paracetamol overdose), one clinician said:

> If her overdose of paracetamol was really significant, I mean if she had taken 100 paracetamol and very likely the harms were going to kill her, I'm sure we would say that she lacked capacity. If she had taken 10 paracetamol, and frankly it wasn't going to do anything, we'd go, "How can we help you?"[278]

One clinician even suggested that within the medical context, the presumption of capacity only existed for patients who were not objecting to the doctor's proposed treatment, as in this situation, it does not matter whether the person has capacity or not,

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[275] J. Herring, 'Peter Skegg and the Question No-One Asks: Why Presume Capacity?' in M. Henaghan and J. Wall (eds), *Law, Ethics, and Medicine: Essays in Honour of Peter Skegg* (Thomson Reuters 2016).

[276] Interview [anonymised] (Oxford, July 2017).

[277] Interview [anonymised] (Oxford, April 2017).

[278] Interview [anonymised] (Oxford, July 2017).

since the person will be treated anyway.[279] Another stated that capacity was a problem that 'tends to come up if we feel the patient is making an unwise decision'.[280] In a similar vein, others suggested that doctors might not even bother to conduct capacity assessments if the person was agreeing,[281] which echoed the findings of the House of Lords' in its review of the MCA, in which 'several witnesses expressed concern that in medical settings it appeared that an assessment was triggered in most cases only when treatment was refused.'[282] This was especially true of emergency medicine.[283]

Other doctors saw the capacity threshold as contingent on the severity of the outcome. One gave the example of a man with schizophrenia who had been stabbed in his abdomen, but was refusing surgery out of a fear that the surgeon would insert a chip into him. Given the grave consequences, their 'threshold to determine that he lacked capacity was very low.'[284] Meanwhile, in considering the vignette of Isobel, the woman with mild dementia refusing a hip replacement, the same doctor suggested that they would place their 'threshold for capacity at a completely different level' if she was suffering from a life-threatening heart condition rather than pain and stiffness.[285] Others similarly felt that the 'the higher the risk… the higher the bar, and the more

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[279] Interview [anonymised] (Oxford, July 2017).

[280] Interview [anonymised] (Oxford, March 2017).

[281] Interview [anonymised] (Oxford, July 2017).

[282] House of Lords (n12), [75].

[283] ibid, [75].

[284] Interview [anonymised] (Oxford, April 2017).

[285] ibid.

formal the assessment needs to be',[286] while another referred to a 'sliding scale of capacity' whereby patients needed to show a greater display of capacity where the consequences were more serious.[287]

This was a particular problem in the emergency setting, where as noted above, there will often be insufficient information to make robust assessments of capacity. Doctors frequently suggested that when faced with uncertainty, there was a tendency to err on the side of caution, illustrated by comments such as 'we just go ahead and save the person's life and think about everything else that would follow on at a later point';[288] and 'you get them treated…and then assess afterwards.'[289] One consultant even suggested that when training junior doctors, they told them to write that the patient lacked capacity 'as a safety net.'[290] In response to the vignette of Laura, which involved a woman refusing a blood transfusion because of a wish to keep her body 'pure',[291] one consultant suggested that:

> I would just go ahead and assume that she lacks the capacity, and treat her and probably deal with the consequences of giving her the transfusion later on. We just don't know enough about somebody.[292]

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[286] Interview [anonymised] (Oxford, April 2017).

[287] Interview [anonymised] (Oxford, April 2017).

[288] Interview [anonymised] (Oxford, March 2017).

[289] Interview [anonymised] (London, July 2017).

[290] Interview [anonymised] (London, July 2017).

[291] Laura is brought into A&E having been involved in a car crash. She has sustained an injury to her head in the crash, and while at times she seems quite lucid, at others she appears to lack awareness of where she is and what is happening. She requires a blood transfusion but even when lucid she is refusing the transfusion. She says that she does not believe in transfusions because she likes to keep her body pure.

[292] Interview [anonymised] (Oxford, March 2017).

Likewise in respect of Oscar, a 85 year old whose wife had died a year earlier and who had now attempted suicide as he felt it was 'the right time to go',[293] one consultant said that both the 'magnitude' of the risk and the imminence of it, would 'push you towards treating'.[294] They went on to suggest that 'because of the emergency situation the bar [for finding the person to have capacity] is that much higher'.[295] Notably this also seems to be turning the presumption of capacity on its head.

Interestingly, one doctor suggested that the very fact someone has been brought into the emergency department in an ambulance might lead the treating doctor to feel that they had a 'high risk of not being able to weigh up the pros and cons of treatment'[296] that would not be present in a 'different environment'.[297] Another went so far as to say that a person who refused treatment in the context of A&E was almost by definition incapacitated:

> if somebody's come to a place that has this *raison d'être* to save human life, then it is not logical to then come here and then say, "I want to leave", if you've tried to kill yourself. You cannot be balancing properly because this place is known to – its reason for existence – is to save human life.[298]

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[293] Oscar is an 85-year-old man. He is brought into hospital having taken a paracetamol overdose, in an attempt to commit suicide. When asked, he says that the suicide attempt had been planned for some time, and that he does not want any treatment as he would like to end his life. He explains to the doctors, that his wife of 60 years died over a year ago, and that, although he is not depressed, he continues to miss her. He tells the doctors that he has had a good life, with a fulfilled career and a happy marriage, but that, without any children or grandchildren, there is nothing left to give meaning to his life, and so he believes this is the 'right time to go'.

[294] Interview [anonymised] (Oxford, March 2017).

[295] Interview [anonymised] (Oxford, April 2017).

[296] Interview [anonymised] (London, July 2017).

[297] ibid.

[298] Interview [anonymised] (London, July 2017).

This is not to claim that *all* doctors thought the consequences of the decision was influencing the way that they conducted capacity assessments – one doctor suggested that they 'hoped' this was not the case. However, it does indicate that a number of clinicians readily accept it as a factor in their determinations, thus highlighting the vulnerability of the capacity test to being manipulated to achieve what the doctor regards as being in the patient's best interests. This was recognised by Justice Baker in *PH v A Local Authority and Others*,[299] who cautioned that

> there is a risk that all professionals involved with treating and helping that person – including, of course, a judge in the Court of Protection – may feel drawn towards an outcome that is more protective of the adult and thus, in certain circumstances, fail to carry out an assessment of capacity that is detached and objective.[300]

Linked to concerns about the outcome of the assessment, was a fear of the legal ramifications of deciding one way or the other. As one doctor summed it up:

> Fundamentally, we never receive a complaint for over-treatment but we do receive complaints for under-treatment… So, there is an intrinsic bias to over-treat because of fear of litigation.[301]

That a fear of litigation 'drives a lot of [doctors'] actions',[302] was acknowledged by a number of interviewees. One consultant was clear that:

> I take the position that I would rather face a judge for assault, than negligence that led to death. Therefore, I take a more heavy-handed approach with patients and I treat them. I always discuss, I ring their relatives, I do what I can, but in the end, if I've got somebody who will die without treatment then I believe it's better I treat them. I'm well aware there are things I've done that I could be guilty of assault for.[303]

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[299] [2011] EWHC 1704 (Fam).

[300] ibid, [16, xiii].

[301] Interview [anonymised] (London, July 2017).

[302] ibid.

[303] Interview [anonymised] (London, July 2017).

Another suggested that unless they have a family member to 'share the blame' with, 'we edge on the side of incapacity more than we edge on the side of capacity'.[304] One consultant meanwhile, characterised the 'bottom line' when determining whether or not to give a Jehovah's Witness a blood transfusion as whether to let the person die or 'run the risk of being sued by a Jehovah's Witness.'[305]

This does not reflect the views of all of the consultants interviewed — some said their position in law was not something that they thought much about. Others suggested that this would not affect their assessment but it would lead them to want support for their decision, or a second opinion,[306] for example:

> I would escalate that immediately to the lawyers. She probably has capacity, but if we are going to be risking her dying because we are not giving her a life-saving intervention, we need back up for that decision.[307]

However, overall the evidence suggests that when faced with a very difficult decision over whether or not the person has capacity, the legal ramifications of the decision also push the decision-maker towards finding them to lack capacity.

(a) Conclusions

The effect of the capacity 'cliff edge' is that doctors (and other decision-makers) are able to interfere with a person's decision *only* if they are found to lack capacity. When faced with a situation in which the person wishes to do something harmful to

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[304] Interview [anonymised] (Oxford, March 2017).

[305] Interview [anonymised] (Oxford, March 2017).

[306] Interview [anonymised] (London, July 2017).

[307] Interview [anonymised] (Oxford, March 2017).

themselves, the doctor is thus faced with a difficult decision: either they must find the person to have capacity and allow them to do something that is harmful to them, or they may use the discretion afforded to them in the MCA to find the person to lack capacity, and thus be able to intervene and prevent that harm. Evidence suggests that doctors often choose the latter course, and, in an attempt to mitigate the harshness of the law's approach, are more willing to rebut the presumption of capacity where the outcome of the decision will be grave.

This exacerbates the problems identified in the previous section, both in that it increases the likelihood of inconsistent application of the MCA, and because it leaves a person's right to autonomy even more vulnerable to the idiosyncrasies of the particular assessor, and what they regard to be a 'good' outcome clinically, or an outcome that carries fewer risks of legal liability. Clearly, this is difficult to reconcile with a legal system which is committed to allowing people to live their lives according to those values and beliefs that they regard as important, even if in doing so they expose themselves to harm. It also sits uneasily alongside the key principle underpinning the MCA, that a 'person is not to be treated as unable to make a decision merely because he makes an unwise decision.'[308]

If doctors' assessments of capacity are being influenced by external factors (such as the perceived harm that will result from the decision), this dilutes even further the accuracy of the capacity test as a means of determining when a person has autonomy. Where this is the case, giving doctors such unmediated powers to interfere in the decisions of those who lack capacity becomes hard to justify. For the person may in reality be deciding in an autonomous manner, and thus to treat them against their

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[308] MCA, s1(4).

wishes amounts to a huge invasion of their autonomy and their bodily integrity, as well as constituting a legal battery. As MacFarlane LJ remarked in *PC v York CC*,[309] if the 'structure and provisions of the MCA' are not applied with 'clarity and care', then the autonomy of the individual may be 'eroded by the court.'[310] The capacity threshold thus no longer serves to represent a clear line in the sand, marking out the boundaries of appropriate state intervention.

IV Conclusions

This chapter has highlighted a number of problems with the way that the test for capacity is being applied, which has resulted in it failing accurately and reliably to distinguish those people who are capable of making autonomous choices from those who are not. The narrow conception of autonomy contained in the act allows for people to be found to have capacity, even when they may in fact be making decisions which are not autonomous, resulting in capacity assessors being forced to stretch the meaning of other provisions in the Act in order to account for this problem. The broadly framed provisions in the Act which facilitate such an approach however, also leave substantial discretion to the individual assessor in applying the Act more widely, with the result that in practice, assessors have tended towards finding a person to lack capacity in the face of any uncertainty, in order to avoid potential harm to the person, or risk facing legal liability themselves. If this is the case however, and the act is being applied over-inclusively, then it is difficult to justify maintaining a cliff-edge approach to capacity,

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[309] [2013] EWCA 478 (Civ).

[310] ibid, [51].

according to which a person loses almost all say over their decisions once they are found to lack capacity.

Once it is recognised that ambiguity exists on the cusp of capacity, with the result that substantial disagreement may arise over whether a person has capacity or not and they may reasonably be found to fall on either side of the threshold, it follows that a finding of incapacity in those instances ought *not* to be treated in absolute terms. The views of the person do not suddenly become irrelevant: they may retain important elements of autonomy, even if they are found to fall just below the threshold. This is especially true if capacity assessments are being influenced by factors outside of the patients' decision-making ability (such as what the doctor perceives as a good outcome, or one which will not expose them to a risk of liability), as this suggests that these tests may not always deliver an accurate reflection of the person's capacity for autonomy. While this will be explored in more detail below, it is also important to note at this point that if we recognise that a person's values and beliefs are an important component of their autonomy, it follows that even if a person may be cognitively impaired (and thus lack capacity), they may nonetheless still have strongly and deeply held beliefs which are of profound importance to them. There is good reason, therefore, to continue to attach considerable importance to a person's wishes and feelings even after they lose capacity.

The following chapter will therefore explore the extent to which the current law is accounting for the fact that a person may retain important aspects of autonomy even if they lack capacity, by examining the way in which best interest assessments are being made, and how they far people who lack capacity are being empowered in decisions about their treatment and care.

II The implications of falling off the cliff edge

The previous chapter raised a number of concerns about the robustness of the capacity threshold. If it cannot reliably distinguish those who are capable of making autonomous decisions from those who are not, then the line between respecting individual autonomy and legitimate state intervention becomes markedly less clear cut – and the large degree of interference currently sanctioned for those who lack capacity is that much harder to justify.

This problem is mitigated through the provisions in section 4 of the MCA, which require the decision-maker to take into account the person's wishes and feelings when determining what is in their best interests. This, however, is just one factor among many to be considered, and the Act offers no guidance on how to weigh up the different factors. As a result, it is very difficult for doctors or care-workers to feel comfortable prioritising the person's wishes where doing so will expose the person to a risk of harm. By leaving it to each decision-maker to strike their own balance between empowering and protecting the individual, the Act offers no protection from liability should that harm later materialise. It is therefore no surprise that while the courts have largely (though not entirely) prioritised the individual's wishes in their decisions, this has not filtered through to the decisions being made on the ground. Here risk-aversion and a 'doctors know best' mentality still dominate, with best interests often understood in a clinical sense which fails to capture the full range of interests in question. If people who lack capacity are to be empowered in such decisions, the law needs to be amended to provide greater guidance and support for decision-makers.

I The need to soften the capacity cliff-edge

As chapter 1 set out, autonomy is not an all-or-nothing concept, but rather admits of degrees and variety of impairment. As a result, a person could retain important aspects of autonomy, even if they have been deemed unable to make a decision independently. Indeed the very nature of the test for capacity is such that a person has to fail only one limb of the test to be found to lack capacity, even though their other abilities may not be substantially impaired. It remains important therefore, even in the context of incapacity, to continue to protect those aspects of a person's autonomy as far as possible.

Importantly, this also means that while a cognitive impairment might inhibit a person's ability to understand and retain information, or to reason in respect of it, this does not necessarily undermine or distort the values, beliefs and priorities which the person holds. As Mary Donnelly explains:

> capacity impairment is not necessarily a barrier to people having views and preferences (acting autonomously in a thin sense) or having values, life narratives and a sense of selfhood, and seeking to formulate ways in which to give effect to these (acting autonomously in a thicker sense).[311]

District Judge Eldergill captured this eloquently in *Westminster City Council v Sykes*, when he suggested that Ms Sykes was

> still able to appreciate and express the value of being at liberty and being allowed autonomy. The importance of individual liberty is of the same fundamental importance to incapacitated people who still have clear wishes and preferences about where and how they live as it is for those who remain able to make capacitous decisions. This desire to determine one's own interests is common to almost all human beings. Society is made up of individuals, and each individual wills certain ends for themselves and their loved ones, and not others, and has distinctive feelings, personal goals, traits, habits and experiences. Because this is so, most individuals wish to determine and develop their own interests and course in life, and their happiness often depends on

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[311] M. Donnelly, 'Best Interests in the Mental Capacity Act: Time to Say Goodbye' (2016) 24(3) *MedLRev* 318–332, 322.

> this. The existence of a private sphere of action, free from public coercion or restraint, is indispensable to that independence which everyone needs to develop their individuality, even where their individuality is diminished, but not extinguished, by illness. It is for this reason that people place such weight on their liberty and right to choose.[312]

This may be particularly true when the person suffers from a condition such as dementia (as in *Sykes*), where their impairment often relates to their attention and recall, rather than their values and beliefs. A person's wishes and feelings are therefore important not only because respecting them will protect aspects of the person's autonomy, but because the values and beliefs that a person holds are instrumental in determining what course of action is best for them. Where a person has clearly expressed wishes, these wishes (and conversely, the effect on the person of overriding them) are likely to weigh heavily in the assessment of what, on balance, is in their best interests.

That a person's desires and priorities remain important even if they are found to lack capacity poses challenges for an approach premised on capacity operating as an all-or-nothing threshold. Some of the harshness produced by the law's cliff-edge approach is mitigated through its provisions in sections 4(4) and 4(6) MCA, which introduce an important element of substituted judgement (according to which the surrogate decision-maker ought to choose as the incompetent person would do were they competent to do so[313]), despite its focus on the person's objective best interests.[314] Section 4(4) requires the decision-maker to 'permit and encourage the person to

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[312] *Sykes* (n183).

[313] A. Buchanan & D. Brock. *Deciding for Others* (Cambridge: Cambridge University Press, 1989), 112.

[314] *Mental Incapacity*, Law Com No 231 (HMSO, 1995), 3.25.

participate' in the decision. Under s4(6) meanwhile, the decision-maker must, 'so far as is reasonably ascertainable', consider:

> d) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by [them] when [they] had capacity),
> e) the beliefs and values that would be likely to influence [their] decision if [they] had capacity, and
> f) the other factors that [they] would be likely to consider if [they] were able to do so.

At the time of drafting the Law Commission explained this provision on the basis that 'people who cannot make decisions can still experience pleasure and distress.'[315] Thus, as Mary Donnelly observes, it aims to represent 'a more appropriate and workable response to the goal of preserving patient autonomy notwithstanding the patient's loss of capacity'.[316] The question, however, is whether the provisions are currently achieving this aim.

As noted above, none of the factors in section 4 are, on the face of the statute, accorded priority in the best interest assessment.[317] This was deliberate. Both the Report of the Joint Committee on the Draft Mental Incapacity Bill[318] and the Government Response to this Report[319] commented at the time of drafting, that the need for flexibility when it came to making such assessments was best served by leaving it to the decision-maker to 'take account of a variety of circumstances, views

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[315] ibid, 3.29.

[316] M. Donnelly, 'Best Interests, Patient Participation and the Mental Capacity Act 2005' (2009) 17 *MedLRev* 1, 16.

[317] See for example, *Re M* (n33), [32], per Mr Justice Munby.

[318] HL 189-1, HC 1083-1 (TSO, 2003).

[319] Government Response to the Scrutiny Committee's Report on the Draft Mental Incapacity Bill (February 2004) Cm 6121.

and attitudes which may have a bearing on the decision in question.'[320] To prioritise one factor, it was felt, would 'unnecessarily fetter their operation in the many and varied circumstances in which they might fall to be applied'.[321] As a result, the Code of Practice accompanying the MCA is clear: while the individual's wishes and feelings, beliefs and values 'should be taken fully into account', they will 'not necessarily be the deciding factor'.[322]

The effect of this is to leave the decision-maker — be that clinician, carer or court — a large degree of discretion to decide how to balance the various factors set out in section 4, so as to come to a conclusion about what constitutes the person's best interests. These include the likelihood of the person regaining capacity;[323] the need to encourage them to participate in the decision;[324] to never be motivated by a desire to bring about death;[325] the person's wishes and feelings, and the values and beliefs that would have been likely to influence their decision if they had capacity;[326] and the views of those involved in the care of the person, as to what they would have wanted.[327] In order to evaluate whether the empowering provisions in section 4 are

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[320] Report of Joint Committee (n318), [89].

[321] Government Response (n319), 15.

[322] MCA Code of Practice (n266), 5.38.

[323] MCA, s4(3).

[324] ibid, s4(4).

[325] ibid, s4(5).

[326] ibid, s4(6).

[327] ibid, s4(7).

sufficient to ‘soften’ the capacity cliff-edge, it is thus necessary to understand how decision-makers are exercising this discretion, and whether they are giving substantial weight to the empowering provisions of ss4(4) and 4(6) when assessing what is in a person’s best interests.

II How are best interest decisions being made?

Given the lack of guidance in the Act on how the factors in section 4 ought to be balanced, it is no surprise that in the early years of the MCA, competing views emerged on how section 4 ought to be interpreted.[328] In *Re S and S (Protected Persons)* for example,[329] Judge Marshall QC regarded there as being a rebuttable presumption in favour of following the person’s wishes and feelings:

> where P can and does express a wish or view which is not irrational (in the sense of being a wish which a person with full capacity might reasonably have), is not impracticable as far as its physical implementation is concerned, and is not irresponsible having regard to the extent of P's resources (ie whether a responsible person of full capacity who had such resources might reasonably consider it worth using the necessary resources to implement his wish) then that situation carries great weight, and effectively gives rise to a presumption in favour of implementing those wishes, unless there is some potential sufficiently detrimental effect for P of doing so which outweighs this.[330]

She explained:

> What, after all, is the point of taking great trouble to ascertain or deduce P's views, and to encourage P to be involved in the decision making process, unless the objective is to try to achieve the outcome which P wants or prefers, even if he does not have the

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[328] For a more detailed discussion, see A. Ruck Keene and C. Auckland, ‘More presumptions please? Wishes, feelings and best interests decision-making’ (2015) Elder LJ, 293-301.

[329] *Re S and S (Protected Persons), C v V* ([2009] WTLR 315.

[330] ibid, [57].

> capacity to achieve it for himself?'[331]

However, just months later in *Re P*, Lewison J accused Judge Marshall of 'slightly overstat[ing] the importance to be given to P's wishes',[332] a view which then gained the support of Munby J in *Re M,*[333] who thought that although 'wishes and feelings will always be a significant factor to which [the decision-maker] must pay close regard',[334] the weight to be attached to them 'will always be case-specific and fact-specific'.[335] In some cases, they may be 'preponderant', in others, they would carry 'little weight'.[336] Far from there being a rebuttable presumption therefore, the individual's wishes and feelings were just one factor among many factors which must be weighed in the balance sheet. He set out some of the factors which would influence the weight to be accorded to these wishes:

> a. the degree of P's incapacity, for the nearer to the borderline the more weight must in principle be attached to P's wishes and feelings ...
> b. the strength and consistency of the views being expressed by P;
> c. the possible impact on P of knowledge that her wishes and feelings are not being given effect to;
> d. the extent to which P's wishes and feelings are, or are not, rational, sensible, responsible and pragmatically capable of sensible implementation in the particular circumstances; and
> e. crucially, the extent to which P's wishes and feelings, if given effect to, can properly be

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[331] ibid, [55].

[332] *Re P* [2009] EWHC 163 (Ch) at [41].

[333] *Re M* (n33).

[334] ibid, [35].

[335] ibid.

[336] ibid.

> accommodated within the court's overall assessment of what is in her best interests.[337]

While Munby J’s view has been reiterated in many of the cases that followed,[338] disagreement nonetheless remained. In *Re G(TJ)* for example,[339] Morgan J remarked that best interests could include an ‘element’ of substituted judgement, and in the absence of any countervailing factors, respect for the person's wishes could define what would be in their best interests. The court was not obliged to give effect to what the person wanted, but what they wanted would often be what was best for them. This echoes Mill’s point that individuals are usually best placed to know for themselves what is good for them: there are occasions where this is no less true, even where those individuals lack capacity. As the first of Munby J’s factors recognises, this is especially true where the person is on the cusp of capacity, as they may be no less able to appreciate how the decision affects them.

It was against this backdrop that the Supreme Court took the chance to clarify the application of section 4 in *Aintree v James,*[340] the first case on the MCA to come before the Supreme Court. The case concerned the lawfulness of withdrawing treatment from a 68-year-old man who had been in intensive care for seven months. In determining what is in a person’s ‘best interests’, Lady Hale suggested that the decision-maker

> must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what

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[337] ibid.

[338] See for example *VAC v JAD and Others* [2010] EWHC 2159 (Ch) and *NT v FS and Others* [2013] EWHC 684.

[339] [2010] EWHC 3005.

[340] *Aintree* (n26).

> it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.[341]

She rightly rejected the Court of Appeal's suggestion that the patient's wishes and feelings ought to be considered objectively (what a 'reasonable patient' would have thought), noting that 'the purpose of the best interests test is to consider matters from the patient's point of view'.[342] That did not mean that the person's wishes would always prevail, but:

> insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.[343]

While this judgment emphasises the individual at the heart of the decision and the need to approach the question of what is best for them through the lens of what *they* value and prioritise (and not what they ought to value or prioritise), Lady Hale certainly could have been more firm about how later courts should approach the weighting of factors in section 4. Noting that the person's wishes and feelings should be 'taken into account' because they are a 'component' in making the choice that is best for them implies that there are other components that might also be important in determining what is best for that person, while giving no guidance as to how these different 'components' ought to be weighted. It does not then, go as far as Morgan J in *Re*

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[341] ibid, [39].

[342] ibid, [45].

[343] ibid, [45].

G(TJ),[344] when he suggested that respecting a person's wishes, beliefs and values will *often* be what is best for the person, indicating that it should be the starting point of any assessment. Perhaps as a result, there has been some inconsistency in later judgments over how this statement ought to be interpreted. While most of the judges in the cases that have followed have read Lady Hale's judgment as requiring great weight to be placed on the person's wishes and feelings (some, far more so than her judgment in fact supports), discrepancies remain between judges, with some judges attaching relatively little weight to the views of the individual involved. These will be discussed in more detail in section (b), suffice to say however that it is perhaps regrettable that the Supreme Court did not take this opportunity to provide greater guidance on how to weigh the different factors in section 4, albeit that they were clearly limited by the terms of the Act.

(a) A sea-change in approach post-*Aintree*?

Notwithstanding the problems identified, Lady Hale's judgment has pervaded the cases that have followed. In *Re M (Best Interests: Deprivation of Liberty),*[345] Peter Jackson J was clear that 'the court must surely have regard to the person's *own assessment* of her quality of life',[346] rather than striving merely to prolong the person's life at all costs. Accordingly, he permitted the woman to be allowed to return to her own home, rather than remaining in a care home against her wishes. Similar concerns underpinned the

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[344] *Re G(TJ),* (n339).

[345] [2013] EWHC 3456 (COP).

[346] ibid, [38].

decision in *Westminster City Council v Sykes*[347] in which District Judge Eldergill said of a woman with dementia

> It is her welfare in the context of her wishes, feelings, beliefs and values that is important… In this important sense, the judge no less than the local authority *is her servant, not her master* [emphasis added][348]

Despite dementia affecting her recall, she was described as 'intelligent, articulate and knowledgeable', with 'her core personality' still 'intact'.[349] Accordingly, after noting that she was 'still able to appreciate and express the value of being at liberty and being allowed autonomy',[350] Judge Eldergill concluded that a one-month trial at home should be attempted. He observed:

> *It is her life.* Several last months of freedom in one's own home at the end of one's life is worth having for many people with serious progressive illnesses, even if it comes at a cost of some distress. If a trial is not attempted now the reality is that she will never again have the opportunity to live in her own home. Her home will be sold and she will live out what remains of her life in an institution. She does not want that, it makes her sufficiently unhappy that sometimes she talks about ending things herself, and it involves depriving her of her liberty.[351]

In *Newcastle-upon-Tyne Foundation Trust v LM,*[352] Peter Jackson J went further. Although he found the woman (a Jehovah's Witness) to have the capacity to refuse a blood transfusion, he continued that even had she lacked capacity, he would still have maintained that a transfusion was not in her best interests: 'applying s.4(6) in relation

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[347] *Sykes* (n183).

[348] ibid.

[349] Ibid.

[350] ibid.

[351] ibid.

[352] [2014] EWCOP 454.

to the specific issue of blood transfusion, her wishes and feelings and her long-standing beliefs and values carried *determinative weight'*.[353] A finding of incapacity was not then sufficient to impose treatment on her that ran so contrary to her fundamental beliefs, even if it was necessary to save her life. Indeed in this situation, her wishes and beliefs defined what was best for her.

Nowhere is this point made more clearly, however, than in *Wye Valley*[354] — a case concerning a man with schizophrenia who suffered from auditory hallucinations involving the voices of angels and of the Virgin Mary. Responding to the Trust's submission that 'views expressed by a person lacking capacity were in principle entitled to less weight than those of a person with capacity',[355] Peter Jackson J stated

> This is in my view true only to the limited extent that the views of a capacitous person are by definition decisive in relation to any treatment that is being offered to him so that the question of best interests does not arise. However, once incapacity is established so that a best interests decision must be made, there is no theoretical limit to the weight or lack of weight that should be given to the person's wishes and feelings, beliefs and values. In some cases, the conclusion will be that little weight or no weight can be given; in others, very significant weight will be due.[356]

He went on to explain that:

> This is not an academic issue, but a necessary protection for the rights of people with disabilities. As the Act and the European Convention make clear, a conclusion that a person lacks decision-making capacity is not an *"off-switch"* for his rights and freedoms. To state the obvious, the wishes and feelings, beliefs and values of people with a mental disability are as important to them as they are to anyone else, and may

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[353] ibid, [23].

[354] *Wye Valley* (n7).

[355] ibid, [10].

[356] ibid, [10].

> even be more important. It would therefore be wrong in principle to apply any automatic discount to their point of view.[357]

It was important that people were not, by virtue of their disability, 'deprived of the range of reasonable outcomes that are available to others.'[358] Indeed denying people with a disability control over their own lives 'may be experienced as an even greater affront that it would be to others who are more fortunate.'[359] Accordingly, he acceded to Mr B's wish to refuse a leg amputation, even if it would result in his death. He could see no benefit in

> tak[ing] away his little remaining independence and dignity in order to replace it with a future for which he understandably has no appetite and which could only be achieved after a traumatic and uncertain struggle that he and no one else would have to endure.[360]

The clear trend discernible since *Aintree* in favour of giving priority to the person's wishes has in part been facilitated by increased participation by the person in legal proceedings. In *Wye Valley* for example, 'given the momentous consequences of the decision either way', Peter Jackson J did not feel able to reach a conclusion without meeting Mr B himself.[361] He found that the advantages of face-to-face meetings 'can be considerable, and proved so in this case',[362] giving him a 'deeper

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[357] ibid, [11].

[358] ibid, [12].

[359] ibid.

[360] ibid, [45].

[361] ibid, [18].

[362] ibid.

understanding of Mr B's personality and view of the world'.[363] This was illustrated in the scrupulous description he later gave of him:

> Mr B has had a hard life. Through no fault of his own, he has suffered in his mental health for half a century. He is a sociable man who has experienced repeated losses so that he has become isolated. He has no next of kin. No one has ever visited him in hospital and no one ever will. Yet he is a proud man who sees no reason to prefer the views of others to his own. His religious beliefs are deeply meaningful to him and do not deserve to be described as delusions: they are his faith and they are an intrinsic part of who he is. I would not define Mr B by reference to his mental illness or his religious beliefs. Rather, his core quality is his *"fierce independence"*, and it is this that is now, as he sees it, under attack.[364]

This 'eloquent, moving and lucid judgment',[365] inspired Mostyn J to meet the patient for himself in the later case of *A Hospital NHS Trust v CD*:[366]

> It was an enlightening experience and one which I would recommend to any judge hearing a similar case. Mr Justice Jackson met Mr B and it is obvious from his judgment that the encounter was critically valuable. The reason it was enlightening for me was that the person I met was different in many respects to the person described in the papers. CD was engaging and polite. She was articulate. She was amusing. She listened carefully to questions and answered them equally carefully. True, there were comments that suggested powerful delusional forces; and Dr FH explained that she was heavily medicated. But even so, the person I met was a world away from the violent sociopath described in the papers.[367]

This approach is clearly valuable, and as Lucy Series notes, has been encouraged in a number of recent cases by the European Court of Human Rights.[368] Amendments to the

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[363] ibid.

[364] ibid, [43].

[365] [2015] EWCOP 74, [18].

[366] ibid.

[367] ibid, [31].

[368] L. Series, *The participation of the relevant person in proceedings in the Court of Protection: A Briefing Paper on International Human Rights Requirements* (2015), Version 1.2, available at: < http://sites.cardiff.ac.uk/wccop/files/2014/09/Briefing-on-Personal-Participation-in-the-CoP-v1-2.pdf>

Court of Protection Rules in 2015 to include rule 3A have aided this,[369] requiring the Court to consider how the person ought to participate in proceedings, including whether they 'should have the opportunity to address (directly or indirectly) the judge determining the application'.[370] This could be taken further. Emily Jackson, for example, suggests that there ought to be a presumption that the judge should, where reasonably practicable, meet [the patient] in order to hear from her directly.[371] While space precludes a detailed consideration of this proposal, there is certainly intuitive appeal to it, especially since such meetings have been shown to be so helpful in giving the judge a clearer sense of the person's character, priorities and values.

The emphasis now placed on the person's wishes has also extended beyond those on the cusp of capacity, to cases in which the person, though not currently able to contribute to the decision (being in a coma or minimally conscious state (MCS)), has previously expressed views which indicate what they would now want. This is exemplified by comparing three cases on withholding artificial nutrition and hydration (ANH) from someone in MCS.[372]

(accessed 12/08/2018). See e.g. *Shtukaturov v Russia* 44009/05 [2008] ECHR 223; *X and Y v Croatia* 5193/09 [2011] ECHR 1835; *Ivinović v Croatia* 13006/13 [2014] ECHR.

[369] The Court of Protection (Amendment) Rules 2015, available at < http://www.legislation.gov.uk/uksi/2015/548/pdfs/uksi_20150548_en.pdf>.

[370] ibid, 3A(2)(d).

[371] Jackson (n4).

[372] For a detailed assessment of all of the recent case law on those in a minimally conscious state, see R. Huxtable and G. Birchley, 'Seeking Certainty? Judicial Approaches to the (Non-)Treatment of Minimally Conscious Patients' (2017) 25(3) *MedLRev* 428–455.

In *W v M* (pre-*Aintree*),[373] Baker J stuck rigidly to the 'conventional' balance sheet approach, finding it to be in the patient's best interests to continue life-sustaining treatment, despite the evidence of her family that she would not have wanted to live in her current condition. They drew the court's attention to a specific incident in which she stated that Tony Bland ought to be 'allowed to die', and to her response to her grandparents' declining health, which prompted clear statements that she would not wish to live like that, that she would not wish to be dependent on others, and that she 'wanted to go quickly'.[374] Baker J nonetheless found that

> the various statements made by M prior to her illness in 2003 were informal, and not specifically addressed to the question I have to decide. Accordingly, whilst I take those statements into account, they are not binding and in all the circumstances I do not consider they carry substantial weight in my decision. The factor which does carry substantial weight, in my judgment, is the preservation of life.[375]

He concluded that it would be 'wrong to attach significant weight to those statements made prior to her collapse', and since there was no evidence that she had specifically considered the question of ANH or being in a MCS (Bland had been in a persistent vegetative state), the sanctity of her life took precedence.[376]

While there is good reason to not attach undue weight to 'throw-away' comments made many years previously, any comments which give a sense of what the person would want in such circumstances will *have* to have been made prior to the person's loss of capacity, since a person in a MCS cannot, by definition, comment in

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[373] [2011] EWHC 2443 (Fam).

[374] ibid, [230].

[375] ibid, [6]-[7].

[376] ibid, [249].

their current state. Moreover it will be rare for such comments ever to relate to the *exact* treatment that is currently being contemplated (that is, for it to discuss ANH, as opposed to continued ventilation, or simply being 'kept alive by machines'). That someone has not *expressly* put their mind to the question of continued ANH in a MCS does not, however, mean that such evidence cannot give a clear picture of what the person considered to be (or not to be) an acceptable or desirable quality of life. Arguably, 'in the absence of experience or anticipation of illness, M nevertheless had indicated her views about dignity, dependence and what she felt was an acceptable quality of life.'[377]

Accordingly, Pauffley J's approach in *United Lincolnshire NHS Trust v N*[378] differed considerably from that of Baker J. Evidence was relayed to the court of a conversation between N and a friend, in which they both professed that if they were in a car accident, they would not wish to live with reduced capacity. In addition, various family members expressed their conviction that N would have found her current existence undignified and intolerable. Despite the evidence being no more convincing that than in *W v M*[379] (arguably even less so), Pauffley J attached far greater weight to it, suggesting that 'what the views of the patient might be, and what the views of the family are, are *highly material factors* when considering best interests, although not

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[377] C. Johnston, N. Banner and A. Fenwick, 'Patient narrative: an "on-switch" for evaluating best interests' (2016) 38 *Journal of Social Welfare and Family Law* 249, 254.

[378] [2014] EWCOP 16.

[379] *W v M* (n373).

determinative'.[380] Drawing on Lady Hale's judgment in *Aintree,* she was left 'utterly convinced' that continued treatment was not in the patient's best interests.[381]

Similarly, in *M v Mrs N,*[382] Hayden J engaged in the most detailed and intimate examination of Mrs N's values and personality, drawing on the accounts of her family, and calling on evidence going back to when she was 18 years old.[383] He commended the way that her family had brought 'her personality into the courtroom', giving a 'clear and compelling impression of who Mrs. N is and what her values were'.[384] He concluded:

> I am left with little doubt that Mrs. N would have been appalled to contemplate the early pain, increasing dependency and remorseless degeneration that has now characterised her life for so long. I have no difficulty in accepting the family's view that she would not wish to continue as she is. More than that, she would have wished to have discontinued her treatment some considerable time ago.[385]

That he was engaging with what the particular patient would want, and not merely what a 'reasonable person' in P's position would do, was made abundantly clear when he observed, 'some might well have endured all that Mrs. N has with phlegmatism and fortitude. Mrs. N is simply not such a person'.[386] His rendering of the word 'she' in bold throughout his 'conclusions' section lends credence to this view. He stressed that

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[380] ibid, [58].

[381] ibid, [66].

[382] [2015] EWCOP 76 (Fam).

[383] [50]-[61].

[384] ibid, [59].

[385] ibid, [60].

[386] ibid, [61].

he was ‘entirely satisfied that there is no prospect of her achieving a life that **she** would consider to be meaningful, worthwhile or dignified’,[387] and that therefore he had ‘come to the conclusion that it would be disrespectful to Mrs. N to preserve her further in a manner I think **she** would regard as grotesque.’[388] In doing so, he reiterated his stance in *Sheffield Teaching Hospitals NHS Foundation Trust v TH & Anor*, [389] where he was critical of the Official Solicitor for not ‘absorb[ing] the full force of Baroness Hale's judgment in *Aintree* and the emphasis placed on a ‘holistic’ evaluation when assessing both ‘wishes and feelings’ and ‘best interests’.[390]

Given the recent Supreme Court ruling in *An NHS Trust v Y*,[391] which held it to be unnecessary to obtain a court order to withdraw ANH where doctors and family are in agreement, cases of this nature are less likely to come before the courts in the future. These cases (along with others which space precluded a detailed analysis of here[392]) nonetheless illustrate a clear change of approach since Lady Hale’s judgment in *Aintree* when it comes to withholding treatment from those in a MCS, not only in terms of the weight accorded to the person’s previous statements as to their wishes, but also

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[387] ibid, [74].

[388] ibid, [75].

[389] [2014] EWCOP 4, [55].

[390] ibid, [54].

[391] [2018] UKSC 46.

[392] In *M v A Hospital* [2017] EWCOP 19 for example, Peter Jackson concluded: ‘Where a patient is suffering from an incurable disability, the question is whether she would regard her future life as worthwhile... In this case, the evidence satisfied me that it was no longer in M's interests for her life to be artificially continued by CANH. I accepted the evidence of the family and the clinicians. They had reached their positions after the most careful thought, placing M at the centre of their concern, and concluding that she would not have wanted to go on living as she was, nor endure the inevitable continued decline in her terminal condition’ (para 24-26).

in the holistic way in which the person's interests are being conceived. This led Johnston *et al* to conclude that 'the way a person has lived their life — what we could describe as their narrative up to and beyond the point of incapacity — seems increasingly to have legal relevance in the determination of current best interests.'[393]

(b) Divergent approaches

While the general tenor of judgments since *Aintree* has emphasised the importance of the individual's views, none of the cases set out any strong statement of principle about the weight that ought to be accorded to the person's wishes and feelings. Instead judges have reiterated that this is 'case specific and fact specific'. Notwithstanding the careful and empathetic judgment of Peter Jackson J in *Wye Valley*, he remained clear that 'in some cases, the conclusion will be that little weight or no weight can be given; in others, very significant weight will be due.'[394] In *M v N,* meanwhile*,* Hayden J stressed that:

> Respecting individual autonomy does not always require P's wishes to be afforded predominant weight. Sometimes it will be right to do so, sometimes it will not. The factors that fall to be considered in this intensely complex process are infinitely variable e.g. the nature of the contemplated treatment, how intrusive such treatment might be and crucially what the outcome of that treatment may be for the individual patient. Into that complex matrix the appropriate weight to be given to P's wishes will vary.[395]

Almost all of these cases have only been heard at first instance and not by an appellate court. In the absence of any guidance on how to approach this issue from either the Act, or the Supreme Court therefore, it is unsurprising that notwithstanding the humane

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[393] Johnston et al (n377).

[394] *Wye Valley* (n7), [10].

[395] *M v N* (n382), [28].

and compassionate way that many of these judges have engaged with the individual, they have still not felt able to enshrine this approach as a matter of principle applicable to everyone. While this may enable judges to retain maximal flexibility in the cases that come before them, the effect has been to introduce a lack of clarity over the level of importance that ought to be attached to the individual's views. This can be seen in the way that judgments have diverged, both in the *obiter* comments of different judges over the appropriate weight to be accorded to the individual's wishes; and in the outcome of the cases. Unless the Act is amended, or the Supreme Court takes the opportunity to clarify the issue in much more clear and unequivocal terms than those put forward in *Aintree*,[396] these problems are likely to continue.

(i) Diverging obiter dicta: *how much weight?*

The failure in either the Act or the case law to set out clearly how the person's wishes and feelings ought to be weighed against other factors, has resulted then in a lack of consistency and clarity on this issue. For example, notwithstanding the outcome in *M v Mrs N*,[397] Hayden J's dictum appears to ascribe far less weight to the person's wishes and feelings than other judges have been prepared to do. Hayden J deduced from *Aintree* only that while wishes and feelings, where ascertainable, are to be afforded 'great respect'; they 'will rarely, if ever, be determinative of P's 'best interests.' [398] This reading would seem to dilute the strength of Lady Hale's judgment even further: to say (as she did) that a person's wishes ought to be taken into account because they are a

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[396] *Aintree* (n26).

[397] ibid.

[398] ibid, [28].

component of what is best for them, suggests that there are other components which may also contribute to the determination of what is best. She does not however say anything about how these different components ought to be weighted. To take from this then, that other components will almost always outweigh the person's wishes, and so the wishes will rarely, if ever, be determinative, would seem to go a step further than Lady Hale was willing to go. Peter Jackson J meanwhile, clearly does think that a person's wishes can be determinative of what is in their best interests: in *LM* for example, the woman's values (as a Jehovah's Witness) *did* carry 'determinative weight'.[399] While a Jehovah's Witness refusing blood transfusions (as in *LM*) *could* be one of the 'rare' situations that Hayden J envisages here, it is certainly not an entirely exceptional situation.

That Hayden J appears to endorse a different view of the weight to be ascribed to the person's wishes is reinforced by his judgment in *NHS Foundation Trust v Q,*[400] when he noted:

> The wishes and feelings of those who suffer from delusional beliefs are not automatically, in my judgement, to be afforded the same weight as the beliefs articulated by an individual who has had the fortune to possess the powers of objective reasoning and analysis. There is nothing in *Wye Valley v B* which supports anything to the contrary. *The kernel of the issue is that delusional beliefs should never be discounted merely because they are irrational.* They are real to the individual concerned. The weight they are to be afforded will differ from case to case and, as always, will fall to be considered within the broader context of the evidence as a whole.[401] [emphasis added]

Yet to read *Wye Valley* as supporting only the proposition that delusional beliefs should not be discounted entirely, is to downplay the significance that Peter Jackson J attributed to them in that case. While he did indeed suggest that 'it would be wrong in

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[399] *LM* (n352).

[400] [2017] EWCOP 11.

[401] ibid, [31].

principle to apply any automatic discount to their point of view',[402] this must be seen in the context of statements such as, 'the wishes and feelings, beliefs and values of people with a mental disability are *as important to them as they are to anyone else, and may even be more important'*;[403] that 'people with a disability are not – by the very fact of their disability – deprived of the range of reasonable outcomes that *are available to others*';[404] and that Mr B's Article 9 right is '*no less engaged than it would be for any other devout person.*'[405] These statements suggest that Peter Jackson J was advocating more than merely that the person's wishes should not be ignored altogether. Rather, they suggest that they ought to be given significant weight, akin to those of people who have capacity – a parity which Hayden J himself appeared to endorse in *M v Mrs N*, when he suggested that the wishes and feelings of those who lack capacity, when cogent and authentic, 'are to be afforded no less significance than those of the capacitous.'[406] It is clear then that the lack of guidance — either from the statute or the preceding cases — has resulted in some divergence between judges on the weight to be ascribed to the person's wishes, feelings, values and beliefs.

(ii) Outlying cases

Judges have still, post-*Aintree*, sometimes given little weight to the person's clearly ascertainable views, or attention to explaining why they have not been followed. *RB*

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[402] *Wye Valley* (n7), [11].

[403] ibid.

[404] ibid, [12].

[405] ibid, [14].

[406] *M v N* (n382), [32].

(By His Litigation Friend the Official Solicitor) v Brighton and Hove City Council[407] for example, concerned whether a previous alcoholic who had sustained a serious head injury (in addition to other injuries, including the effective loss of the use of his left hand) ought to be able to leave his neurorehabilitation facility and resume living independently. To start with, he cooperated with his treatment programme, but after arrangements to move him into his own flat collapsed, he resumed his former lifestyle, habitually going out and getting drunk. Accordingly, the council obtained various authorisations, including to restrain him at the care home and to permit him to leave only with an escort. These restrictions were strongly resisted by RB: while accepting that he needed some support (with showering, dressing and cutting up food), he maintained that he could, with assistance, live independently. The court however scarcely engaged with RB at all, saying:

> Both the Council and the court are aware of RB's wishes, namely to live independently in the community. The MCA section 4(6)(a) requires both the Council and the court to take those wishes into account. I do so. Unfortunately it is not possible for the time being to comply with those wishes.[408]

Little was provided by way of reason for this clear dismissal of RB's wishes, with Jackson LJ stating only that

> RB's physical and mental disabilities are such that he is not currently capable of independent living outside an institutional setting. Such a setting is necessary (a) to deliver day to day personal care and (b) to prevent RB drinking to excess and suffering dire consequences.[409]

While there may well have been reasons why independent living was not possible for

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[407] [2014] EWCA Civ 561.

[408] ibid, [81].

[409] ibid, [80].

RB, a more detailed discussion of why this was, and whether there were other, less intrusive, means by which he could have been protected, would certainly have been welcome.

In other cases, the dismissal of the individual's views is less overt, but there still appears to be less weight being accorded to the person's wishes and feelings in the best interest assessment. *A Local Authority v E*[410] concerned a 32-year-old woman who had been controlling her eating since the age of 11. She had spent over half her time between the ages of 26 and 30 in placements at specialist eating disorder units, and by the time the case came to court, had not eaten any solid food for a year. Her problems with eating were compounded by alcohol dependency, and a borderline personality disorder. Given her years of suffering, and very low chance of ever recovering, she expressed a consistent and unequivocal wish to be entitled to refuse treatment, even if that ended her life:

> She describes her life as "a pure torment". All the things she had wanted to do have proved impossible because of her illness. She can't achieve any of her goals and she feels crushed. She feels she is in a situation where she is able to give nothing to the world and the world is able to give nothing to her.[411]

Even her parents supported her in this wish:

> It upsets us greatly to advocate for our daughter's right to die. We love her dearly but feel that our role should now be to fight for her best interests, which, at this time, we strongly feel should be the right to choose her own pathway, free from restraint and fear of enforced re-feed. We feel that she has suffered enough.[412]

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[410] *E* (n24).

[411] ibid, [76].

[412] ibid, [80].

Given the seriousness of E's case, any therapies for her eating disorder (and other problems) could only be embarked on if her BMI could be raised to 17 (it was currently 11.3), which would necessitate 'forcible feeding under physical or chemical restraint for not less than a year.'[413] This, as Peter Jackson J acknowledged, would 'not merely entail bodily intrusion of the most intimate kind, but the overbearing of E's will in a way that she experiences as abusive',[414] as it replayed the serious sexual abuse she had sustained as a child.[415] Nor was this treatment plan without its own risks, with doctors predicting that, given her frailty and the intensity of this medical intervention, 'her chances of surviving or not surviving treatment are no more than equally balanced.'[416] Dr Glover, the court-appointed expert, described it as 'a gargantuan task to take her from where she is now to where we want to go'.[417] Against these 'weighty factors' however,[418] weighed E's life, and it was estimated (albeit with some caution) that there was around a 20% chance of recovery (defined as 'returning to a quality of life that she would regard as being worthwhile'[419]). It was this which ultimately dictated the outcome:

> The competing factors are, in my judgment, almost exactly in equilibrium, but having considered them as carefully as I am able, I find that the balance tips slowly but

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[413] ibid, [88].

[414] ibid, [131]

[415] ibid, [89].

[416] ibid, [71]

[417] ibid, [98].

[418] ibid, [136].

[419] ibid, [72].

> unmistakably in the direction of life-preserving treatment. In the end, the presumption in favour of the preservation of life is not displaced.[420]

One does not envy the position of Peter Jackson J in this case, who in determining what was in E's best interests, had to weigh this chance of her recovery against the overwhelming likelihood that she would never recover from her mental illness, and would either die, or suffer intolerably, in the course of treating it. Arguably however, it is precisely in cases such as this — in which the factors on each side of the assessment are so finely balanced — that the person's own perception of what is best for them ought to take on the greatest significance. That E lacked capacity to make decisions about the ingestion of food did not in any way diminish her ability to experience suffering at her situation. As Peter Jackson J himself noted, her wishes are 'not the slightest bit less real or felt merely because she does not have decision-making capacity.'[421] Given this, to override her clear and consistent wish — especially in such a physically invasive and psychologically traumatic manner — would seem very difficult to justify.

The concern with the assessment of best interests in this case cannot only be with the weight accorded to her wish both to refuse food and to be left alone to die. Were this the case, then a strong and unequivocal wish would determine her best interests irrespective of her chances of recovery. Given the overwhelming odds that E would never recover, it is difficult to see how inflicting such a large degree of suffering could ever be in her best interests. In other circumstances, if there had been a good chance of total recovery, it might be considered that even a substantial degree of

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[420] ibid, [140].

[421] ibid, [127].

suffering would be warranted in order to achieve this outcome. In E's case, however, the judgement not only failed to take account of her wishes, but also gave insufficient weight to other factors when weighing up her best interests, namely the very high chance that the suffering that she would have to endure would be in vain.

The paradox in E's case is that her suffering is to some extent self-inflicted: if she had not objected to being fed, her treatment would most likely have been less traumatic, and that being the case, it must be considered in her best interest to undergo treatment with a 20% chance of recovery. However, it is precisely because she wished not be fed that she was faced with the force-feeding that caused her so much anguish: her suffering was not only a cause of her wishes then, but also a consequence of them.

This perhaps weighed with Peter-Jackson J in reaching his judgment. By deciding in favour of force-feeding however, he concluded that the relatively low risk of recovery outweighed both her unequivocal wish to end her life and her very reasonable objection to a regime she experienced as violent and abusive — a conclusion which would seem to attach far less weight to her wishes than the disordered beliefs of Mr B received in *Wye Valley.*[422] In reaching his conclusion, Peter Jackson J suggested in this case that 'the balancing exercise is not mechanistic but intuitive'.[423] Yet to deny a patient, especially one as acutely aware of their situation as E, any say over an issue as deeply personal and intimate as how the final moments of her life plays out, on the basis of an individual judge's 'intuition' of what is right or wrong, is deeply problematic. Something more than mere 'intuition' is therefore

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[422] *Wye Valley* (n7).

[423] ibid, [129].

necessary if this cliff-edge approach to capacity is to be justified in instances such as this.

(c) Conclusions

It is clear that, at least following Lady Hale's judgment in *Aintree,* judges in the Court of Protection have generally been alive to the need to place the individual at the heart of proceedings, and in many recent cases have given considerable weight to the person's wishes and feelings. But the failure of either Parliament, or the Supreme Court to lay down any firm statement of principle about how much weight should be given to the person's wishes has allowed a wide divergence of opinion on the issue, leading to very different outcomes. The dicta of the judges in some of the cases remains hard to reconcile, and outlying cases remain in which only scant consideration has been given to the patient's views. As the Law Commission noted:

> the law fails to give sufficient certainty for best interest decision-makers on how much emphasis should be given to the person's wishes and feelings. On the one hand, it can be said that there is no hierarchy between the various factors listed in section 4. This was clearly the policy intention behind the legislation. On the other hand, the Supreme Court has clarified in the *Aintree* case that best interests requires consideration of matters from the person's point of view and that the person's wishes and feelings are an important factor, arguably attaching some level of primacy to this factor. Similarly, in some cases the Court of Protection has gone to great lengths to make the decision the person would have wanted. But equally, in other cases, the outcomes have been expressly inconsistent with what the person wants or would have wanted.[424]

Judges could benefit then, from a more unified starting point.

However, only a very small proportion of cases ever come before the courts. It is therefore essential to examine how these provisions are being applied in practice, both by doctors on the wards making treatment decisions, and by local authorities when deciding about a person's care arrangements. There is evidence that the

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[424] Law Commission, 'Mental Capacity and Deprivation of Liberty', Consultation Paper No 222, 12.47, accessible at < http://www.lawcom.gov.uk/wp-content/uploads/2015/07/cp222_mental_capacity.pdf>, 12.42.

prioritisation of the individual that now characterises many judicial decisions has not percolated through to the decisions being made on the ground.

III Best interests decisions on the ground

In its post-legislative scrutiny of the MCA in 2014, the House of Lords was critical of the way that the provisions in s4(6) had been implemented in practice, observing that 'the empowering ethos of the Act has not been widely implemented'.[425] It found that the wishes, thoughts and feelings of the person lacking capacity were 'not routinely prioritised',[426] rather 'clinical judgements or resource-led decision-making predominate.'[427] These criticisms were soon after echoed by the Department of Health in respect of people with learning disabilities, autism and mental health conditions.[428] Most recently, the Law Commission received evidence that families and carers often felt professionals would 'pick and choose' at random which of the factors in section 4 to prioritise.[429] They quoted from an advocacy provider (Pohwer), who said that:

> Whilst the best interest checklist was well crafted in the Mental Capacity Act, inherent risk aversion within the health, social care and other sectors too frequently results in insufficient weight being given to the wishes and feeling of people subject to the Act.[430]

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[425] House of Lords (n12), [8].

[426] ibid, [104].

[427] ibid, [104].

[428] Department of Health, 'No Voice Unheard, No Right Ignored — A Consultation for People with Learning Disabilities, Autism and Mental Health Conditions' (2015) Cm 9007, pages 13; 33-34.

[429] Law Commission Consultation Analysis (n15), accessed 25/09/18.

[430] ibid.

Similar conclusions were also reached by the Alzheimer's Society who, in gathering evidence for the Department of Health, found that

> almost one in five people with dementia who responded felt that, either all or most of the time, decisions were made for them without them being asked first…. In fact the results show that the MCA was only correctly followed for almost a third of the people who responded.[431]

It seems then, that the trend towards greater empowerment seen in the case law has not trickled down to the decisions being made on the ground. Evidence from the interviews conducted as part of this research supports these findings, with best interests often conceptualised not as a question about what clinical course of action is best *in light of* the person's values and priorities, but rather as though there is an objective right clinical course, which must be qualified in certain instances by the person's wishes and feelings.

Some clinicians interviewed for this thesis clearly regarded best interests as a clinical decision, with the patient's wishes being only a secondary consideration. One doctor, for example, gave the following example of a woman with dementia in a care home who falls and breaks her hip:

> I know that she will be better cared for going into hospital, having her hip fixed, and then coming back out again. I'm not really interested in what she is going to say about going into hospital or not, I know that her suffering will be made worse - much, much longer - and she will be disabled for longer if we do nothing about this. What is in her best interests I will enforce on her, irrespective of what is in the care plan. Just simply because that's an inalienable truth. Certainly, the Capacity Act would say, actually you have to probably work out what everybody else will feel about that [but]…while somebody is lying on the floor, you can't have that conversation.[432]

By contrast,

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[431] S. Cox, 'Decision-making and dementia – how well does the Mental Capacity Act serve people living with the condition?' (2015) Eld LJ 74-83, 79.

[432] Interview [anonymised] (Oxford, July 2017).

> If somebody with cancer was to develop renal failure, would I do anything about it? No. Because, what I'd be doing is perpetuating that individual's pain and suffering from their underlying illness. You've got to die of something, and dying of renal failure isn't that bad. If somebody developed a chest infection, and they got severe CAPD, or pulmonary breath loss, severe heart failure or severe dementia - well in fact, dying from pneumonia is not that bad either, you just go to sleep.[433]

While acknowledging that they could 'get pulled up in court' for some of their decisions, this doctor explained that they would defend themselves on the basis of their 'Hippocratic oath, or the Good Samaritan approach to things.'[434] Central to this is that they regard themselves as doing the 'right' thing for the patient, even if this is not what the patient wants. They went on to appraise the MCA in the following way:

> It doesn't give me carte blanche to overrule what an individual says. There are times where I find it intensely frustrating, because I think that people may not necessarily make the right decisions, but I think, as an older doctor, I'm now happy to live with that, because not everybody does what you tell them to do.[435]

Sometimes, suggested one clinician, patients are not 'emotionally equipped' to make uncomfortable decisions:

> Take any six-year-old child with a fear of needles. Tell [them], "this is leukaemia – without giving you chemical therapy, you might die" and then show them a large needle, and of course they're going to refuse. The law doesn't allow children capacity to make that decision because it recognises they just can't. They're not emotionally equipped to do so. The thing is many adults are also not emotionally equipped to do so but the law makes no allowance.[436]

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[433] ibid.

[434] ibid.

[435] ibid.

[436] Interview [anonymised] (London, July 2017).

Another doctor spoke of the need to 'coax' patients into making the decision which was best for them.[437] However, these views were not representative of all of the clinicians interviewed, and certainly within some specialisms (specifically psychiatry and geriatrics), doctors appeared to place much greater emphasis on the importance of giving effect to the person's wishes even where they lacked capacity. One geriatrician, for example, reported 'we generally try and facilitate the patients' wishes, even if we feel that there may be an element of risk or unwiseness'.[438]

The most common decisions for geriatricians and old age psychiatrists were decisions about the discharge of patients, and whether or not the person would be permitted to return home or would be put into a cared-for setting such as a residential or nursing home. Doctors repeatedly stated that the 'default' or 'preference' was to get people back into their own homes, 'unless there's a very, very good reason that they can't'.[439] Echoing the concerns raised earlier that even those who lack capacity may appreciate the effects of such decisions, one doctor explained:

> Trying to force somebody against their wishes to move into a care home is not fun. We try as hard as we can. If somebody really wants to stay at home, we really try to keep them at home.[440]

They went on to explain that their aim when treating patients is to be flexible: 'We are not saying to the person, "Look, you do this." What we're saying is, "How can we facilitate? How can we work with you?"' Another doctor explained that 'what you're

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[437] Interview [anonymised] (Oxford, March 2017).

[438] Interview [anonymised] (Oxford, March 2017).

[439] Interview [anonymised] (Oxford, April 2017).

[440] Interview [anonymised] (Oxfordshire, May 2017).

usually doing is trying to listen to what they're saying and see how far you can go along that route without significant harm being caused'. So while there are certain areas in which medical paternalism may dominate, it should not be assumed that this is the case for all doctors.

This difference of approach appeared to reflect a deeper divergence of opinion over what the 'best interests' test was attempting to ascertain, reminiscent of the dialogue seen in the early case law. Some doctors presented best interests as an objective 'cost-benefit' analysis:[441] 'the potential benefit and the potential harm of doing something versus the potential benefit and potential harm of not doing the thing or doing an alternative.'[442] This tended to place greater emphasis on the clinical factors — which aligns with the House of Lords finding that 'best interests' is 'all too often' interpreted 'in a medical/paternalistic sense'.[443] Others presented best interests as involving two separate constituent elements — the clinical view of what was best for the person; and the person's wishes.[444] The final determination was often viewed as a 'compromise' between these two elements, with the objectively 'best' clinical course having to be qualified in certain situations by the person's wishes and feelings.

Some doctors meanwhile — particularly in geriatrics and psychiatry — regarded best interests as having a much greater subjective element. For one doctor, the best interests assessment was a means of determining 'what would they want for

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[441] Interview [anonymised] (Oxford, May 2017).

[442] Interview [anonymised] (Oxford, July 2017).

[443] House of Lords (n12), [90].

[444] Interview [anonymised] (Oxford, March 2017).

themselves if they can choose for themselves?'[445] Several suggested that they would want to talk to the family to discover what 'the person would have wanted, and what their previous life course was, and what their life decisions had indicated about them'.[446] They would 'try to get the best idea as to what the patient would have wanted beforehand';[447] or 'ask them what they think his wish would have been if he hadn't been under a delusion';[448] or to 'try and understand what the patient's wishes would have been before they lacked capacity, and the type of person they were, and [what] decisions they've made in other similar situations.'[449] These doctors clearly regarded best interests as bordering on substituted judgement, aimed at ascertaining what the patient would have wanted were they to have capacity. Clearly then, there is a very wide and divergent understanding among clinicians about what constitutes best interests. Given this, it is unsurprising that there should be inconsistency in the way they apply the test.

The case law concerning local authorities, meanwhile, suggests that their actions in this area are dominated by aversion to risk. This is illustrated by numerous instances in which very little weight has been given to the individual's wishes. In *Hillingdon LB v Neary*[450] for example, a 21-year-old man with autism and learning

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[445] Interview [anonymised] (Oxford, May 2017).

[446] Interview [anonymised] (Oxford, March 2017).

[447] Interview [anonymised] (Oxford, April 2017).

[448] Interview [anonymised] (Oxfordshire, March 2017).

[449] Interview [anonymised] (Oxford, March 2017).

[450] [2011] EWHC 1377 (COP).

disabilities was kept in a residential support unit for a year against his wishes (and those of his father). The judge subsequently found the DOLS authorisation to have been 'flawed' because the best interests assessment had not mentioned his wish to go home at all.[451] Similarly in *G v E*,[452] Baker J criticised the 'deplorable failure' of the local authority to take into account the close relationship between the young man (who had autism) and his carer, and their 'failure to arrange any contact for several months between this vulnerable young man and the person who had been his carer – his mother-figure – for most of his life'.[453]

While these cases both concerned young men with learning disabilities,[454] *Essex County Council v RF*[455] concerned a 91-year-old man with dementia who was unlawfully removed from his home and deprived of his liberty for around 13 months. In a damning indictment of the behaviour of the local authority, District Judge Mort declared himself unable to comprehend why this was 'considered to be a reasonable and proportionate solution to the problem [of his vulnerability to financial abuse] or why his removal and detention was thought to be in his best interests.'[456] In

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[451] ibid, [182].

[452] [2010] EWHC 621 (Fam).

[453] ibid, [85].

[454] While there is not space to consider every case in detail here, other notable examples include *A Local Authority* v *WMA & Ors* [2013] EWHC 2580 (COP) and *Northamptonshire Healthcare NHS Foundation Trust* v *ML (Rev 1)* [2014] EWCOP 2 both of which concerned young men with learning disabilities being taken out of the care of their families and placed in other living arrangements against their wishes, and that of their families.

[455] [2015] EWCOP 1.

[456] ibid, [55].

all of these cases local authorities acted in a highly interventionist manner, ignoring the wishes and feelings of the individual at the centre of the decisions.

While these cases may not be representative of the decisions which do not make it to court, the evidence from both the House of Lords inquiry and the Law Commission consultation corroborates the assertion that local authority care decisions are frequently driven by aversion to risk. Dr Ruth Allen, for example, representing the College of Social Work, stated that 'the MCA is not yet fully understood across any profession as an enabling piece of legislation... it is often seen as bolstering the desire to protect and, in some ways, control people's choice making'.[457] Other contributors suggested that social workers veered 'towards overprotection and safeguarding',[458] and that 'most practitioners would feel more comfortable defending a decision to protect rather than being accused of being neglectful'.[459] This was also acknowledged by some local authorities. Lancashire County Council observed that[460]

> enabling someone to take risks is scary, and workers can be under tremendous pressure from families and within their own agencies — what if something goes wrong? Whose name will be headlined? The MCA has not made us any less risk averse.[461]

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[457] House of Lords (n12), [86], quoting from response to Q139.

[458] ibid, [87].

[459] ibid.

[460] ibid, [88].

[461] ibid, quoting from Lancashire County Council DoLS Team.

IV The need for reform

Here lies the crux of the problem: ‘what if something goes wrong? Whose name will be headlined?’ It is understandable that practitioners should be anxious to avoid any risk, knowing they are ultimately legally responsible for the decision that is being taken, and could face serious liability for any harm that might result. But the way that the current law is framed exacerbates this problem, as it does not provide practitioners with any kind of support for taking reasonable risks with the person’s physical safety, even where doing so respects their wishes. The Act instructs practitioners to consider a range of factors, but offers no guidance in situations where these factors pull in different directions, leaving it to each individual decision-maker to perform their own balancing act, based on the aspects that he or she considers most important. As Helen Taylor observes:

> The MCA has drawn attention to the need for decision makers to consider a range of issues wider than the patient’s clinical interests, yet provides insufficient guidance on how the statutory principles should be applied in practice.[462]

The decision-maker struggling to strike the correct balance between empowering and protecting the individual, finds there is little by way of ‘protection’ in the Act for them if the person later suffers harm as a result. It is no defence to say they were enacting the person’s wishes, since those wishes are only one factor among many which must be ‘taken into account’ under the Act.

The doctors interviewed for this study were well aware of this difficulty. Even though ‘from an intellectual level’, stated one, they believed there were circumstances in which it was in a person’s best interests to allow them to die, ‘from a real-life level,

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[462] H. Taylor, ‘What are “best interests”? A critical evaluation of “best interests” decision-making in clinical practice’ (2016) 24 *MedLRev* 176.

no. Because I think it would be very difficult for me as a hands-on doctor to argue that in court… we would always have to err on the side of life.'[463] Another suggested that regardless of their wishes, it is 'rare' for it to be deemed in a person's best interests to not have life-sustaining treatment.[464] Notably, this is not a fear shared by judges, who unlike doctors do not risk a negligence claim, disciplinary action or prosecution if the patient dies, so feel better able to make empowering decisions.

Conversely, as long as the doctor or care-worker can say they 'took into account' the person's views, it is very difficult to challenge even the most overly paternalistic decisions. As the Law Commission noted:

> Section 4 sets out a procedure, rather than a substantive outcome, and, as one consultee put it, it is difficult to see how almost any best interests decision could be unlawful provided that the decision-maker has consulted the right people and turned their minds to the relevant considerations.[465]

Outside the most extreme cases identified above in which no mention was made of the person's wishes in the best interests assessment at all, it is almost impossible for a decision to be impugned for not giving 'sufficient' weight to the person's wishes. By contrast, a claim could be brought in negligence if the decision-maker attached too much importance to the person's wishes and allowed them to do something harmful as a result. Clearly then, decision-makers would be wise to be overly cautious when making these decisions.

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[463] Interview [anonymised] (Oxford, July 2017).

[464] Interview [anonymised] (Oxford, July 2017).

[465] Law Commission, *Mental Capacity and Deprivation of Liberty* (Law Com No 372), 14.11, 13th March 2017, available at <http://www.lawcom.gov.uk/app/uploads/2017/03/lc372_mental_capacity.pdf> accessed 24/08/18.

Risk-aversion is thus coming at the cost of enabling individuals to pursue those things which *they* regard as valuable — which may, for the reasons given above, be just as important to someone found to lack capacity, as it is for anyone with capacity. Ultimately, as Judge Eldergill observed in *Sykes,* 'it is her life'.[466] In a liberal democracy committed to value pluralism, a person ought then to be able live according to their own values, beliefs and commitments, providing that in doing so, they do not cause harm to others. As Rob Heywood notes:

> if the law is to take seriously views about freedom of religion, expression, and the right to respect for private and family life, it must attach genuine significance to medical decisions which are underpinned by those values.[467]

The importance of value pluralism is not extinguished merely because a person is no longer able to make an autonomous decision which furthers the values and commitments that have hitherto guided their life. We would not deem it acceptable to force pork upon an objecting Jew, or alcohol on a resistant Muslim, merely because their cognitive faculties had become impaired. Rather, we must continue to allow people to live in accordance with their values and beliefs *even* if they lack capacity, and *even* where those values are not ones we can endorse — and this means being guided by them in the decisions we make for that person. This has been recognised in the Court of Protection cases above: in *LM*, Peter Jackson J regarded the views of a Jehovah's Witness refusing a blood transfusion as carrying 'determinative weight' even though she lacked capacity,[468] while in *Wye Valley,* he regarded Mr B's religious

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[466] *Sykes* (n183).

[467] R. Heywood, "Parents and Medical Professionals: Conflict, Cooperation and Best Interests" *M.L.R* 20 (2012) 29, 33.

[468] *LM* (n352), [23].

beliefs, though stemming from hallucinations, as engaging his article 9 right to freedom of thought and religion.[469]

Respecting the diverse values of those who lack capacity is even more important when one acknowledges that in any best interests determination, the assessment of what is best for the person will never be incontrovertible or verifiably correct. As best interests is not a purely clinical question, there is room for reasonable disagreement over how to weigh the factors and interests at issue (medical, psychological, social, religious or cultural), and over which ought to be of primary importance. That it is better for an old and frail person to stay in her own home despite the risk that she might fall and break her hip, is not a fact readily susceptible to proof, but a risk-benefit analysis that different people might legitimately disagree over. The same is true of whether it is preferable for a cancer patient to lengthen his life through chemotherapy at the expense of feeling wretched in his final months; or indeed, whether it is better to end one's life prematurely by refusing a blood transfusion, rather than face alienation from one's community for the rest of one's life and eternal damnation thereafter. Once these are accepted as value judgements about how a person's interests are best served, it follows that to the extent that we know things about the person's values and priorities that would have informed how *they* would have struck the balance in these circumstances, these ought to inform how we do so on their behalf. This is not only essential to determining most accurately what is 'best' for them in the given circumstances (especially when one considers the effect that forcing interventions will have on them), but to do otherwise would be to treat the test for

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[469] *Wye Valley* (n7), [14].

capacity as though it somehow extinguishes their individuality, beliefs and values entirely.

To dismiss the person's own view of what is best for them in favour of another's in situations where there is room for reasonable disagreement, would also amount to a very large interference with a person's private life by the state, as represented by local authorities and doctors. This is hard to reconcile with Article 8, which protects a person's 'right to respect for their private and family life'.[470] As the Law Commission explains, departing from a person's wishes and feelings

> should be permitted only where it is necessary and proportionate. This is mandated, we consider, by the obligations imposed by Article 8(1) of the ECHR, which emphasises the importance of having respect for the autonomy of the person and the need to justify any interference with that autonomy.[471]

It might be suggested that *any* intervention which promotes the person's welfare is 'necessary and proportionate' according to Article 8(2). Yet overriding a person's own assessment of what is 'best' for them, merely because it does not accord with what the decision-maker considers to be 'best', does not appear either necessary or proportionate. In the jurisprudence on Article 8, 'necessary' has been taken to imply 'the existence of a "pressing social need" for the interference'.[472] Moreover, The European Court of Human Rights was clear in *Dudgeon v United Kingdom* that

> According to the Court's case-law, a restriction on a Convention right cannot be regarded as "necessary in a democratic society" - two hallmarks of which are tolerance and broadmindedness - unless, amongst other things, it is proportionate to the legitimate aim pursued.[473]

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[470] See *A Local Authority v E* (n24). For a discussion of this, see A. Ruck Keene and C. Auckland (n328).

[471] Law Commission, 'Final Report' (n722), 14.18

[472] *Dudgeon v United Kingdom* (1983) 5 EHRR 573, [51].

[473] ibid, [53].

If best interest determinations involve a weighting of factors or interests which may legitimately be balanced differently by different people, then it follows that there is room for reasonable disagreement in any given situation, not least between patient and doctor. Given this, the current provision would seem to go beyond what is necessary to achieve its aim of protecting vulnerable adults from causing harm to themselves, since it allows the decision-maker to interfere with the person's choices wherever they disagree about what is best for them, *even* in cases where the person's wishes do not expose them to harm. The interference may therefore be disproportionate to its aim, especially when considered in the context of the importance attached to 'tolerance and broadmindedness' in a democratic society. To force the doctor's view on the patient would therefore seem to represent a significant intrusion into the private sphere.

Not only does this represent a substantial interference with the person's autonomy but, as David Feldman notes, such interferences may be experienced as demeaning or undignified:

> non-consensual treatment can be seen as interfering with their dignity, in that the patient may both feel demeaned and be regarded by others as being subject to demeaning domination by the decision-makers, whether medical or judicial.[474]

While the meaning of dignity remains hotly contested,[475] certainly as Emily Jackson argues, 'preserving a patient's sense that she is a person whose views count is an important way of treating her as a subject, rather than as an object to whom things can be done without asking first.'[476] This is especially important given, as Jackson

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[474] D. Feldman, 'Human Dignity as a Legal Value: Part II' (2000) *Public Law* 61, 69.

[475] For a full discussion of different notions of dignity, see C. Foster, *Human Dignity in Bioethics and Law* (Hart 2011).

[476] Jackson (n4), 264.

observes, that 'one of the most frightening aspects of the loss of capacity through conditions such as dementia is the feeling that one is no longer treated as someone of value.'[477] Engaging with the person's views is thus not only important as a means of determining what is best for them, but also as a way of demonstrating that they remain someone of value, not diminished in any essential way by the loss of their capacity.

While it is not possible to do justice here to the vast body of literature on dignity, it is notable that many others commentators have emphasised the importance of respecting the dignity of the individual through giving weight to their wishes. Jeremy Waldron, for example, understands dignity in a procedural rather than a substantive sense. He argues that the very nature of law

> is a mode of governing people that acknowledges that they have a view or perspective of their own to present on the application of the norm to their conduct and situation. Applying a norm to a human individual is not like deciding what to do about a rabid animal or a dilapidated house. It involves paying attention to a point of view and respecting the personality of the entity one is dealing with. As such it embodies a crucial dignitarian idea – respecting the dignity of those to whom the norms are applied as beings capable of explaining themselves.[478]

If Waldron is right that the processes adopted by the law inherently respect dignity, then the processes applied to people lacking capacity ought to likewise pay heed to their dignity.

This is the philosophy at the heart of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), whose purpose is to promote respect for the 'inherent dignity' of people with disabilities, through ensuring that they are able to

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[477] ibid, 264.

[478] J. Waldron, 'How law protects dignity' (2012) *Cambridge Law Journal,* 71, 200–222, 210.

participate fully and effectively in society, on an equal basis with others.[479] The UK is a signatory to this Convention, which although not binding in domestic law, imposes obligations on the UK government which are difficult to reconcile with the MCA's approach to best interests decision-making. While the implications of Article 12 as a whole will be considered in Chapter 5, pertinent to the current discussion is Article 12(4), whereby signatories undertake to 'ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person.'

'Respecting' the person's will, as Jackson notes, 'implies more than simply taking [their] views into account'.[480] Even with the most substantial weight accorded to the person's wishes, section 4 of the MCA as currently framed will likely still fall short. According to a General Comment by the UN Committee on the Rights of Persons with Disabilities for example, the 'best interests' principle is not a safeguard which complies with article 12 in relation to adults.[481] This opinion has been reinforced by the Essex Autonomy Project[482] and a number of other commentators. Mary Donnelly, for example, observes that 'although the expanded best interests standard in the MCA, which requires account to be taken of the person's wishes and feelings, shows more respect for individual subjectivity than prior iterations of the standard, it

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[479] UN General Assembly, *Convention on the Rights of Persons with Disabilities: resolution adopted by the General Assembly*, 24 January 2007, A/RES/61/106, Article 1.

[480] Jackson (n4), 266.

[481] Committee on the Rights of Persons with Disabilities, *General Comment No 1 (2014) Article 12: Equal Recognition Before the Law* (adopted at the Eleventh session of the Committee, 31 March –11 April 2014, Geneva, CRPD/C/GC/1) at [21].

[482] W. Martin et al, 'Three Jurisdictions Report: Towards Compliance with CRPD Art. 12 in Capacity/Incapacity Legislation across the UK' (2016) Essex Autonomy Project, 40. Available at: < https://autonomy.essex.ac.uk/wp-content/uploads/2017/01/EAP-3J-Final-Report-2016.pdf >.

does not meet the requirements of Article 12, as interpreted by GC1.'[483] Others have been explicit about the need for reform. Genevra Richardson maintains that, 'the priority afforded to the objective assessment of best interests over the currently expressed wishes of the person might… need to be reconsidered.'[484] Peter Bartlett meanwhile suggests that including factors other than Sections 4(4) and 4(6) in the best interests assessment falls short of the CRPD, and thus 'legislative amendment will be required' if it is to comply.[485]

If, in recognition of the problems that afflict the test for capacity (and in line with our obligations under the ECHR and CRPD), we are to prioritise the views of people who lack capacity in decisions about their treatment and care, we must give practitioners cause to feel more confident in taking risks.

> The fact is that all life involves risk, and the young, the elderly and the vulnerable, are exposed to additional risks and to risks they are less well equipped than others to cope with. But just as wise parents resist the temptation to keep their children metaphorically wrapped up in cotton wool, so too we must avoid the temptation always to put the physical health and safety of the elderly and the vulnerable before everything else. Often it will be appropriate to do so, but not always. Physical health and safety can sometimes be bought at too high a price in happiness and emotional welfare. The emphasis must be on sensible risk appraisal, not striving to avoid all risk, whatever the price, but instead seeking a proper balance and being willing to tolerate manageable or acceptable risks as the price appropriately to be paid in order to achieve some other good - in particular to achieve the vital good of the elderly or vulnerable person's happiness. What good is it making someone safer if it merely makes them miserable?[486]

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[483] Donnelly, 'Time to Say Goodbye' (n311), 319.

[484] G. Richardson, Mental Disabilities and the Law: From Substitute to Supported Decision-Making? (2012) 65 *Current Legal Problems,* 333–354, 348.

[485] P. Bartlett, 'The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law' (2012) 75 MLR 752; 766.

[486] [2007] EWHC 2003 (Fam), [120].

As Munby J identifies, the practice of autonomy is not without risks. Under the present law however, doctors and care-workers can only allow a person to take risks, by taking a risk themselves. It is no surprise then, that they choose instead to shut down all risk, protecting their patient, but also protecting themselves. If people on the cusp of capacity are ever to be empowered as they ought to be, then the legal framework must provide decision-makers with far greater support for risk-taking at the wish of the patient. It must give doctors and local authorities the reassurance they need to be able to take decisions which empower the individual – even if doing so exposes the person to risk, and even, in some cases, if that means allowing the person to end their own life.

III Augmenting our understanding of autonomy

Before considering how the capacity cliff-edge ought to be softened to respond to the problems identified in the previous chapter, it is first necessary to consider how the test for capacity might be improved so that it can more reliably distinguish those who are capable of making autonomous decisions from those who are not. Chapter 1 identified a number of problems with the current test for capacity which was resulting in it failing to do so with sufficient accuracy. The most significant of these failings is that it relies on too narrow a conception of autonomy: because it does not interrogate the substance of the values or beliefs underpinning a person's decision, a person may be found to have capacity, even though they are acting on beliefs which are clearly disordered. In order to mitigate the effects of this anomaly, doctors have frequently manipulated the capacity test, adopting a strained interpretation of when a person's ability to 'use or weigh' information is impaired. By 'stretching' the test in this way, however, they undermine the clarity, consistency and transparency with which the test is applied. This chapter will therefore examine how the law might better address this problem, through narrowing the 'use or weigh' criterion, and introducing a new limb of the capacity test which focusses on the authenticity of the person's values or beliefs.

It will begin by examining how autonomy ought to be conceptualised, and what 'abilities' or 'attributes' are essential to it. It is suggested that autonomy (at least as understood in a traditional liberal sense) contains two essential components. The first is authenticity — that the person has to be guided by values, desires, and characteristics that are authentic to them. The second is competency — that the person has the capacities necessary in order to be able to live in accordance with their authentic self.

The chapter will go on to explore the extent to which the test for capacity (and in particular, the use or weigh limb of this) is able to capture impairments in either of these components of autonomy. It will be argued that it is able to accommodate impairments in the person's competency conditions, including where that impairment affects the person's ability to evaluate the information in light of their values and beliefs, rather than their cognitive ability to reason in abstract. However, as noted in Chapter 1, it is unable to capture impairments in the authenticity of the person's values. The remainder of the chapter will therefore consider how the law ought to be amended to address this problem.

I A more demanding conception of autonomy

Given the problems identified in Chapter 1, there is a need for the MCA to adopt a more demanding conception of autonomy than at present. To draw on Coggon's taxonomy,[487] autonomy ought instead to be understood in the 'best desire autonomy' sense — that is, the person must be able to make a decision that accords with, or reflects, their values and beliefs. This concurs with most contemporary understandings of autonomy, most notably that of Harry Frankfurt[488] and Gerald Dworkin.[489] They introduced a hierarchical model of autonomy in which autonomy demanded not just the freedom to make choices, but that the person is capable of making choices which reflect their values, beliefs and priorities. As Gerald Dworkin wrote, autonomy is

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[487] Coggon (n112).

[488] H. Frankfurt, *Freedom of the Will and the Concept of a Person* (The Importance of What We Care About edn, Cambridge: Cambridge University Press 1987).

[489] G. Dworkin (n109).

> a second-order capacity of persons to reflect critically upon their first-order preferences, desires, wishes, and so forth and the capacity to accept or attempt to change these in light of higher-order preferences and values.[490]

Likewise, in the view of Frankfurt, to exercise autonomy a person must reflect upon and evaluate their first-order desires, deciding which they wish to endorse or promote.[491] This clearly demands more than 'current desire autonomy' (which as Chapter 1 notes, is what is currently reflected in the MCA) according to which there is no need for a person to reflect upon or evaluate their desires in order to reach a decision which accords with their values and beliefs. In exercising this capacity, Gerald Dworkin argues that people will 'define their nature, give meaning and coherence to their lives, and take responsibility for the kind of person they are.'[492] In a similar vein, Ronald Dworkin considers that autonomy, at least when understood in this more demanding sense, 'makes each of us responsible for shaping his own life according to some coherent and distinctive sense of character, conviction, and interest', which allows us to be what we have made ourselves.[493] To be capable of making an autonomous decision then, a person must be able to reflect upon their immediate desires and to prioritise or deprioritise these in light of one's longer-term goals and values.

At the core of these conceptions are two essential components of autonomy: an 'authenticity' component and a 'competency' component. The 'authenticity'

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[490] ibid, 20.

[491] Frankfurt (n488).

[492] G. Dworkin (n109).

[493] R. Dworkin (n70), 5.

component demands that to be autonomous, the individual must be guided by the values, desires, and characteristics that are 'authentic' to them, rather than any which are imposed on them from external sources. As John Christman puts it, autonomy means:

> to be one's own person, to be directed by considerations, desires, conditions and characteristics that are not simply imposed externally upon one, but are part of what can somehow be considered one's authentic self.[494]

Catriona Mackenzie and Wendy Rogers similarly suggest that to have autonomy, one must be 'able to determine one's *own* beliefs, values, goals and wants, and to make choices regarding matters of practical import to one's life free from undue influence'.[495] The opposite of self-determination is, in their view, where one's views or actions are determined either by other people, or by external forces or constraints.[496] Other commentators have expressed this idea in similar terms: the autonomous nature of a decision depends on whether it reflects the decision-maker's endorsed beliefs or desires,[497] their underlying and enduring commitments,[498] or how genuinely it expresses 'the self or individuality of the person', however this may be understood.[499]

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[494] J. Christman, 'Autonomy in Moral and Political Philosophy' in *The Stanford Encyclopedia of Philosophy* (Spring 2018 Edition), E. Zalta (ed.), available at <https://stanford.library.sydney.edu.au/archives/win2015/entries/autonomy-moral/>.

[495] C. MacKenzie and W. Rogers, 'Autonomy, vulnerability and capacity: a philosophical analysis' [2013] Int'l J L Context 37, 43.

[496] ibid.

[497] A. Jaworska, 'Respecting the margins of agency: Alzheimer's patients and the capacity to value.' (1999) *Philos Public Aff* 28(2): 105–138.

[498] A. Buchanan & D. Brock. *Deciding for Others* (Cambridge: Cambridge University Press, 1989), 41

[499] O. O'Neill. *Autonomy and Trust in Bioethics* (Cambridge, Cambridge University Press; 2002), 34.

While the exact nature of what it means for a value or belief to be authentic will be discussed later, suffice for present purposes to say that in cases such as *Mrs T,*[500] *St George*[501] or *Wye Valley*[502], the fact that the belief or value at issue stemmed from a mental illness is reason to doubt its authenticity.

As Meyers sums it up, 'autonomous people are acquainted with their true selves, *and* they act in accordance with their true selves.'[503] Competency conditions therefore, involve those capacities that are required in order to be able to live in accordance with one's authentic values and beliefs. According to Christman, this involves the capacities for 'rational thought, self-control, and freedom from debilitating pathologies, systematic self-deception and so on'.[504] Jillian Craigie, terming it 'self-expression', observes that there has been much dispute over what attributes this entails,[505] and some accounts are certainly more demanding than others. Aspects discussed have included: 'reasoning that enables the coherent pursuit of current desires; reflection on and endorsement and rejection of desires; an ability to project oneself imaginatively into the future; planning and policy making; impulse control; and the

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[500] *Mrs T* (n117).

[501] *St George* (n141).

[502] *Wye Valley* (n7).

[503] D. Meyers, *Self, Society, and Personal Choice* (New York: Columbia University Press 1989), 44.

[504] Christman (n494).

[505] J. Craigie, 'A Fine Balance: Reconsidering Patient Autonomy in Light of the UN Convention on the Rights of Persons with Disabilities' (2015) *Bioethics*, 29: 398–405, 401.

ability to conceive of one's life as a whole.'[506] Meyers, for example, requires a person to have competencies in the skills of self-knowledge, communication, and deliberation,[507] while Kim Atkins, drawing on Meyers' work, argues that the person must have 'a minimal understanding of how one's motives, values, beliefs, emotional dispositions, desires, and foibles can be related together and how they might influence one's choices and attitudes.'[508] Clearly not all of the attributes listed above could be included explicitly within a legal test for capacity. However, while both the nature of and the detail with which different philosophers state these competencies varies, it seems at its core that the ability to make a decision that reflects one's authentic values and commitments requires two essential qualities: to understand the nature and consequences of the decision at hand; and to be able to evaluate that information in light of one's own values, beliefs or desires, thus attributing value to it. The question then, is to what extent the law as it is currently framed captures this more demanding conception of autonomy.

II Does the MCA capture autonomy in this more demanding sense?

Autonomy properly understood then, demands both that the person's values or beliefs are themselves authentic *and* that the person is able to act in accordance with those values or beliefs. Chapter 1 argued that the MCA fails to capture instances where the person's values are themselves distorted by illness (the authenticity component) —

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[506] ibid.

[507] Meyers (n503).

[508] K. Atkins, Autonomy and autonomy competencies: a practical and relational approach (2006) *Nursing Philosophy*, 7, 205, 211.

Mrs T,[509] *St George*[510] or *Wye Valley*[511] are all examples of this. Before examining the ways in which the law could be reformed to address this problem however, it is first necessary to consider whether the MCA *can* encompass situations in which the person's values are intact, but something is impairing the person's ability to act *in accordance with* those values (the competency component).

As the previous section suggests, this requires a combination of cognitive abilities to understand and reason about the information, and affective attitudes – that is, being able to evaluate the information *in light of* one's values and priorities, and to attribute weight or value to different outcomes. Some of these abilities are clearly captured by the MCA. The requirement to understand and retain information is stated in straightforward fashion in section 3(1)(a)-(b) MCA, and the Code of Practice further sets out that the relevant information for making a decision includes 'the nature of the decision; the reason why the decision is needed, and the likely effects of deciding one way or another, or making no decision at all.'[512]

The difficulty lies in the extent to which the MCA, through its 'use or weigh' criterion, is able to capture impairments in the person's ability to evaluate the information in light of their values, goals and priorities. Richard Huxtable notes for example, that the MCA 'purports to focus upon functioning (and thus process and rationality) rather than on the substance of, or the reasons (and values) underpinning,

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[509] *Mrs T* (n117).

[510] *St George* (n141).

[511] *Wye Valley* (n7).

[512] MCA Code of Practice (n266), 4.16

the decision'.[513] But while the Act undoubtedly applies to impairments in the person's cognitive reasoning processes (for example where a person with a severe learning disability or brain injury is unable to formulate a reasoned decision, acting only on impulse), the difficulty comes in instances where it is not the person's ability to weigh up the consequences of a decision in the abstract which is disputed (here the Act clearly applies), but where something (an overwhelming fear, anxiety of emotion for example) is interfering with their ability to evaluate that information in light of their values, and reach a decision which reflects these, and attributes appropriate weight to those things that they regard as important. For example, although a person may rationally know that the healthy birth of their baby is more important than avoiding an injection, the anxiety caused by their needle phobia might overwhelm them, causing them at that moment to refuse the intervention.[514] Or a person with anorexia may be able to rationally understand and accept that their desire to avoid weight gain is being caused by an illness, which is disrupting their life and putting them in physical danger, and therefore that they ought to consume more calories, but 'at the same time, the profound emotions tell them that eating to put on weight is dangerous and that they will

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[513] R. Huxtable, 'Autonomy, Best Interests and the Public Interest: Treatment, Non-treatment and the Values of Medical Law' (2014) 22(4) *MedLRev* 459-493, 463.

[514] In this sense it differs from the impairments discussed in Chapter 1, since her values have not become distorted (the phobia doesn't diminish the value she places on the healthy birth of her child) — only her ability to accord in accordance with these.

be safer if they lose still more weight,'[515] making it impossible for them to weigh the competing factors in the balance, and attribute weight to the different outcomes.[516]

As Louis Charland observes, the ability to make autonomous decisions requires far more than simply the ability to reason:

> without the emotion system to generate values and fix preferences to guide and direct reason, the prefrontal subject remains hopelessly paralysed in the face of innumerable theoretical possible alternatives and hypothetical consequences.[517]

He further argues that people cannot fully appreciate the choices they face unless those choices have some personal resonance for them: they 'must have the capacity to attribute personal significance to events and situations.' The question then, is whether the 'use or weigh' criteria also captures impairments in the person's evaluative judgements. It is suggested here that it is capable of doing so.

'Use or weigh' has been described as the limb of the capacity test which is the 'most conceptually difficult to understand and empirically difficult to test or measure'.[518] Certainly the MCA does little to elucidate the precise meaning of 'use and weigh', or how it should be tested and applied. Consequently, there has even been some debate in the case law, over whether or not the person must be able to both 'use' and 'weigh' the relevant information to be found to have capacity, or whether either is sufficient. While MacDonald J suggested in *Kings College NHS Foundation Trust v*

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[515] T. Hope and al, 'Agency, ambivalence and authenticity: the many ways in which anorexia nervosa can affect autonomy' (2013) 9 *Int'l J L Context* 20, 29.

[516] This distortion in the person's ability to act in accordance with their desires might operate in addition to the person's values themselves becoming disordered, as discussed in Chapter 1.

[517] L. Charland, 'Is Mr. Spock mentally competent? Competence to consent and emotion' (1998) 5 *Philosophy, Psychiatry & Psychology*, 67, 72.

[518] Banner (n265).

C[519] that both must be present for the person to be found to have capacity, this has been criticised by commentators,[520] and would seem to run contrary to the case of *IM v LM* which preceded it, where the court was clear that

> It is important to emphasise that s.3(1)(c) of the Act refers to the ability to use or weigh information as part of the process of making the decision. In some circumstances, having understood and retained relevant information, an ability to use it will be what is critical; in others, it will be necessary to be able to weigh competing considerations.[521]

The wording of the statute ('use *or* weigh') would seem to corroborate this analysis, though the different elements of this limb are rarely distinguished in the judgments. The Code of Practice goes a little further than the Act in explaining this limb of the test for capacity, noting that:

> For someone to have capacity, they must have the ability to weigh up information and use it to arrive at a decision. Sometimes people can understand information but an impairment or disturbance stops them using it. In other cases, the impairment or disturbance leads to a person making a specific decision without understanding or using the information they have been given.[522]

Described thus, the test seems to focuses on a person's cognitive and reasoning abilities rather than their ability to attribute weight to certain outcomes in light of their values or priorities, asking whether the person has used the correct information when forming their conclusions. This might suggest that the MCA *cannot* cover all of the different ways in which a person's ability to act in accordance with their authentic

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[519] *C & V* (n193).

[520] See for example the commentary of 39 Essex Street, available at: https://www.39essex.com/cop_cases/kings-college-nhs-foundation-trust-v-c-and-v/ (accessed 11th November 2018).

[521] *IM v LM* [2014] EWCA Civ 37, [52].

[522] MCA Code of Practice (n266), 4.21.

values might be impaired, and certainly Herring and Wall have read the Act in this way, arguing that:

> Capacity, under the MCA, is expressed in terms of rational reasoning. It is about understanding evidence, using it and weighing it. Unfortunately, it is not made explicit what using and weighing the information involves. It does not make it clear that emotions, giving practical reasoning vision, are an essential aspect of capacity. As a result, the MCA does not provide the apparatus to address scenarios where the impaired interaction between a person's affective attitudes (their values, preferences, beliefs, goals or commitments) and their cognitive attitudes (knowledge of facts) limits or undermines their capacity for autonomous decision making.[523]

Many of the doctors interviewed for this study seemed to interpret the provisions in a similar way:

> It is about executive functioning – it is about being able to process or reason through – you need to have the ability to think abstractly, to be able to think in terms of being able to imagine the future, [to] understand concepts.[524]

Other doctors framed 'use or weigh' as being about whether the person can 'weigh up the risks and benefits of whatever you're suggesting and come to a reasoned conclusion'[525], while another psychiatrist explained it as being about testing whether the person can provide reasons for their actions and beliefs.[526] However, while nothing in the Act explicitly refers to the person's ability to attribute weight to certain outcomes based on their emotions or values, 'use or weigh' is framed in sufficiently broad terms that it can legitimately encompass situations where a powerful affective attitude is undermining the person's evaluative judgement. The question being asked of the person is then whether they can use and weigh the information to come to a

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[523] Herring and Wall (n1), 705.

[524] Interview [anonymised] (Oxford, May 2017).

[525] Interview [anonymised] (Oxford, July 2017).

[526] Interview [anonymised] (Oxford, May 2017).

decision *which reflects their values and priorities*. Any impairments in the person's decision-making process which prevent them from doing so will therefore be captured within use or weigh.

This is how some doctors have understood 'use or weigh'. One psychiatrist interviewed, for example, suggested that the criterion was about 'how much they are factoring in the relevant information about that decision against their background, beliefs and values and wishes'.[527] Another stressed the importance of the person being able to put the information in their 'own context' and to appreciate how it applies to them.[528] But it is also how the courts have responded to such impairments, legitimising this interpretation. In *A Local Authority v E*[529] for example, although Peter Jackson J was clear that E could 'understand and retain the information relevant to the treatment decision and communicate her decision',[530] he found that

> for E, the compulsion to prevent calories entering her system has become the card that trumps all others. The need not to gain weight overpowers all other thoughts.[531]

Notwithstanding evidence from studies such as Tan *et al's* then,[532] that people with anorexia can reason in the abstract and weigh up information, he found her to be

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[527] Interview [anonymised] (Oxford, May 2017).

[528] Interview [anonymised] (Oxford, May 2017).

[529] *E* (n24).

[530] ibid, [48].

[531] ibid, [49].

[532] Tan et al (n123).

unable to use and weigh the information: her 'obsessive fear of weight gain'[533] meant she was unable to attach weight to any outcome which involved her taking in calories, even where the consequences of doing so were that she would die. Similarly in *NHS Foundation Trust v X,*[534] (also concerning a woman with chronic anorexia), Cobb J approved the finding of her treating clinician that

> due to on-going severe body dysmorphia, false beliefs about her weight shape and nutritional state and absolute fear of weight gain from her anorexia, she was and is unable to apply the information to herself or believe in the need for it. In addition the absolute fear of weight gain and anxiety induced around the same overrides any loose connection she might have to the information pertaining to herself. The reality and importance of the associated risks including death in her malnourished state are therefore not truly appraised which means she is unable to weigh up the information provided in the decision-making process.[535]

There are numerous other instances of the 'use or weigh' criterion being employed where people's strong affective or emotional responses undermine their ability to attach weight to different outcomes. The Code of Practice cites needle phobia as an example of a failure to use or weigh,[536] and both doctors and judge clearly perceived this as falling within its scope in *Re MB*.[537] In this case, despite repeatedly consenting to a caesarean section (and even requesting it on two occasions), when it came to having the anaesthetic, the woman refused to consent. In finding her to lack capacity, Dr F made it clear that while she undoubtedly understood and accepted the need for the

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[533] *E* (n24), [49].

[534] [2014] EWCOP 35.

[535] ibid, [27]-[29].

[536] MCA Code of Practice (n266), footnote to 4.21.

[537] [1997] EWCA Civ 3093.

caesarean section, 'at the moment of panic… her fear dominated all.'[538] He explained that the nature of phobias was such that, typically, on encountering the object of the phobia, it 'triggers a panic and the patient's sole thought is to distance themselves from the object which threatens them.'[539] As a result, despite her clear wish to undergo the procedure (and thereby to ensure the safety of her baby), 'at that moment the needle or mask dominated her thinking and made her quite unable to consider anything else.'[540] So although she was thought able to reason in accordance with her priorities when away from the needle, when faced with the object of her phobia, the effect was to distort her reasoning so that she could not weigh the information in such a way as to make the decision that achieved her main goal – the healthy birth of her child. Accordingly, Lady Butler Sloss concluded that MB was unable to use and weigh the information, and so lacked capacity.

Even in the absence of a phobia, the 'pain and emotional stress' of childbirth has alone been deemed sufficient to render a woman incapable of weighing up information. In *Rochdale Healthcare (NHS) Trust v C* for example,[541] Johnson J found a woman to lack the capacity to refuse a caesarean section, notwithstanding that the treating obstetrician regarded her as capacitous:

> The patient was in the throes of labour with all that is involved in terms of pain and emotional stress. I concluded that a patient who could, in those circumstances speak in terms which seemed to accept the inevitability of her own death, was not a patient who was able properly to weigh-up the considerations that arose so as to make any valid decision, about anything of even the most trivial kind, still one which involved her own

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[538] ibid, [11].

[539] ibid, [10].

[540] ibid, [12].

[541] *Rochdale Healthcare (NHS) Trust v C* [3 July 1996] (unreported).

life.[542]

What these cases show is that the fluid definition of ‘use or weigh’ in the MCA permits it to capture not only cognitive deficits, but also situations where an impairment affects a person’s ability to attach weight to certain outcomes, such that their decision does not reflect their values and beliefs.

It is only then, where the impairment relates to the substance of a person’s values or beliefs (the authenticity component of autonomy), that the MCA requires augmenting. To briefly recall Chapter 1, in cases such as *Mrs T,*[543] *St George*[544] or *Wye Valley,*[545] it is the content of a person’s values or beliefs which is disordered (for example, the person believes that blood is evil), rather than the person’s decision-making process (that is, their ability to act in accordance with that belief or value). It is this that must therefore be addressed in any amendments to the Act.

III Capturing impairments in the person’s values and beliefs: a new limb of the test for capacity

How then, might the law better capture these situations in which a person is not able to make a decision in accordance with their values, because those values have become impaired to the point that they are no longer authentic? The most effective way is through introducing a new limb of the test for capacity which requires an examination of the content of the wishes, feelings, values or beliefs being expressed by the person.

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[542] ibid.

[543] *Mrs T* (n117).

[544] *St George* (n141).

[545] *Wye Valley* (n7).

The result would be that the 'use or weigh' criterion would apply only to situations where the person's decision-making *process* is impaired, either at a cognitive level (i.e. they are unable to reason abstractly about the decision), or because an illness, phobia or extreme emotional response has distorted their ability to attribute weight to different outcomes so that they are unable to make a decision which accords with their values. The new limb of the capacity test meanwhile, would apply to situations where the person's values or beliefs were themselves impaired or distorted (rather than their ability to act in accordance with those values), for example, by a depressive illness, anorexia nervosa or the psychotic symptoms of schizophrenia or bipolar disorder.[546]

Some commentators have doubted whether authenticity is a sufficiently robust concept as to warrant inclusion in a test for capacity. Jesper Ahlin, for example, has written that a 'method to reliably determine the authenticity (or inauthenticity) of a desire cannot be determined',[547] while Hope *et al* have suggested that it might be problematic to use authenticity as a separate basis for overriding the wishes of a patient in this way:

> We are wary of such an argument on the current poorly developed theoretical and empirical understandings of authenticity. At the time when decisions about treatment refusal need to be made, it is unlikely that we would have a sufficiently robust understanding of what would count as the persons authentic, as opposed to inauthentic, wishes, or what the authentic wishes would be. The concept of authenticity might well be valuable to an individual in struggling with inner conflict and attempting self-development. It is quite different to reify the authentic self to such an extent that it can be unmasked by others and brought forward to bear witness that, despite what the person is saying, we are respecting her autonomy by overriding her requests.[548]

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[546] It is important to note that some mental illnesses will affect both the content of the person's values, and their decision-making processes.

[547] J. Ahlin, 'The impossibility of reliably determining the authenticity of desires: implications for informed consent' (2017) 21(1) *Med Health Care and Philos* 43–50, 43.

[548] Hope et al, 'Anorexia Nervosa' (n122), 28.

If these concerns are to be countered therefore, a more ‘robust understanding’ of when a person’s values or beliefs would be inauthentic must be developed. Despite the widespread acceptance that autonomy includes an authenticity component, accounts of authenticity vary widely. Jesper Ahlin provides a useful taxonomy for engaging with these different accounts, dividing them into ‘sanctionist theories’, ‘coherentist theories’ and ‘originist theories’.[549] Sanctionist theories (such as that of Frankfurt[550] and Dworkin[551]) view authenticity as being concerned with the person’s attitudes towards their desires. Accordingly, desires are authentic if they are ‘in one way or another sanctioned by the desire-holder.’[552] ‘Coherentist theories’ (such as Christman’s[553]) focus on the coherence of the desire-holders desires: ‘a person’s desires are authentic if and only if they fit with her socio-historical or autobiographical narrative’.[554] Originist theories meanwhile (such as Tan *et al*[555] and Jon Elster[556]), focus on the origins of the desire and whether they originate in the person’s cognitive process or are caused by a mental illness or disorder. It will be argued while neither sanctionist nor coherentist

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[549] Ahlin (n547), 43.

[550] Frankfurt (n488).

[551] G. Dworkin (n109).

[552] Ahlin (n547), 47.

[553] J. Christman, *The politics of persons: Individual autonomy and socio-historical selves* (Cambridge: Cambridge University Press, 2009).

[554] Ahlin (n547), 48.

[555] Tan et al (n123).

[556] J. Elster, *Sour grapes: Studies in the subversion of rationality* (Cambridge: Cambridge University Press, 1983).

accounts of authenticity could be implemented in the law, originist theories provide a workable model of authenticity which the law can and should adopt in its test for capacity.

(a) Sanctionist theories of authenticity

According to sanctionist theories, authenticity requires the person to be able to reflect upon and endorse (or identify with) their own values, desires and priorities. Different theorists have expressed this slightly differently: Frankfurt, for example, asked whether the person 'endorses reflectively' their desires;[557] while Dworkin thought the person must be able to question whether they identify with or reject their reasons for acting.[558] Broadly, however, the key question is whether the person either rationally endorses their reasons for acting, or — in a hypothetical scenario in which they understood all their reasons for acting ––*would* endorse that reason.

Posed as an empirical question (i.e. does the person rationally endorse their reasons for acting?), the answer is very difficult to establish with any degree of accuracy. This is particularly so in the context of mental illness, where it can be hard to pinpoint exactly how much insight the person really has into their disorder, and the illness might affect the endorsement process itself. In *A Local Authority v E* for example,[559] although E undoubtedly understood that her reasons for acting were caused by an illness (anorexia), it would be difficult for her to prove that she nonetheless *rationally* endorsed the decision to refuse food, since she would have to demonstrate

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[557] H. Frankfurt, 'Freedom of the Will and the Concept of a Person' (1971) 68(1) *The Journal of Philosophy* 5–20, 10.

[558] G. Dworkin (n109), 15.

[559] *E* (n24).

that her thinking process was not itself affected by the disorder. Phrased as a question of whether the person in fact endorses their reasons for acting therefore, it would not provide clear answers to the question of whether a decision is autonomous in the very cases where authenticity concerns are most pertinent: where the person is suffering from a mental illness.

If, however, the test is framed as a hypothetical question (*if* the person knew of all their reasons for holding that belief, *would* they rationally endorse it?) then there is a real risk that the answer to this would depend on scarcely more than whether the decision-maker regarded that belief as valuable or worthwhile. If there seems to be some value in holding it, then the decision-maker is likely to be more inclined to say the person would rationally endorse it, while a belief that is self-destructive and irrational is unlikely to be thought to be one which a person would knowingly endorse. For example, since most would agree that prioritising thinness over one's life is neither rational, nor beneficial to a person, it is difficult to think of any circumstances in which a decision-maker would conclude that the person would hypothetically rationally endorse their desire to be thin, even if they understood it was caused by an eating disorder. The same might be true of Mrs T's belief that blood is evil.[560] Other beliefs or values, however, *might* be regarded as beneficial or valuable to the person, even if stemming from a disorder. In *Wye Valley*, for example, Mr B's religious delusions were 'deeply meaningful to him',[561] and were even credited with stopping him from thieving.[562] A decision-maker might be more inclined then to answer the question of

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[560] *Mrs T* (n117).

[561] *Wye Valley* (n7), [43].

[562] ibid, [19].

whether he would hypothetically endorse in them in the affirmative, given that they provide Mr B with a source of comfort and a positive ethical framework by which to live his life. Or, to use an even clearer example, a widower who ‘hears’ or ‘sees’ their dead spouse talking to them and who takes instructions of what to do in certain situations from them. (This is relatively common: a study in 2015 found that between 30% and 60% of widowed people had suffered from a hallucination of this sort.[563]) In this situation, a decision-maker might be more inclined to say that the person would endorse this belief, even knowing it was a hallucination, because of the comfort it brings at a difficult time. Posed as a hypothetical question then, the answer will depend largely on whether the assessor considers the belief to be the kind of belief that someone might reasonably hold, or which might bring some benefit to them. Not only is this very subjective, depending on the particular assessor and their values or beliefs, but it would also result in the reasoning behind assessments becoming very opaque — failing to enhance either the consistency or the transparency with which the test is currently being applied. Whether framed as an empirical question, or as a hypothetical question then, sanctionist theories fail to provide a workable test for when a belief will be authentic.

Often sanctionist and originist theories will overlap: a person will not endorse a belief because of its origins. As Manne Sjostrand and Niklas Juth explain,

> desires and values that are the result of indoctrination, irrational beliefs, brainwashing, hypnosis, self-deception, fear, or phobia and other psychological disorders are such that we typically would be inclined to disapprove of having them, if we were convinced that this is how they came about. [564]

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[563] A. Castelnovo et al, ‘Post-bereavement hallucinatory experiences: A critical overview of population and clinical studies’ (2015) 186 *Journal of Affective Disorders* 266-74.

[564] M Sjöstrand and N. Juth, ‘Authenticity and psychiatric disorder: does autonomy of personal preferences matter?’ (2014) 17(1) *Medicine, Health Care and Philosophy* 115–122, 121.

If the law were to adopt an originist test then, instead of a sanctionist one, it would capture many of the same situations, but without running into the difficulties noted above. But this will not always be the case, and people might endorse beliefs even if they are known to have been caused by a mental illness, or the overbearing influence of another. This was illustrated above with the examples of *Wye Valley*[565] and the grieving widow: in both cases despite knowing the belief was caused by hallucinations, it was thought that the sufferer might hypothetically endorse them, as they were nonetheless meaningful to them.[566] In such cases, there would seem to be good reason for according such values and beliefs respect: if the value of autonomy is in allowing people to live in accordance with those things which matter to them, this ought to apply equally to values or beliefs which although disordered in origin, are nevertheless deeply meaningful and important to the individual, such that they would want to continue to hold them even if they understood their origins. If a sanctionist approach to authenticity were therefore to be abandoned in favour of an originist account, such beliefs will be deemed inauthentic, and a person's decision based on them, non-autonomous.

While this is undoubtedly a weakness of originist accounts, from a legal perspective, the price of capturing these cases is simply too high. Not only would this mean subjecting all values and beliefs to an extremely subjective and value-laden test in order to capture a few exceptional cases, but also, the consequences of getting this assessment wrong are grave, leaving an extremely vulnerable person to make a

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[565] *Wye Valley* (n7).

[566] This is perhaps even clearer where the belief stems from the overbearing influence or indoctrination of another, where there is substantial evidence that people may endorse those beliefs, such as in the case of religious indoctrination.

potentially harmful decision based on values known to be disordered. Given that the question of whether the person endorses (or would endorse) their beliefs is neither falsifiable nor susceptible to accurate testing, to find someone to have capacity when, as in *Wye Valley,*[567] they are refusing life-saving treatment because figures in their hallucinations have instructed them to do so, would seem a dereliction of the law's duty to protect those who are ill and vulnerable. The effect would be to accord him unfettered rights to make decisions about that treatment irrespective of the harm that would result. Indeed the very problem with the cliff-edge approach to capacity in such cases is precisely that: once a person has been found to have capacity, the decision-maker loses all ability to balance the weight of his beliefs against the harm he will suffer — there is no mechanism then, to protect a person from harm despite their clear vulnerability. It would also strain our notion of a capacitious decision purely so as to include a few, exceptional cases such as this. In reality, it is not that we regard Mr B's decision as autonomous in this case, but that we consider it warrants respect, given how deeply meaningful his beliefs are to him.[568] A better solution then, would be to treat the fact that the person might endorse the disordered belief not as a reason for finding them to have capacity, but as a reason for according it great weight in any best interest assessment (as Peter Jackson J did in *Wye Valley*[569]). Sanctionist theories then, while not capable of being part of the test for legal capacity, do help to identify people

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[567] ibid.

[568] In fact in *Wye Valley*, Mr B also mistakenly believed that his foot would get better on its own if he was allowed to walk on it, and so would have been found to lack capacity regardless.

[569] ibid.

for whom the capacity cliff-edge operates particularly harshly, and whose wishes ought therefore to be given substantial weight in best interest determinations.

(b) Coherentist theories of authenticity

Coherentist theories, by contrast, state that a decision will be inauthentic if it is not consistent with the person's values, attitudes, characteristics and life goals. The fact that a person's values or beliefs are inconsistent with those expressed in the past is not however, sufficient to render them inauthentic, even if it may be a good reason to inquire further into their authenticity. People's desires, values and beliefs are constantly changing and evolving. Indeed, an inability to change one's mind would itself be problematic: circumstances change all the time, and we must adapt to these and learn from them. No person has an entirely coherent narrative then, and many people's values and beliefs when taken together might seem contradictory, even incoherent.

To try to formulate a 'coherent narrative' for a person with sufficient clarity and certainty to be able to discern 'outlying' values or beliefs, is impossible. It would demand knowledge of the person's decision-making in a whole host of areas, over a substantial time period — information that is unlikely to be forthcoming given the paucity of time and resources already available to gather information about the patient. Nor should people's previous desires or belief-structures define the decisions they can later make. It would be strange, for example, to deem a life-long vegetarian's decision suddenly to eat a sausage as 'non-autonomous', merely because it is uncharacteristic. These difficulties are particularly pronounced in the treatment and care context, where a person's change of circumstances — being ill or disabled, or vulnerable and dependent on others — might well trigger a change in perspective, causing the person to reassess those things they value most highly, as might simply the fact of getting old and nearer to physical incapacity. Research has frequently shown for example, that people have a tendency to underestimate the quality of life of people with disabilities,[570] who often report themselves as having high levels of satisfaction with life.[571] To attach too much importance to what people said before, might deprive them of those things that now give their life value.

Nowhere are the problems with formulating a stable narrative for the person more acute however, than where a person is suffering from a mental illness — precisely the situation in which authenticity concerns are most prominent. Many mental illnesses are characterised by unstable preferences, changeable behaviour and shifting value systems. How does one formulate a narrative for someone suffering from bipolar disorder for example, for whom erratic, impulsive and changeable behaviour is 'normal'?

In addition to concerns about whether the assessor can formulate an accurate 'narrative' of the person, doing so would also necessitate them making a series of value-judgements, which may undermine the objectivity of assessments. Firstly, the assessor's view of what constitutes the person's narrative will inevitably depend on their own 'sense' of the person, based on their (often limited) experience of them. Then, having formed their view of what the person is 'like', they will have make an assessment of which values or beliefs ought to be regarded as within that narrative (i.e. 'authentic') and which ought to fall outside of it (i.e. 'inauthentic'). To use a crude example, if someone who has always professed to be heterosexual and had partners of

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[570] L.C. Vogel et al, 'Long-term Outcomes and Life Satisfaction of Adults Who Had Pediatric Spinal Cord Injuries' (1998) 79 *Archives of Physical Medicine and Rehabilitation*, 1496.

[571] A. Asch, 'Distracted by Disability' (1998) 7 *Cambridge Quarterly of Healthcare Ethics* 77.

the opposite sex suddenly announces that they are homosexual, they are unlikely to be regarded as acting ‘inauthentically’ by expressing a preference for a relationship with someone of their own sex. This is based however, on a judgement that this ‘new’ expression of their desires is in some way more significant — or ‘authentic’ — than their previous ones. Our perception of their narrative is thus reconfigured to include this development, rather than regarding it as an outlier from their ‘authentic self’. If meanwhile, the person did something less emphatic — for example, they one night kissed a person of the same sex — we might be more inclined to regard it as outlying behaviour. The assessment of whether a person’s value, belief or desire is coherent with their narrative thus becomes susceptible to the assessor’s own preconceptions both about the person, and about the importance of the value, belief or desire being expressed.

Nothing about this helps to enhance the consistency or transparency with which capacity assessments are made: rather it hands substantial discretion over to decision-makers to determine when a person’s actions ought to be considered ‘uncharacteristic’. And since they must choose which parts of the person’s ‘narrative’ to emphasise, they will invariably be able to point to *some* decision or behaviour during the person’s life to support their version of the narrative, so their reading of events become, in all practical terms, irrefutable. Clearly then, coherentist theories cannot provide a workable model of authenticity. Once again, however, even if coherency with the person’s narrative is insufficient in itself to render a value or belief authentic (or inauthentic), it does provide *evidence* that a belief might be authentically and deeply held, which would, as will be argued in Chapter 5, provide a good reason for according it greater weight in any best interests assessment.

(c) Originist theories of authenticity

Originist theories of authenticity focus on the origins or source of the person's desires or beliefs. To be authentic, the desire has to originate in a cognitive process which is within the control of the person. Conversely, a decision will be 'inauthentic' if, as Elster puts it, it is 'shaped by irrelevant causal factors'.[572] These might include an illness or disorder, or the overbearing influence of others.

It is important to note at the outset, that while a person's values may be influenced by any number of factors (the influence of others, societal and gender norms, indoctrination), it is only those which fall within the remit of the MCA, and thus can reasonably be said to be 'caused by' an 'impairment of, or a disturbance in the functioning of, the mind or brain',[573] that are relevant for the purposes of this discussion. The Code of Practice explains that this includes situations where a person suffers from 'a disability, condition or trauma' which affects the way their mind or brain works.[574] Even where a person's values have been distorted by something other than an illness or impairment of the brain however, they may nonetheless fall within the jurisdiction of the vulnerable adults jurisdiction (discussed in the Introduction), which provides important protection for those who, while not lacking capacity, nonetheless have their autonomy impaired to some degree. Indeed many of the cases under that jurisdiction have concerned situations in which a vulnerable person has been subject to the undue influence of another, which often have a religious or cultural dimension to them.

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[572] ibid, 15.

[573] MCA, s2(1).

[574] Code of Practice (n266), 4.3.

At first sight then, focussing on the cause or origins of a value or belief would seem markedly more straightforward than considering either a person's hypothetical attitudes towards that belief; or whether it is consistent with their previous beliefs or attitudes. Certainly many of the examples considered above could easily regarded be as inauthentic on this basis: in *Mrs T*[575] or *Wye Valley,*[576] it is clear that the decision was based on beliefs that stemmed from the person's hallucinations or delusions; while the values of an anorexic who refuses food might be easily attributable to their disorder.[577] Ahlin suggests that determining the origins of a persons' desires would require 'deep psychological analysis' and 'socio-historical biographical investigation', which would likely 'have to include interviews with people who were close to the desire-holder'.[578] However, these are not insurmountable obstacles, particularly given that authenticity concerns will usually arise in the context of psychiatry, where a standard psychiatric assessment would involve taking a detailed history of the person's life from birth, and obtaining a collateral history from someone close to the person. Psychological analysis and understanding the person's background are therefore standard practice.

Examining people's values and beliefs in this way is also a regular facet of decision-making in this context. If the doctor *does* find the person to lack capacity, they must next decide what is in that person's best interests. Under section 4, the doctor

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[575] *Mrs T* (n117).

[576] *Wye Valley* (n7).

[577] *E* (n24).

[578] Ahlin (n547), 48.

must consider the person's past and present wishes and feelings[579] and the beliefs and values that would be likely to influence his decision if he had capacity.[580] They are also obliged to encourage the person to participate in the decision themselves,[581] and to consult with those involved in the person's care or interested in their welfare,[582] with a view to helping them elicit information about the patient and what they valued. Neither engaging with and testing the patients' motivations for deciding as they have, nor discussing the decision with the patient's family or friends to determine whether it accords with their value and belief structures, would therefore be new or onerous duties for the treating doctor. Rather, they already represent standard practice when it comes to making capacity and best interests assessments.

This engagement with the patient's values and priorities is also demanded in other areas of law. In *Montgomery* for example,[583] the Supreme Court imposed a duty on clinicians to disclose all 'material risks' to the patient, with 'materiality' assessed not only by reference to what a 'reasonable person' in the patient's position would consider germane, but also those risks that 'the doctor is or should reasonably be aware that the particular patient would be likely to attach significance to.'[584] It is therefore an assessment which is 'fact-sensitive, and sensitive also to the characteristics of the

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[579] MCA, s4(6)(a).

[580] MCA, s4(6)(b).

[581] MCA, s4(4).

[582] MCA, s4(7).

[583] *Montgomery* (n103).

[584] ibid, [87].

patient',[585] and which will demand a 'dialogue' with the patient.[586] As Lord Kerr and Lord Reed explained:

> The relative importance attached by patients to quality as against length of life, or to physical appearance or bodily integrity as against the relief of pain, will vary from one patient to another. Countless other examples could be given of the ways in which the views or circumstances of an individual patient may affect their attitude towards a proposed form of treatment and the reasonable alternatives. The doctor cannot form an objective, "medical" view of these matters, and is therefore not in a position to take the "right" decision as a matter of clinical judgment.[587]

Accordingly, 'the doctor's duty of care takes its precise content from the needs, concerns and circumstances of the individual patient'.[588] So if doctors are already engaging with their patients' priorities and desires in the context of risk disclosure, it would not seem particularly onerous for this also to form part of determining the capacity of the person. To assist them in this task, they could be provided in the Code of Practice with a non-exhaustive list of factors which they ought to take into account when determining whether a value or belief is authentic; or with a list of examples of the sorts of cases where authenticity concerns might arise, for example where the person is suffering from delusional or distorted thinking on account of a psychosis.

While conducting such a dialogue may be desirable in theory, the question remains of whether it will prove meaningful in practice. One of the key problems identified in interviews was that doctors simply do not have the time to conduct capacity assessments in any depth. There is a risk therefore that any assessment of

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[585] ibid, [89].

[586] ibid, [90].

[587] ibid, [46].

[588] ibid, [73].

authenticity will be superficial. However, many of the most difficult cases from an authenticity perspective (discussed below) are characterised by chronic mental illness, as in *A Local Authority v E,*[589] *Wye Valley,*[590] and *Re C*.[591] In these cases, the psychiatrist (or social worker) may have had a lasting relationship with the patient reaching back over many years, or at the very least, have access to very extensive notes. While this is not to say that there will not be emergency situations, as in cases such as *St George*,[592] it does suggest that the contexts in which authenticity might have the most traction are those in which comprehensive and detailed assessments can be, and to a large extent already are, made.

This discussion suggests that a model of authenticity based on the origins of a person's belief will often not prove problematic. However determining whether a decision is 'caused' by, or is the product of a 'mental illness or disorder' will not always be so easy. To examine this, it is helpful to consider two different situations in which authenticity concerns might arise, but pose difficulties for originist accounts. The first is where the person has a diagnosis of a mental illness, but it is difficult to know exactly *how* that is affecting the particular values or beliefs in question. The second is where the person does not have a diagnosis of illness, but the values or beliefs they are exhibiting may seem symptomatic of one. Each will be considered in turn. It is suggested however, that while hard cases are inevitable (the human mind is

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[589] *E* (n24).

[590] *Wye Valley* (n7).

[591] *Re C* (n142).

[592] *St George* (n141).

immensely complex and infinitely variable), this is not a reason to abandon the originist model of authenticity. It does not make assessing how a person is being affected by their illness any more difficult than it already is under the current law, while introducing much greater transparency, which allows this inherent ambiguity to be properly scrutinised, challenged, and captured in any best interest determination that follows.

(i) Understanding how a person's mental illness is affecting their values

Even if a person is known to have a mental illness, it can be difficult to know how, if at all, this is affecting their values and beliefs. This will generally be less so where the illness manifests in specific ways, such as in eating disorders or, to a lesser extent, depression; but it can prove difficult where the disorder is connected with attitudes, behaviours or psychosis, the exact nature of which may manifest differently between people. While schizophrenia often gives rise to hallucinations or delusions for example, the nature of these hallucinations may differ substantially, making it difficult to know which of a person's beliefs (if any) ought to be attributed to that illness.

In the interviews conducted as part of this thesis, for example, doctors were given the vignette of Max: a schizophrenic Christian in his 60s with a kidney stone, who was refusing any kind of treatment because he believed his pain was God's punishment for his sins.[593] Nearly all were anxious to determine whether Max's feelings about God were isolated religious beliefs which were not 'part of the wider

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[593] Max suffers from schizophrenia, and experiences persecutory delusions. He has a kidney stone, which is causing him some abdominal pain, and he requires an operation to remove it. He understands the medical evidence in favour of having the operation, and the consequences of not having it, because he believes the pain is God's punishment for the sins he has committed during his life. He thinks doctors should not interfere with the actions of God, and that it is only God that will decide his fate. As a devout Christian throughout his life, he believes God will not let him die.

pattern of schizophrenic symptoms',[594] or whether they were a consequence of the disorder. One doctor suggested that a 'huge focus of the assessment' would be 'the boundary around his Christian beliefs and his psychosis',[595] while another suggested that 'you'd have to explore whether you felt this view about God was a part of his psychotic illness at the moment, or whether that is consistent with his previous belief system'[596] This view was supported by other doctors who questioned 'whether or not as a devout Christian, his beliefs were actually a reflection of his persecutory delusions'.[597] It was difficult to know in this case therefore, whether the beliefs being expressed were caused by his long-standing faith or by his schizophrenia. Although in *Wye Valley*, it was clear that Mr B's religious beliefs were the result of persistent auditory hallucinations in which he heard the voices of angels and of the Virgin Mary, Mr Peter Jackson noted that the line between faith and delusion is not always clear-cut:

> Religious beliefs are based on faith, not reason, and some can strongly influence the believer's attitude to health and medical treatment without in any way suggesting a lack of mental capacity. Examples include belief in miraculous healing or objections to blood transfusions.

Understanding the causal origins of a belief, and whether it originates from an illness, or an authentic process, can therefore be difficult. In fact, one particularly challenging instance of this is where the person's beliefs are based on unusual religious beliefs, in obedience to which they have refused an intervention. As religious experience is a different order of experience which is not capable of rational interrogation, this can

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[594] Interview [anonymised] (Oxford, April 2017).

[595] Interview [anonymised] (Oxford, July 2017).

[596] Interview [anonymised] (Oxford, March 2017).

[597] Interview [anonymised] (Oxford, July 2017).

make it very difficult to distinguish between authentically held religious beliefs or genuinely felt religious experiences, and delusional beliefs brought about by a mental illness (as in *Re C*[598] or *Wye Valley*[599]). There may also be a cultural dimension to some beliefs which exacerbate these difficulties. Demonic possession is a feature of many sharmanic cultures, for example. The boundary between disordered and unusual or eccentric can be a very fine one.

Another context in which distinguishing the disordered from the authentic can prove difficult is in cases of chronic mental illness, where, over many years, pre-existing 'authentic' and disordered 'inauthentic' belief-systems may become inextricably intertwined. In these circumstances, identifying whether a particular value or belief is attributable to illness may be almost impossible. In *Wye Valley* for example, Mr B's religious beliefs were described as 'an intrinsic part of who he is',[600] which had affected the whole ethical framework by which he lived his life, evidenced by the fact that he gave up thieving on account of them. Would any decision then, founded on his religious beliefs, thus become inauthentic? For someone like Ian Brady meanwhile, whose personality disorder manifested itself in 'narcissism; egocentricity; histrionicity; obsessionality; need for control; paranoia; litigiousness; lack of remorse; and lack of empathy',[601] it is difficult to conceive of any of his beliefs or values being totally unaffected by his disorder.

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[598] *Re C* (n142).

[599] *Wye Valley* (n7).

[600] ibid, [43]

[601] *R v Collins and Ashworth Hospital Authority ex parte Brady* [2001] 58 BMLR 173, [36].

(ii) What constitutes 'disordered' values?

If cases of mental illness can cause problems in establishing authenticity, even more difficult are those cases in which it is simply not clear whether a person's values or beliefs evidence a disorder at all. While there is a clear conceptual difference between a person who is insecure about their weight who goes on a diet, and a person suffering from anorexia, these positions sit on a spectrum, and there will inevitably be a grey area somewhere in between. According to the DSM-5 for example, the diagnostic criteria for anorexia nervosa are as follows:

(a) Refusal to maintain body weight at or above a minimally normal weight for age and height.

(b) Intense fear of gaining weight or becoming fat, even though underweight.

(c) Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.

(d) In postmenarcheal females, amenorrhoea, i.e. the absence of at least three consecutive menstrual cycles.

While the criteria in (a) and (d) might be objective, both (b) and (c) clearly introduce a large degree of subjectivity into the assessment. Many people have a distorted view of their own bodies, and it is not uncommon for this to affect the person's self-evaluation. Determining whether or not a person has anorexia is not therefore a simple 'yes' or 'no' answer; rather the psychiatrist must make a judgement about whether or not the person's symptoms are *sufficiently* extreme as to render the person disordered.

This difficulty was recognised by both the doctors and Justice Macdonald in *Kings College Hospital NHS Foundation Trust v C & V,*[602] a case in which a woman was refusing dialysis (following a suicide attempt) on the grounds, amongst others, that her life had 'lost its sparkle'. The description given of her is illuminating:

> C is a person to whom the epithet 'conventional' will never be applied… C has led a life characterised by impulsive and self-centred decision-making without guilt or regret. C has had four marriages and a number of affairs and has, it is said, spent the money of her husbands and lovers recklessly before moving on when things got difficult or the money ran out. She has, by their account, been an entirely reluctant and at times completely indifferent mother to her three caring daughters. Her consumption of alcohol has been excessive and, at times, out of control. C is, as all who know her and C herself appears to agree, a person who seeks to live life entirely and unapologetically on her own terms; that life revolving largely around her looks, men, material possessions and 'living the high life'. In particular, it is clear that during her life C has placed a significant premium on youth and beauty and on living a life that, in C's words, 'sparkles'.[603]

Against this background, the evidence of the psychiatrists was that while her symptoms were in keeping with a personality disorder,

> the question of whether a particular person has a histrionic or narcissistic personality disorder, as opposed to simply a very strong or difficult personality can be an area of some controversy and... there are no validated tools in this area to ascertain a baseline of 'normal' in the context of diagnosing personality problems.[604]

In the event, Justice Macdonald found C to have capacity to make the decision to refuse treatment, even if this would not be a decision which would 'accord with the expectations of many in society.'[605] Given the presumption of capacity contained within the MCA, this decision is surely correct. He noted however that

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[602] *C & V* (n193).

[603] ibid, [8].

[604] ibid, [44].

[605] ibid, [97].

> with regard to the question of causation, and in particular whether what was being seen might be the operation of a personality disorder or simply the thought processes of a strong willed, stubborn individual with unpalatable and highly egocentric views, the evidence was likewise somewhat equivocal.[606]

Hard cases will therefore arise in which determining whether or not the person's values can be said to be 'disordered' will be difficult. The doctor will then have to make a value judgement about whether or not they regard it as sufficiently 'outside of the norm' as to reflect an underlying disorder, and there is a risk that in doing so, those beliefs that do not reflect established religions or accepted belief-systems will be more likely to be regarded as disordered. In fact, even the determination of whether something is a disorder or not involves a value judgement about whether those values or behaviours are sufficiently abnormal as to be classified as a 'mental illness'. As Derek Bolton and Natalie Banner argue:

> The problem of defining mental disorder has long vexed philosophers and psychiatrists keen to distinguish conditions warranting healthcare from those variations and eccentricities of human experience that, whilst negative, are considered normal and not illness.[607]

This is especially so as our classifications of mental illness have changed over time, occasioned by changes both in clinical understanding and in social values. To put it simply, what is considered 'sufficiently outside of the norm' will change depending on what is regarded as the 'norm' at that particular time. Approaches to sexuality and gender provide perhaps the clearest example of this. It was not until 1973 that the American Psychiatric Association, on the basis of a vote of members, chose to de-classify homosexuality as a mental illness in the DSM. Even after this, it was replaced

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[606] ibid, [94].

[607] D. Bolton and N. Banner, 'Does mental disorder involve loss of personal autonomy?' in Lubomira Radoilska (ed), *Autonomy and Mental Disorder* (Oxford, Oxford University Press 2012), 78.

first with ‘sexual orientation disturbance’ (where an individual with same-sex attractions found them distressing and wanted to change) and later 'Ego Dystonic Homosexuality’, before it was removed entirely in 1987.[608] Transgenderism is following a similar trajectory, having originally been included as ‘transexualism’ in the DSM-III in 1980; before being renamed to ‘Gender Identity Disorder’, and dwindling eventually, in 2013, to gender dysphoria, which no longer focuses on the person’s gender identity but on the distress that transgender people may experience.[609] This distress is inevitably influenced to some extent by social attitudes to transgenderism: in the future then, transgender issues could disappear altogether from psychiatry.

The very notion of what constitutes a mental illness, or what amounts to ‘disordered’ values, is therefore not a purely clinical assessment, but one that involves a number of value judgements which will be influenced by society’s attitudes to certain belief structures. Far from being objective therefore, originist theories are inherently value-laden, and hand over considerable discretion to decision-makers to judge when a value or belief is rightly regarded as disordered.

(iii) Responding to difficulties at the margins

The boundary between a person’s mental illness and their ‘authentic’ self is inherently porous, and so capacity assessments will always, whatever their formulation, involve complexities and problems at the margins. There will always be hard cases in which it is difficult, even impossible, to unpick how far a person’s values are being affected by

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[608] J. Drescher, ‘Out of DSM: Depathologizing Homosexuality’ (2015) *Behav Sci (Basel);* 5(4): 565–575.

[609] American Psychiatric Association, *Diagnostic and statistical manual of mental disorders* (2013) (Arlington, VA: American Psychiatric Publishing, 5th ed).

their illness — indeed, the very fact that these cases come to court shows how far this area is from being clear-cut. That some cases will pose difficulties — either because of a lack of clarity over whether the values can be attributed to a person's illness, or because of uncertainty over whether they suffer from an illness at all — is not, however, a good reason to abandon any inquiry into whether a person's values are being interfered with by a mental illness.

While understanding whether certain belief-systems are symptomatic of a mental illness is undoubtedly difficult, judgements of this nature form the bedrock of a psychiatrist's work. The very nature of diagnosis involves examining the symptoms and manifestations of a person's thought-processes, and deciding whether or not they are sufficiently serious as to be attributable to a mental illness. This is not to say that psychiatrists will always find these determinations easy — but that they are a challenging but not uncommon feature of clinical practice, which they must grapple with all the time. Most importantly however, as the case of *C & V*[610] clearly illustrates, these judgements are already demanded by the test for capacity, since a person's inability to make a decision must be *caused by* an impairment in the functioning of the mind or brain.[611] Whether brought out into the open through a separate limb of the capacity test, or dealt with more opaquely via a straining of the use or weigh criterion then, a decision must still be made about whether a person's decision-making impairment can really be attributed to an illness or not. However, by requiring decision-makers to shoehorn this discussion into the current terms of the Act,

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[610] *C & V* (n193).

[611] This was stressed in *PC & NC v City of York Council* [2013] EWCA Civ 478.

specificity and nuance is necessarily lost: decision-makers cannot talk in detail about how the illness is affecting the person's ability to 'use and weigh' the information in many of these cases, precisely because this is not how the illness is operating on the person. It is unsurprising therefore, that many judgments either do not address the issue of the causative nexus at all (Alex Ruck Keene et al found it to be considered in only 52.5% of Court of Protection cases[612]), or are extremely vague when discussing this issue (*C & V*[613] being the exception). All a limb based on originist theories demands then, is that when that impairment is a mental illness, the decision-maker must be more specific about exactly how it is that the person's autonomy is being impaired or affected by that illness. This would have be valuable in *C & V*.[614] Despite deeming C to be unable to 'use or weigh' the information *because of* her personality disorder, the only evidence Dr R provided to support this, was that she demonstrated 'black and white thinking', which *could* be a symptom of personality disorder.[615] This would seem a fairly lose causal connection on which to deny her the right to make a decision about how and when to end her life. In this case, the evidence presented by C's family was clear: the values being exhibited by C were those that had guided her decisions throughout her life. They were authentic to her — even if unpalatable to others. A separate criterion might therefore have required the doctor to adduce more evidence to support their conclusions in this case, rather than merely relying on an assertion that C

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[612] A. Ruck Keene et al, 'Taking capacity seriously? Ten years of mental capacity disputes before England's Court of Protection' (2019) 62 International Journal of Law and Psychiatry 56-76, 67.

[613] ibid.

[614] ibid.

[615] ibid, [45].

could not ‘use or weigh’ information. In the absence of clear evidence that the values and beliefs driving the decision were disordered, the judge in this case was right to find C to have capacity to take this decision.

The greater transparency than a separate criterion would introduce is crucial for a number reasons. Firstly, this approach inevitably places very great responsibility in the hands of the decision-maker. In short, he or she must make a value judgement as to whether the person’s behaviour is sufficiently outside of the ‘norm’ as to be deemed disordered. This discretion is not unbounded: the doctor must be able to point to a particular illness in the diagnostic manuals and be able to demonstrate how the person’s values or beliefs could reasonably be said to be attributed to it, which, as the *C & V* case demonstrated, will not always be upheld. Nonetheless any test for capacity — no matter how it is framed — inevitably leaves the decision-maker to make a determination of how, and to what extent, an impairment or illness is affecting the person’s autonomy. Where judgements of this nature are being invoked to deny a person the right to make decisions for themselves, it is imperative that this is done explicitly. Decisions based on such fragile grounds must be open to scrutiny and challenge, rather than being concealed within the nebulous language of ‘use or weigh’.

This is particularly so given the potential this creates for decision-makers to make moralistic judgements about the reasons people have for making decisions. Assessing the person’s capacity ought to be about establishing whether or not they are able to make a decision which reflects their own values, not about replacing the person’s own judgement with what might be regarded as a ‘better’ decision. Under the current law however, the lack of transparency generated by the manipulation of the test allows doctors to make decisions of the latter kind, framed as those of the former kind.

Indeed this may have been what underpinned the decision in *C & V*.[616] As Justice Macdonald observed:

> The decision C has reached to refuse dialysis can be characterised as an unwise one. That C considers that the prospect of growing old, the fear of living with fewer material possessions and the fear that she has lost, and will not regain, 'her sparkle' outweighs a prognosis that signals continued life will alarm and possibly horrify many.... C's decision is certainly one that does not accord with the expectations of many in society. Indeed, others in society may consider C's decision to be unreasonable, illogical or even immoral within the context of the sanctity accorded to life by society in general. None of this however is evidence of a lack of capacity. The court being satisfied that, in accordance with the provisions of the Mental Capacity Act 2005, C has capacity to decide whether or not to accept treatment C is entitled to make her own decision on that question based on the things that are important to her, in keeping with her own personality and system of values and without conforming to society's expectation of what constitutes the 'normal' decision in this situation (if such a thing exists). As a capacitous individual C is, in respect of her own body and mind, sovereign.[617]

By enhancing the transparency of assessments, and making it incumbent on doctors to show exactly how it is that the person's values or beliefs are attributable to a disorder, a separate limb would thus help to ensure that the test for capacity continues to capture those cases, such as *Mrs T*,[618] where the person is making a harmful decision on basis of clearly disordered values, while not capturing cases such as *C & V*,[619] in which the person's decision, though regrettable, is nonetheless authentic. That a person's values might be repugnant does not make them disordered, and so it is essential that when assessing a person's values, this is done openly, so that judgements about their capacity do not become conflated with judgements about the virtue of their values or beliefs.

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[616] ibid.

[617] ibid, [97].

[618] *Mrs T* (n117).

[619] *C & V* (n193).

However this transparency is also necessary because the very complexities that make these capacity assessments so challenging ought to be reflected in the way we then respond to the capacity assessment once made. While there will always be cases in which there is a degree of ambiguity over whether or not the person's decision is being caused by disordered values or not, it imperative that such uncertainty is brought out into the open, so that it can be taken into account when determining what is in the person's best interests. The very fact that the person's autonomy falls within a 'grey area' on the cusp of capacity, ought to be a very strong reason for giving substantial weight to their wishes and beliefs when assessing what is best for them. In *A Local Authority v E*[620] for example, the fact that E had a whole host of rational, and perfectly understandable reasons for wishing to refuse force-feeding — namely that her illness caused her unbearable suffering and she was now unable to achieve all those things that she regarded as giving her life value — while not being sufficient to render her decision capacitous, ought to be given very great weight in any best interests assessment. Moreover, understanding the exact way in which a person's illness is affecting their decision-making is important when determining what is 'best' for them. If an illness is affecting the person's cognitive processes (as is often the case with forms of dementia), their best interests will usually be served through making decisions which give effect to and further those values and beliefs that are important to them. If, on the other hand, the illness is distorting the values and beliefs themselves, then permitting them to decide in accordance with those disordered values will rarely be what is best for them. Isolating exactly how the impairment operates on the person is

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[620] *E* (n24).

therefore not only important when it comes to assessing capacity, but also, if they are found to lack it, to determining what is in their best interests.

Finally, while chronic illnesses do pose difficulties for originist accounts of authenticity, arguably this a lesser problem for this account than for others. Where a person has had an illness for much of their life, trying to conjure up a hypothetical 'them' without their illness, who can stand at a distance and decide whether to endorse or reject values and beliefs which are an inherent part of who they are, might seem meaningless. Under originist accounts of authenticity however, the assessor does not need to engage with whether the beliefs are a reflection of the person's narrative, or whether they would hypothetically endorse them, but simply with whether they stem from a disorder. For example, in *A Local Authority v E,*[621] E*,* now 32, had been controlling her eating since the age of 11, and was first admitted into a specialist unit for adolescent eating disorders aged 15. That *E* had disordered values for much of her life however, does not make those values any less disordered, or her any more autonomous in decisions to refuse food — following an originist authenticity test then, it is still right to find her to lack capacity on this basis (even if, as noted above, there might be good reason to attribute significant weight to her wishes in a best interests assessment). The same is true for Mr B's religious beliefs in *Wye Valley,*[622] and Brady's personality disorder[623] — in fact in the latter case arguably the problem relates more to breadth of his illness and the way it impinged upon so many different aspects of his life, than its longevity. These cases do not then, provide sufficient reason to

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[621] ibid.

[622] *Wye Valley* (n7).

[623] *Brady* (n601).

abandon an originist account of authenticity: rather than stretching notions of capacity to encompass cases such as this, it would, as noted above, be better to accept such decisions as incapacitious, but nonetheless worthy of respect.

IV A new limb of the capacity test

In order to capture concerns over the origins of the person's desires and values, an additional limb of the test for capacity ought to be introduced, which asks whether the content of the wishes, feelings, values or beliefs being expressed by the person have been engendered by or altered as a result of a disease, illness or disorder. The 'use or weigh' criterion would then be narrowed in the Code of Practice guidance to apply only to impairments in the person's decision-making *process*, while the authenticity limb would instead focus on the *content* of the values underpinning the decision. Cases such as *Re MB*[624] would therefore remain instances of a failure to 'use or weigh' the information, since the phobia in this case interfered with the woman's ability to act on their values and priorities, or to attach weight to certain outcomes. The

the nature and consequences of the decision, and can they reason about that decision, evaluating that information in light of their values?); while the fourth limb would assess the authenticity of the decision, capturing those situations where the problem lies in the disordered source of the person's stated values.

There would be a number of advantages to such an approach. Most obviously, it would mean that doctors and care workers are no longer placed in a difficult position, whereby they must either deem the person to lack capacity via a somewhat dubious application of the Act; or else allow them to make a decision which they (rightly)

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[624] *Re MB* (n537).

regard as non-autonomous, and which may cause the person serious harm. Amending the law in this way would thus enable doctors to act in an ethically desirable way, without having to expose themselves to a potential battery claim in order to do so. By expanding the legally recognised reasons for disputing capacity, it would also bring authenticity concerns within the protections of the defence contained in section 5. In the difficult cases above therefore, where doctors have reasonable grounds for regarding the decision as inauthentic, they would be protected from legal liability.

As well as ensuring that the law supports doctors faced with these difficult decisions (rather than frustrating them), an authenticity criterion would also allow doctors, particularly psychiatrists, to speak more openly and clearly about what they consider the nature of the problem to be in each case, as they do not have to 'fit' the nature of the impairment within the current framework. They will thus be given a 'language' with which to communicate their concerns to other professionals, and the patient themselves, thus allowing for a more clear and transparent communication between patient and doctor in these cases.[625]

While such a test would leave substantial discretion in the hands of the decision-maker to decide when a value or belief ought to be regarded as disordered,

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[625] This communication is particularly important in the care and treatment of people with mental illness, as evidence suggests that where the patient feels more involved in decisions, this can result in better compliance with treatment courses, as well as positive effects on the patient's self-esteem, well-being, and their confidence: see B. Winick, 'The Rights to Refuse Mental Health Treatment: A Therapeutic Jurisprudence Analysis' (1994) 17 *International Journal of Law and Psychiatry* 99, 100; D.L. Finfgeld, 'Empowerment of Individuals With Enduring Mental Health Problems'(2004) *Adv Nurs Sci* 27(1):44–52, 48. Priebe et al for example, found that patients admitted under the MHA tended to have more favourable treatment outcomes where they were more positive about the proposed treatments, and they highlighted the importance of discussing the appropriateness of such treatments with the patients beforehand" Priebe et al, 'Predictors of clinical and social outcomes following involuntary hospital admission: a prospective observational study' (2011) Eur Arch Psychiatry Clin Neurosci 261:377–386, 383-4.

this discretion is not new to capacity assessments. Given the broad powers currently afforded to doctors under the 'use or weigh' limb, and the evidence that it is already being used to capture authenticity concerns, introducing a separate criterion of authenticity would not, in practice, greatly increase the doctor's scope for intervention. While it is true that the grounds for *legitimate* intervention would increase (whereas at least under the current law it is possible, at least in theory, to challenge doctors for going beyond the scope of the MCA), in reality, such challenges are rare and hard to sustain, given the broad range of arguable interpretations of 'use or weigh', and the additional safeguards for doctors contained in section 5. Indeed it is notable that in all of the examples given above except *St George*[626] (which was itself appealing the decision of Hogg J granting a declaration that the actions of the doctors were lawful), the court supported the doctor's decision that the individual was unable to 'use or weigh' the information, lending support for the idea that doctors already possess a wide discretion to deem the person to lack capacity. These reforms are therefore unlikely to grant decision-makers significantly more powers to intervene in a person's decision. They would, however, ensure that where they do intervene, these decisions were made with a important degree of transparency not hitherto seen, which both opens up the value-judgements inherent in these assessments to challenge, and helps to identify cases on the cusp of capacity, where the cliff-edge approach may operate particularly harshly, and so there may be good reason for attributing substantial weight to the person's wishes in any best interest assessment that follows.

Despite these clear advantages, there remain two potential objections which must be addressed. The first is that a separate limb of the capacity test which asks

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[626] *St George* (n141).

whether or not a person's values or beliefs are disordered could return the law to a status-based approach to capacity, whereby any diagnosis of a disorder would render the person incapacitated; the second, is over how the proposed framework would deal with situations in which a person has multiple reasons for acting, only some of which are based on values or beliefs that are disordered. Each will be considered in turn, though neither, it will be suggested, are insurmountable obstacles to the proposed reforms.

(a) Returning to a status-based approach to capacity?

Concerns have been raised that adopting an originist account would risk returning the law to a status-based approach to capacity, in which any diagnosis that the person is suffering from a disorder would be enough to render their decision inauthentic and them incapacitated. These fears are unlikely to be realised.

Firstly, the issue of authenticity only arises where the person's decision is being shaped by their disordered values or beliefs. If, therefore, the decision is unrelated to the disorder, this issue will simply not arise. That a person has anorexia, or a schizophrenic belief that their blood is evil, does not affect the authenticity of their values in respect of say, taking contraception – since that decision is not underpinned by the distorted values. Even where the decision *does* relate to the nature of their illness and disordered thinking however, it may be too straightforward to suggest that they will *never* be able to make an authentic choice. Rather it depends on what their *reasons* for acting are, and whether or not these can be said to have been directly caused by the illness or not. For example, that a person has anorexia does not mean that they could never refuse food, for *whatever* reason. It might be possible, at least at a theoretical level, for them to refuse food if the reason was *not* because they did not want to put on weight (or other reasons similarly connected to their illness) — such as that they regarded their quality of life as extremely low, or had a principled reason for wishing to end their life or refuse the food (for instance, that it does not comply with their dietary requirements) – since in these cases the value or desire underpinning the decision is *not* disordered.

Of course in practice, trying to distinguish the person's lines of reasoning (and understand whether they are genuine or not) can be very difficult. It is unlikely therefore, that a person with anorexia wishing to refuse food *would* be found to be autonomous in respect that of that decision in anything other than the most exceptional of cases. However as cases such as *A Local Authority v E*,[627] *NHS Foundation Trust v Ms X*[628] and *NHS Trust v L*[629]demonstrate, they are also unlikely to be found to have capacity under the current law: wherever a person with anorexia is refusing food, they will be found to lack capacity on the basis of an inability to 'use or weigh' information. This is not therefore, a reason to abandon an originist model of authenticity.

While the decision of a person with anorexia to refuse food may represent an exception in that it will be rare for the person with that diagnosis to be found to have capacity in relation to a decision about food, in almost all other cases, that the person has disordered beliefs or values will only be relevant if they are the basis on which a person has made their decision *and* they do not have other, non-disordered reasons for acting. In both *Re C*[630] and *Re SB*[631] for example, the fact that the patient had

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[627] *E* (n24).

[628] *NHS v Ms X* (n532).

[629] [2012] EWHC 2741.

[630] *Re C* (n142).

[631] *Re SB* (n227).

schizophrenia in the former, and bipolar disorder in the latter did not render them incapacitated, nor even did the fact that at least some of their reasons for acting were based on those delusions, since they also had a number of other reasons for acting, unaffected by their illness. The same would be true under the proposed changes: it would therefore, reinstate a status-based approach to capacity.

(b) Multiple values or reasons for acting

This discussion also illustrates a second problem: what happens in situations where a person has multiple reasons for acting, only some of which are based on disordered beliefs. This is not a problem specific to incorporating an authenticity element into the capacity test: it arises even under the current law. As noted above, in both *Re C*[632] and *Re SB*[633] for example, the patients both had some reasons for acting which would generally be considered 'rational', and some based on delusional beliefs. In *A Local Authority v E* too,[634] while she did have disordered values (due to her anorexia), E also had some 'rational' reasons for acting – such as to end her suffering. Despite the prevalence of this issue however, judges have not explicitly discussed how much of one's reasoning must be disordered before they lack capacity in any of these cases.

In *Re SB* Holman J appeared to regard the fact that the person had *some* rational reasons for wanting to have an abortion as sufficient to find them to have capacity:

> It seems to me, therefore, that even if aspects of the decision making are influenced by paranoid thoughts in relation to her husband and her mother, she is nevertheless able to describe, and genuinely holds, a range of rational reasons for her decision.[635]

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[632] *Re C* (n142).

[633] *Re SB* (n227).

[634] *E* (n24).

[635] *Re SB* (n227), [44].

A similar conclusion was reached in *Re C*.[636] In this case, although C (who suffered from persecutory delusions and delusions of grandeur) was certain that, contrary to clinical advice, he would survive without the proposed amputation, he was also clear that he did not want to live out the remainder of his life with just one foot, even if that meant he would die. The judge could not establish a direct link between his disordered beliefs, and his decision to refuse the amputation, and accordingly found him to have capacity, regarding his decision to 'result from sincerely held conviction.'[637] In *E* by contrast, her disordered beliefs *were* sufficient to mean that she lacked the capacity to make decisions about the refusal of food, irrespective of her rational reasons for doing so. Clearly then, in cases where a person's reasons for acting are based on both authentic and inauthentic values, decision-makers are deciding on a case by case basis whether or not the inauthentic values are *sufficient* to render the person incapacitated.

This must be correct. It cannot be the case that all of a person's reasons must reflect authentic values or beliefs before the person will be deemed capacitious. If the person would have reached the same decision on the basis of their 'rational' reasons alone, clearly it cannot be right to deem them 'unable to make a decision' merely because they also hold other beliefs which contributed to the conclusion they reached. Thus, if the woman in *Re SB* requested an abortion on the basis that owing to her long history of mental illness, she felt unable to care for a child, it would seem unfair to render her unable to make that decision purely because she had also had other (disordered) reasons that confirmed her decision. As Peter Jackson J said in *JB* (another case concerning both rational and irrational reasoning), 'we should not ask

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[636] *Re C* (n142).

[637] ibid, 293.

more of people whose capacity is questioned than of those whose capacity is undoubted.'[638] However, since the assessor cannot read the person's mind, it cannot be determined with any degree of accuracy whether the person *would* have reached that decision without (or but for) the disordered beliefs: the causal contributions that different values or beliefs make in a person's reasoning process are not susceptible to quantification in this way, nor can a person's reasons be clearly teased apart. We cannot therefore operate any hard 'rules' dictating how *much* of a person's reasoning must be based on authentic values.

Rather each decision-maker will have to make a judgement call based not only on the dominance of the different reasons, but also the relationship between them, and whether the disordered beliefs have affected or influenced the person's authentic beliefs. One criticism that may be levelled at Justice Holman's reasoning in *Re SB* for example, was its failure to examine how the woman's paranoid beliefs might have affected both the existence of, and the weight given to, her apparently 'rational' reasons. For example, her fear at not being able to bring up the child, and the consequent risk that it might be taken into care, may well have been influenced by her conviction that her husband and mother would not support her in caring for the child. Given the clear correlation between the abandonment of her medication and her relapse, it also might be argued that once she resumed her medication, she might have conquered her suicidal thoughts and felt better placed to cope as a parent. This might explain why the clinicians in this case were reluctant to find her to have capacity – quite the opposite conclusion from that in *Re C,* where at least two of the treating

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[638] *JB* (n223), [26].

doctors did regard their patient as capacitous, considering that his delusions had no direct bearing on his decision.

Where a person has multiple reasons for acting then, only some of which are based on disordered values or beliefs, any conclusions as to whether they have capacity must rest on a judgement call by the decision-maker about how and to what extent the disorder has affected the conclusion reached.[639] This must be made against the background position however, that if it is not possible to say reliably which is the 'dominant' reason, or how they interact with one another, the presumption of capacity ought to operate so that unless the decision-maker can demonstrate that the person would not have reached that decision were it not for the disordered belief, they must be found to have capacity.

Once again, this discussion highlights the potential harshness of the capacity cliff-edge. In both *Re C*[640] and *Re SB,*[641] despite holding both rational and delusional beliefs, the patient was found to have capacity, and their wishes were respected. In *E* by contrast, the consequences could not have been more different: she was found to lack capacity, and was subjected to the most invasive of treatments against her clear wishes. While a separate limb of the capacity test will not overcome the difficulties

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[639] In practice, this is subject to the fact that in order to gain the protections of the defence to battery contained in section 5 MCA, the decision-maker must 'reasonably believe' that the person lacks capacity and that they are acting in accordance with their best interests (MCA, s5(1)(a)-(b)). The existence of an authenticity limb of the capacity test would expand the legally recognised reasons for disputing capacity, thus bringing authenticity concerns within the protections of the defence to battery contained in section 5, providing protection for doctors in situations where they have doubts over whether the decision is authentic or not. They would still however, have to demonstrate that it was reasonable to believe that the disordered values were having a sufficiently significant effect on the person's decision as to warrant finding them to lack capacity.

[640] *Re C* (n142).

[641] *Re SB* (n227).

inherent in people having multiple reasons for acting, by placing a greater onus on the doctor to show how the person's disordered values are sufficient to render them 'unable to make a decision', this brings some of their reasoning out into the open, which may facilitate a more nuanced response to people found to lack capacity.

V Conclusions

This chapter has highlighted the importance of introducing a separate limb of the capacity test which asks whether a person's values, beliefs, desires have been caused by an illness or disorder. The benefits are threefold: firstly it gives doctors a legitimate basis on which to intervene in decisions where they have reason to believe the person's decision is being caused by a mental illness or disorder; secondly, it exposes more clearly those cases on the cusp of capacity where determining the effect of an illness on the person is not clear-cut, so that the uncertainty can then be reflected in any best interests decisions that follow; and thirdly, this increased transparency makes dubious assessments easier to challenge.

Despite these advantages, a separate authenticity criterion will not address all of the problems identified in chapter 1. It will not eliminate inconsistencies in the way that the MCA is being applied, as doctors will retain discretion over what degree of autonomy a person must exhibit while also being handed substantial discretion to determine whether a person's values or beliefs are caused by an illness. And while it will better identify those cases where the cliff-edge approach to capacity operates particularly harshly, it will not reduce the starkness of this; albeit that if the decision-maker feels more confident that the decision reflects strongly and authentically-held values and beliefs, they may then not feel quite the same protective imperative. The following two chapters will thus consider how the law might be able to address these remaining concerns.

IV Enhancing the consistency of capacity assessments

Chapter 1 identified a number of reasons why capacity assessments are currently not being conducted in a consistent manner. Capacity is not all-or-nothing state but admits of degrees, and so there can be disagreements on the cusp of capacity over whether a person meets the capacity threshold or not. Since each decision-maker must make their own assessment of whether the person exhibits 'sufficient' autonomy to be found to have capacity, there is inevitably a large degree of subjectivity at the heart of every assessment. To these shortcomings are added a number of difficulties which frequently arise in making such assessments in practice — insufficient collateral information available to the decision-maker about the patient, or a lack of experience of the patient's condition and how it may impair their cognitive function. There is also a lack of clarity over what impairments fall within the remit of 'an impairment of, or a disturbance in the functioning of, the mind or brain',[642] leading to disputes over whether the nature of the person's impairment is in fact captured by the Act at all.

In the face of all of this uncertainty, the decision-maker still has to decide one way or the other, but in the knowledge that should the patient seem likely to cause themselves harm, this can be prevented only by finding them to lack capacity. As a result, as noted in Chapter 1, decision-makers have frequently used the wide degree of discretion they have under the Act to decide what 'degree' of autonomy a person need exhibit to raise the threshold in cases where they fear the patient's decision may prove to be harmful or unwise. While the desire to intervene to protect a vulnerable patient is

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[642] MCA, s2(1).

very understandable, even laudable, the effect has been to further undermine the ability of the capacity test to accurately and consistently distinguish those capable of making autonomous decisions from those who are not. This chapter will therefore begin by considering what, if anything, can be done to address this inconsistency and to enhance the robustness of the test for capacity. This is important. As Chapter 1 noted, the effect of this inconsistency is not only to undermine the rule of law, but also to make the person's autonomy subject to the idiosyncrasies of the individual assessor. If the test for capacity is not capable of being applied consistently, then this suggests that in a number of cases, the cliff-edge approach to capacity operates too harshly and so needs to be reconsidered.

The nature of testing something as intensely subjective as a person's autonomy is that *some* degree of discretion is necessary, especially as it is not possible to set out in advance exactly how much of any component or element of capacity a person must show in order to reach the statutory threshold. There will always then be some inconsistency in the way that this discretion is exercised. While this chapter will suggest steps which might be taken to mitigate this — through the provision of greater guidance for decision-makers on how to identify and respond to impairments in the person's autonomy — it must be accepted that any law which operates a capacity threshold will face difficulties at the margins.

Narrowing the legitimate interpretations of the use or weigh criterion (as suggested in Chapter 3) and providing greater guidance to decision-makers will reduce some of the discretion available to doctors to make outcome-orientated decisions, thereby enhancing consistency. However, the only means of comprehensively tackling the inconsistency problem is to remove the incentive that a doctor has to find a person to lack capacity in order to prevent them from harming themselves. The problem is that once a person passes the capacity threshold, he or she has an unfettered right to self-determination, which forbids a doctor from intervening to protect that person, irrespective of the level of harm that their decision might cause. Doctors are therefore incentivised to declare people incapacitous in these instances precisely because if they do not do so, there is nothing they can do to protect that person from themselves, beyond trying to persuade them to decide differently. The alternative, explored in the latter part of this chapter, is to afford doctors the power to prevent *capacitous* persons from harming themselves, however as this chapter will show, this is impossible without a wholescale reconfiguration of our capacity law. It also strays into extremely paternalistic territory and very likely traverses the boundaries of legitimate state authority. Accordingly, while some measures can be taken to soften the effects of a finding of capacity — such as enabling people to appoint 'supporters' to assist them in making decisions — a bias in favour of finding the person to lack capacity is likely to remain.

I Eliminating inconsistency

Wherever there is discretion, a degree of inconsistency will follow as no two decision-makers will ever exercise their discretion in exactly the same way. In capacity assessments however, some discretion is both inevitable and desirable given the person-specific, treatment-specific, and context-specific nature of decision-making in this area. For this reason, inconsistency can never be eliminated entirely.

To determine accurately whether any given person is capable of making an autonomous decision involves the decision-maker in a twofold assessment: they must first consider the values and beliefs of the person at issue, and then decide whether they are able to act in accordance with these. To conduct such an intimate examination of another's belief structures, goals and motivations,[643] demands a deeply personal and detailed engagement on the part of the clinician.

Moreover, depending on the source and nature of the impairment, the person's decision-making process may be affected in very different ways. Anorexia nervosa will clearly affect someone's capacity differently from, say, a head injury or advanced dementia; while even within any particular condition, the person's capacity may depend on the nature of the decision itself. A person may be able to make capacitous decisions about some things, but not about others. (We have seen how sufferers from anorexia, for instance, may well be capacitous in relation to virtually all decisions except those relating to food.) Capacity therefore cannot be determined with any level of generality, but requires the assessor to engage with the individual's values, priorities and reasoning processes in relation to a particular decision at a specific time – a level of subjectivity and specificity which the law is incapable of capturing in full.

Here is the crux of the problem: while autonomy is inherently individualistic, laws are necessarily general, designed to apply to a whole range of people in a variety of different circumstances. While it is incumbent on the decision-maker to apply the legal principles to the facts of each individual case, the enormous variety of situations and conditions to which the capacity test applies means that the rules have to be expressed in non-specific terms, with a high degree of generality, if they are to be capable of capturing all of these different circumstances. The effect of this is that there

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[643] As suggested above, although concerning negligence rather than battery, the personalised nature of autonomy was recognised by the Supreme Court in *Montgomery v Lanarkshire Health Board* [2015] UKSC 11, which marked a shift in emphasis from focussing on the clinician to recognising the values of the individual patient. This was evidenced by the duty placed on healthcare professionals in this case to disclose any risks that they know, or should reasonably be aware that the "particular patient would be likely to attach significance to it" [89]. Lady Hale explicitly saw this duty as deriving from the need to protect a person's "autonomy, their freedom to decide what shall and shall not be done with their body" [108]. See J Herring et al, 'Elbow Room for Best Practice? Montgomery, Patients' values, and Balanced Decision-Making in Person-Centred Clinical Care ' (2017) 25(4) *MedLRev* 582.

is ample scope for the decision-maker to decide how to interpret and apply these rules to the specific situation before them.

The same is true of other areas where the legal rules are designed to apply to a broad range of situations, such as the 'welfare principle' set out in section 1 of the Children Act 1989[644] or the 'best interests' assessment in section 4 MCA:[645] both are formulated as overarching principles not subject to strict definition, and it is therefore expected that substantial discretion will be left to the decision-maker to apply these broadly-framed principles to the specific case before them. This is not inherently problematic.

Furthermore, as autonomy is not absolute, this confounds the possibility of a totally rigid framework: while the law can (and does) state that a person must exhibit certain qualities or attributes in order to be autonomous, it is impossible to say in advance of any decision, what *degree* of authenticity or understanding or reasoning the person must demonstrate. The decision-maker must therefore decide this for themselves. This is illustrated most clearly in respect of mental illness. Given the multitude of ways in which a person may be affected by mental illness (discussed in Chapter 3), it would clearly be impossible to set out in advance the precise extent to which the illness must interfere with the person's reasoning ability or distort his values

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[644] Notably the 'welfare principle' has also been criticised for the inconsistency with which it has been applied (see S. Gilmour, 'The nature, scope and use of the specific issue order' (2004) 16 *Child and Family Law Quarterly*, 367–386). As J. Herring notes however, some indeterminacy might be inevitable when formulating legal principles that apply to "such a wide range of families, styles of parenting and structures of relationships" (J. Herring, 'Farewell Welfare' (2011) 36(1) *Journal of Social Welfare and Family Law* 159-171, 161).

[645] See chapter 2 for a discussion of how this provision is being understood and applied in the Courts and on the ground.

and beliefs, for their decision to be regarded as non-autonomous. In *Re C*[646] or *Re SB*[647] for example, it is difficult to conceive of any way that the law could have set out in advance how the doctors or judges ought to have responded in these situations in anything other than the most general of terms. Even in far less complex cases however, where the question is what degree of understanding the patient is required to exhibit, difficulties remain. Both the person's particular circumstances and the nature of the decision will have a bearing on the level of understanding required as the person must understand how the decision will affect them personally. Therefore, this has to be determined on a case by case basis and cannot be set out prescriptively in advance.

According some degree of discretion to the decision-maker is both necessary and desirable if the law is to capture the nuanced and complex nature of establishing autonomy. In particular, the decision of when a person's impairment is sufficiently serious as to rebut the presumption must remain in the hands of the decision-maker to decide on a case by case basis — some disagreements will therefore remain. However, it should still be possible to see this discretion exercised with greater consistency. The most obvious way that this might be achieved is through introducing greater guidance for doctors on how to apply the MCA — to help them identify what the capacity issues may be in respect of different conditions, and what sorts of information they ought to be testing for in relation to specific treatments. This guidance — explored in the following sections — could be provided either within the Code of Practice, or in addition to it.

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[646] *Re C* (n142).

[647] *Re SB* (n227).

(a) Disorder- and treatment-specific guidance

Some guidance on conducting capacity assessments already exists, variously in the Code of Practice,[648] from professional bodies,[649] and in material produced by regional initiatives such as the ‘Mental Capacity Assessment Tool Guidance’.[650] It tends, however, to be general in nature, focussing on the key statutory provisions and the basics of conducting the assessments, rather than on the difficulties raised by specific types of impairments or treatment decisions. One of the suggestions put forward by interviewees was therefore that there ought to be more disorder-specific guidance for doctors,[651] identifying those areas of capacity that are likely to prove problematic for people with certain medical conditions, and recommending techniques for how to respond most effectively to these issues. For example, if the patient is suffering from delirium, the primary issue is often with their attention; Alzheimer’s by contrast, usually raises issues of recall; while for someone with bipolar disorder, the problems may relate to the consistency of the views expressed, given the episodic nature of the illness.

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[648] Jackson, (n4).

[649] The Royal College of Emergency Medicine, *Best Practice Guidelines: The Mental Capacity Act in Emergency Medicine Practice* (February 2017), available at <https://www.rcem.ac.uk//docs/RCEM%20Guidance/RCEM%20Mental%20Capacity%20Act%20in%20EM%20Practice%20-%20Feb%202017.pdf> accessed 10th July 2018.

[650] See e.g. Social Care Institute for Excellence, *Mental Capacity Assessment Tool Guidance*, August 2015, available at: < https://www.scie.org.uk/files/mca/directory/mca-tailored-for-you/health/pan-london-commissioner-toolkit/beh-capacity-assessment-tool-guidance.pdf?res=true>; or the Mental Capacity Act Practice Guidance, available at <https://new.devon.gov.uk/care-and-health/guide/mca-practice-guidance/part-6-how-to-assess-capacity/> accessed 10th July 2018.

[651] Interview [anonymous] Oxford, March 2017.

Guidance of this nature would help both doctors and social workers in deciding where the emphasis should be when assessing whether a person has capacity. This would be particularly useful for those called upon to assess the capacity of people with a broad range of learning disabilities, mental illnesses and brain injuries, as routinely happens in emergency medicine, in general practice, and in adult social care. Guidance of this kind would almost certainly help to mitigate the implications of assessments being made by people without specialist knowledge of the particular patient or type of cognitive impairment at issue. It would clearly help to improve the consistency of assessments, by ensuring that even non-specialists could glean some basic understanding of how the condition might be affecting the person, and what indicators might suggest that the patient had impaired capacity.

This guidance might also point to measures which might help enhance the person's ability to make a decision for themselves. In cases of delirium or Alzheimer's for example, given the inherent difficulties with attention and recall, information should be presented in a very concise fashion, and the person ought not to be expected to retain that information for long. For someone who has schizophrenia meanwhile, it may be that they have difficulty in trusting the intentions of others, and therefore it might help their decision-making to have someone in the room that they trust to present the information to them. Measures of this kind would better fulfil the demands of s1(3) of the MCA, which states that 'a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success'.

In a similar vein, even if it is not possible to state with exactitude the *level* of understanding that a person needs in respect of a particular treatment decision, guidance could be provided about the *kind* of information that every patient must understand. This could be provided by each specialism's professional body, who would then include treatments which might be relevant to doctors practising in that specialism. While the context may change, this would supply the basic information about the nature, purpose and consequences of, say, a blood test or hip replacement surgery, that should be understood by *any* patient consenting to that treatment. It would provide a minimum level of understanding applicable to all, which could then be augmented depending on the patient and the circumstances. In doing so, it would mitigate the problem identified by Gunn *et al* above, that even in relation to relatively minor decisions (such as whether to have a blood test), there was a wide variation amongst doctors in the kinds of information they expected their patients to understand.[652] This would strike an appropriate balance between according decision-makers sufficient discretion to be able to respond to the specific individual and circumstances, and helping to enhance the consistency with which such tests are applied: while it would still be left to each decision-maker to determine whether the person exhibits the requisite degree of understanding, a framework would be in place for assessing this.

The value of such an approach was recognised by Emmett *et al,* who suggested that in order to address the 'idiosyncratic' and variable way that capacity assessments were being conducted for people with dementia in decisions about discharge from hospital, 'a more specific test should be adopted' which set out in greater detail what the 'relevant information' was that people ought to be expected to understand.[653] This would include, for example:

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[652] Gunn et al (n245).

[653] Emmett et al (n246), 80.

- Why they have been in hospital (hence, this must have been explained to them);
- The social arrangements that are being proposed for them on discharge, i.e. whether they will be returning home or moving to another place of residence and with whom they will be living, if anyone, (hence, these things should have been discussed with them);
- The ways in which it is being suggested they will or might require help (if at all) after their discharge from hospital and the care options they would have available to them (hence, the relevant issues and options, including the justifiable concerns of others, must have been discussed with them);
- Those persons and services able and willing to provide help and the nature of the help that can be provided (hence, this must have been discussed with them).[654]

Guidance of this nature would provide doctors with a far clearer framework for testing the person's capacity in relation to each decision, which would enhance the consistency with which the test is applied.

(b) The limits of 'impairment' in the 'mind or brain'

Another problem for doctors when conducting capacity assessments was a lack of clarity in the MCA Code of Practice over what impairments are captured within the phrase, 'an impairment of, or a disturbance in the functioning of, the mind or brain'.[655] In particular, when confronted with vignettes, doctors had different views on whether medication, pain, confusion, shock or extreme emotion come within its remit.

For example, the Code of Practice makes reference to alcohol and drugs having the potential to undermine the person's ability to make a decision, and later lists the symptoms of alcohol or drug abuse as examples of things which might constitute an impairment or disturbance in the functioning of the mind or brain,[656] yet it does not refer to the effects of medication in either context. It would seem curious that recreational drug use is mentioned in the Code, and yet prescribed drugs are not. Yet

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[654] ibid.

[655] MCA, s2(1).

[656] MCA Code of Practice (n266), 4.12.

38 pages later in the Code of Practice, response to medication *is* noted as an example of when someone may regain capacity in the future (indicating that it could have caused them to lose capacity in the past),[657] and elsewhere as a reason that it might be appropriate to delay the assessment of capacity until later[658] — both suggesting it *is* captured within the MCA. Including the effects of medication within the list of examples of impairments, rather than dealing with it in this piecemeal fashion would therefore be welcome, especially for specialisms such as intensive care, where the use of powerful drugs is the primary cause of incapacity.

Pain, shock and extreme emotion are similarly not included in the list of examples of impairments affecting the 'functioning of the mind or brain', nor do they obviously fit within the definition. They are, however, mentioned later on, as an example of temporary factors that might affect a person's 'ability to make decisions'[659] — though it is not stated explicitly whether the inability to decide in this instance can be attributable to an impairment of the mind or brain. In *Rochdale*[660] the court found that the 'pain and emotional stress' of labour was sufficient to render a woman incapacitated. Once again therefore, there is a need for greater guidance on whether this falls within the MCA — clearly, a person's right to make a decision for themselves should not hinge on differing interpretations of the remit of the Act.

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[657] ibid, 5.28.

[658] ibid, 3.14.

[659] ibid, 4.26.

[660] House of Lords (n12).

Greater guidance will both enhance the consistency with which capacity assessments are made, and it will limit some of the discretion available to doctors, as it would then become incumbent on anyone who deviates from the guidance to explain why they did so. This, combined with the changes suggested above to narrow the interpretations of the 'use or weigh' criterion, would thus give doctors less scope to make outcome-orientated decisions that are near-immune from challenge.

A separate criterion might also help to modify the motivations of doctors. One of the key reasons for wanting to manipulate the capacity test was to avoid the patient doing something profoundly harmful, especially where doctors felt that their decision was not a reflection of their authentic beliefs or wishes. The introduction of a separate limb of the capacity test to address authenticity concerns removes much of this problem: if the decision-maker can legitimately find the patient incapable of genuine autonomy, there is no longer any need to manipulate the capacity test to get to this end. Conversely, the suggestions put forward in the following chapter will give doctors less incentive to find a person to lack capacity, since it will limit doctors' scope for intervening in the person's 'best interests'.

Neither solution, however, entirely resolves the problem that in order to prevent a harmful outcome — even if that outcome *is* what the person wants — the doctor's only option is to find the person to lack capacity. There will still be cases therefore, where either the doctor thinks that the decision is needlessly harmful and that the person will later regret it (as in the example given by a doctor in chapter 1 of a woman refusing treatment for a tendon injury which was later unrepairable); *or* where the decision is underpinned by values which, while not disordered, the doctor nonetheless finds deeply problematic: as when medical intervention is refused out of a belief that God will intervene or that nature should 'take its course'. Not only will the outcome be one that the decision-maker regards as ethically undesirable, but any doctor or care worker will also be acutely aware that if they get this capacity assessment wrong, they may also face a claim in negligence, or in extreme cases, even gross negligence manslaughter.

As discussed in the introduction, this difficult position is to some extent mitigated by the effects of the Vulnerable Adults (VA) jurisdiction, and the Mental Health Act (MHA), both of which permit doctors to override the decisions of people with capacity in certain circumstances. Neither, however, is a complete remedy: the VA jurisdiction will not apply in situations already captured by the MCA, and the MHA will only apply if the person both has a mental disorder, and if the treatment in question is for *that* mental disorder (not for an unrelated physical illness). It will not apply to cases like that of the tendon injury, or where the person is insisting on letting nature take its course. The question is therefore whether the courts ought to have more far-reaching powers to override the decision of someone who has been found to *have* capacity in these instances, so as to discourage doctors or care-givers from seeking to ‘push’ the person over the capacity cliff-edge.

II Removing the incentive to push the person over the edge

One way of enhancing the consistency with which the capacity test is applied may therefore be to alter the consequences of a finding of capacity in such a way as to give the decision-maker greater powers to intervene in a person’s capacitious decisions. As this section will explain however, according decision-makers such powers would substantially erode the boundary between private decisions and state intervention.

Before the desirability of such a move can be contemplated, it is first necessary to be clear about *when* decision-makers would be permitted to intervene, and what such interventions would entail. Since the VA jurisdiction already grants courts far-reaching powers in cases *not* captured by the MCA, further powers to interfere with capacitous decisions would only be necessary in two situations: either whether the person does not suffer from an impairment at all, or where the person does suffer from an impairment, the nature of which falls within the remit of the MCA, however the impairment is not sufficiently grave as to render them incapacitated. Clearly these powers of intervention could not be as extensive as those provided for by the MCA (which empower the decision-maker to override the person's decision based on an assessment of what is in their best interests), as otherwise this would either erode the boundary between state and private life completely — by permitting the decision-maker to intervene wherever they regarded the person's choice as misguided — or else simply create a new — lower — threshold for intervention, rendering the MCA superfluous. The powers must therefore be more circumscribed than this. There are two ways in which this could be achieved: either by placing substantive limits on the decisions that a person can make (for example, not permitting them to make decisions which is not in their best interests, or which would cause themselves significant harm), or by putting in place procedural requirements, such as demanding that they discuss their decision with someone else before it is legally binding.

Substantive limits would represent a vast interference with a person's autonomy. For the reasons given in Chapter 2, that a decision is not regarded as in a person's 'best interests' cannot be sufficient to justify interference with it. As explained above, there is not one objectively verifiable answer to the question of what is in a person's best interests, and people may legitimately reach different conclusions depending on how they balance the different interests at stake. Were this to act as the threshold for intervention therefore, this would allow the decision-maker to override *any* decision in which they disagreed with the person's prioritisation of values or balancing of interests, allowing any decision which they do not consider 'optimal' to be interfered with. A better threshold for intervention from a normative perspective, would therefore be where the person's actions expose themselves to significant harm, thus giving people a margin of discretion to balance interests differently, which yields only where the person is actively causing themselves significant harm. Even this however, would erode the boundary between a person's decisions and legitimate state intervention. Almost invariably in these cases, the doctor or carer wishes to intervene because they regard the person as doing something that is harmful, while the person either does not consider it to be so, or considers that harm to be outweighed by other benefits. The source of the disagreement is therefore precisely over whether the course of action proposed is more or less harmful than the alternative course of action. In these circumstances, permitting the doctor to apply a significant harm limit would not resolve the tension between autonomy and paternalism, but would merely re-frame the issue to focus instead on what constitutes 'significant harm' and who ought to be able to decide this.

The most comprehensive account of 'harm' can be found in the work of Joseph Feinberg, who acknowledges the 'vague and ambiguous' nature of the word 'harm',[661] which without further explanation, acts merely as a 'convenient abbreviation for a complicated statement that includes, among other things, moral judgments and value weightings of a variety of kinds'.[662] He distinguishes three different accounts of

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[661] J. Feinberg, Harm to Others: The Moral Limits of the Criminal Law Volume 1 (Oxford Scholarship Online, November 2003), 31.

[662] ibid, 32.

‘harm’, focussing on the latter two.[663] The first of these conceptualises harm as a ‘setback to interests’. According to this understanding ‘it is only when an interest is thwarted through an invasion by self or others, that its possessor is harmed in the legal sense’.[664] The test for whether this invasion has taken place, is ‘whether that interest is in a worse condition that it would otherwise have been had the invasion not occurred.’[665] His second meaning of the word harm (which relates closely to the first), views harm as a wrong to another.[666] A person wrongs another where his ‘unjustifiable or unexcusable’ conduct violates the rights of another[667] — which invariably will also involve an invasion of the person’s interests. While almost all harms in the second sense (‘wrongs’) will amount to harms in the first sense however (‘setbacks to interests’),[668] not all setbacks to interests will be wrongs: one might ‘invade another’s interests excusably or justifiably’, or thwart interests which the person ‘has no right to have respected’,[669] for example where the person has consented to the other’s actions. ‘Harm’ as understood in the harm principle espoused by Mill (above) therefore represents an overlap of these two senses of harm: ‘only setbacks of interests that are

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[663] The third account, which he describes as harm in a ‘derivative or extended sense’, he mentions only to dismiss: ibid, 32.

[664] ibid, 34.

[665] ibid.

[666] ibid.

[667] ibid.

[668] ibid, 35.

[669] ibid.

wrongs, and wrongs that are setbacks to interests, are to count as harms in the appropriate sense'.[670]

While the additional requirement that the person in some way wrongs another may be necessary when it comes to applying the harm principle (which concerns when a person ought to be prevented from interfering with another person), when describing a person's self-regarding actions (that is, when they are causing harm only to themselves), it makes little sense to talk of a person 'wronging' themselves by violating their own rights. Without this normative dimension to harm however, it is difficult to see how it (understood as a setback to interests) can form an appropriate threshold for intervening in a person's autonomous decisions. Any given person has a variety of interests, which differ in nature. Feinberg for example, distinguishes between a person's 'ulterior' interests — which encompasses their ultimate goals and aspirations[671] — and their 'welfare' interests, which include those interests

> in the continuance for a foreseeable interval of one's life, and the interests in one's own physical health and vigor, the integrity and normal functioning of one's body, the absence of absorbing pain and suffering or grotesque disfigurement, minimal intellectual acuity, emotional stability, the absence of groundless anxieties and resentments, the capacity to engage normally in social intercourse and to enjoy and maintain friendships, at least minimal income and financial security, a tolerable social and physical environment, and a certain amount of freedom from interference and coercion.[672]

In the cases being contemplated here — where a person requires a health or welfare intervention but are refusing it — the person's actions will invariably be thwarting some welfare interests, undermining their physical health and well-being in a way which, if substantial, could amount to significant harm. Yet they do so out of a

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[670] ibid, 36.

[671] ibid, 37.

[672] ibid.

conviction that this harm is outweighed by the need to protect other interests of theirs, which they, on balance, regard as more important. Where a Jehovah's Witness refuses a life-saving blood transfusion for example, they will certainly suffer harm to their health, but to act otherwise would be to thwart their ulterior interest in 'achieving spiritual grace'.[673] Whichever decision is made then, some interest will be thwarted and some harm will result —which is more harmful, however, will depend on how one values or prioritises the interests at stake. If it is for the individual to decide which outcome is more harmful to them, then a substantive limit would offer no protection to people from decisions that the decision-maker regards as harmful. Yet if the decision of what is more harmful rests with the decision-maker, then this would give them the power to override a person's decision wherever they disagreed with the way that the person balanced the harms or interests in question — thus amounting to little more than a best interests threshold. In a liberal society committed to value pluralism, people *must* be allowed to make decisions that others find incomprehensible — even repellent — providing they do not harm other people. That the decision-maker disagrees with how a person prioritises their values and interests cannot be sufficient to prevent that person from pursuing their own conception of what is best for them. This is powerfully illustrated by the *C & V* decision above. That she wished to refuse life-saving dialysis because of a fear of growing old, living without material possessions, and losing her 'sparkle' might seem objectionable to many, but she ought to be entitled to do so nonetheless.[674]

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[673] ibid.

[674] *C & V* (n193).

The very value in autonomy is, as Kymlicka explains, that it enables people to pursue values and commitments that *they* regard as important: it rarely benefits a person to force objective conceptions of what is valuable on them.[675] To override a person's decisions merely because another person disagrees with the way that the person has prioritised their interests, would undermine the value of autonomy entirely: it would permit an objective (or, in reality, an alarmingly subjective) assessment of what is best for the person to override their own assessment of what is good for them. As Chapter 2 explained, who can know better than the person whether it is best to pursue a course of chemotherapy which might prolong one's life, or feel much better in one's final months. The consequences of refusing this treatment would be undeniably harmful — but only the person can decide whether it is more harmful than the alternative. This would also then encroach upon their rights under Article 8 and Article 9, as many of the cases involve people refusing medical interventions for religious reasons.

Indeed, it may be precisely those decisions which have the most serious and potentially harmful consequences, which are the *least* susceptible to objective appraisal of what is 'best': there is no more deeply personal or intimate issue for example, than how the final moments of a person's life play out. To allow doctors to intervene where their decision exposes them to serious harm would thus deny people a say over those decisions which matter most to them, and in which they have the greatest claim to knowing what is best for them. Meanwhile they would be permitted to make choices which matter far less to them, and which are more susceptible to objectively being

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[675] Kymlicka (n71).

thought to be mistaken as the potential harms are less finely balanced (such as refusing minor treatment on a hand injury to prevent future loss of function).

Introducing substantive limits based on a risk of harm would also move the legal framework from one focussed on the person's capacity to make a particular decision, towards one premised on risk assessment. It is precisely this 'centrality of risk' in the MHA however (where intervention is justified by the need to protect oneself or others from a risk of harm), which has caused it to come under fire in recent years, condemned for being out of step with modern developments in our understanding of, and attitudes to, people with mental illness.[676] As John Fanning explains:

> While the MHA authorises the detention of a mentally disordered person on the basis of risk, no equivalent power exists for physical disorders. As Richardson has argued, there seems to be no justification for singling out mental disorders in this way. Many commentators have criticised the involuntary care and treatment of mental disorders as a crude historical anachronism alien to a modern liberal state. Furthermore, the United Nations Convention on the Rights of People with Disabilities (CRPD) casts doubt on the MHA's compatibility with the UK's international legal obligations. Ten years since the introduction of the MCA, the MHA looks increasingly like an outlier.[677]

Recent discussions on how to reform the MHA have focussed on moving away from a risk-based framework to one that places greater emphasis on individual autonomy, following Northern Ireland's lead,[678] where all treatment decisions (including for those with mental illnesses) are now made on the basis of the person's decision-making capacity. To move in the opposite direction with capacity legislation would thus seem a

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[676] See for example G Richardson, 'Balancing Autonomy and Risk: A Failure of Nerve in England and Wales' (2007) 30 Intl JL Psychiat 71, 73; G Szmukler and F Holloway, 'Reform of the Mental Health Act: Health or Safety?' (2000) 177 Brit J Psychiat 196, 198; T Campbell and C Heginbotham, *Mental Illness: Prejudice, Discrimination and the Law* (Dartmouth 1991) 7.

[677] J. Fanning, 'Continuities of Risk in the Era of the Mental Capacity Act' (2016) Med Law Review 24(3): 415–433, 416.

[678] Mental Capacity Act (Northern Ireland) 2016.

retrograde step. While the powers would be less far-reaching than under the MHA (in not providing for the continued detention of the person); and the harms in question often less speculative (they will eventuate without the doctor's intervention), a new framework premised on risk of harm is nonetheless likely to provoke considerable unease.

Accordingly, any qualification of the capacity cliff-edge must be procedural in nature, demanding the person to do more in certain circumstances for their decision to be legally binding, rather than preventing them from making certain decisions at all. There are other examples of the law putting in place procedural hurdles so as to ensure that the decisions are autonomous: decisions to marry, divorce or purchase property, for example, all entail extensive formalities, including mandatory waiting periods, witnessing and specific documentation. While there are, of course, pragmatic reasons for these formalities (ensuring the person is legally entitled to marry, or providing evidence that the contract occurred for example); they also play an important cautionary function, ensuring that the person is aware that they are making an important and legally binding decision, and placing a check on them doing so thoughtlessly or without due consideration.[679] Safeguards of this nature are too cumbersome for the medical context (given the urgency of decisions), but if they are accepted in other contexts as an important means of ensuring that the person has reflected on the consequences of their decision, this might lend support for some extra protections being warranted in the medical context, where the consequences are arguably even more grave.

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[679] L. Fuller, 'Consideration and Form' (1941) *Columbia Law Review*, Vol. 41(5), 799-824, 800.

This could be achieved through a supported decision-making or co-decision-making procedure, in which a person is appointed to support the individual in making decisions. These exist in a number of common law jurisdictions, most recently being introduced in Ireland. The Assisted Decision-Making (Ireland) Act 2015 provides three different levels of intervention depending on the person's level of capacity: a 'decision-making assistant' who helps the person to understand the information and express a choice which reflects their will and preferences; a 'co-decision-maker' who must make a decision jointly with the appointer if it is to be legally valid; and a decision-making 'representative' who makes a decision on the person's behalf where they are not capable of making a decision even with the assistance of others. There is not one absolute threshold for capacity then, but a series of 'grades', prompting different levels of support. It is in the middle 'grade' that a procedural limitation is put on the person: the co-decision-maker *must* be consulted for the decision to be binding. It is therefore their role to ensure that the person has understood the consequences of their decision, and reached one which best reflects their values and priorities.

The benefits of such a scheme will be considered in more detail in the following chapter. Suffice to say, however, that this would demand a wholesale change to the way that we conceptualise and approach not only the law on capacity, but also the relationship between the individual and the state. Under this model, the boundaries of legitimate state intervention become markedly less clear cut, as the state is accorded far greater powers to intervene in supposedly autonomous decisions. This undermines our commitment to Millian ideas that there ought to be a zone of decision-making free from state coercion.

Accordingly, the Law Commission proposed a less radical scheme, whereby a person could choose to formally appoint a trusted other person to assist in decision-making, similar to the 'decision-making assistant' under Irish legislation. This would be available to those who have capacity and those who lack it as

> there will be many people who retain formal capacity, who may nevertheless benefit from supported decision-making. Such people, if provided with support prior to or at a time when their capacity is beginning to falter, may be able to delay or avoid the need for substituted best-interests decision making.[680]

The functions of the supporter would be to

1) access, collect and obtain information relevant to the decision, or assist the person to do so;
2) explain the relevant information and considerations relating to a decision;
3) ascertain the will and preferences of the person and assist in communicating them;
4) assist the person to make and express a decision; and
5) endeavour to ensure that the person's decision is implemented.[681]

This goes some way towards softening the capacity cliff-edge (recognising that there are people who formally have capacity who might nonetheless benefit from some measure of support); while retaining the notion of capacity as a threshold – which is essential to defining the limits of legitimate state interference. Being voluntary, it also does not amount to such a large encroachment into the private sphere.

Many of the doctors interviewed, while not in principle opposed to the idea, nonetheless raised concerns about the interface between this and other capacity 'roles': Lasting Power of Attorneys (LPA), Independent Mental Capacity Advocates (IMCA), and Care Act advocates (whose role is to assist the person in making decisions about their care and support arrangements). There were fears that introducing an additional role could create confusion, and that the involvement of a further person would make the decision-making process even more slow and burdensome. Others thought the

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[680] Law Commission, Consultation Paper (n424)*,* 12.15

[681] ibid, 12.21

existing roles were sufficient (and thus a new one would be unnecessary), or thought they could be expanded to include this responsibility, as opposed to a whole new role being created.

Their views very much echoed the responses received by the Law Commission in their consultation.[682] Although it would, as they suggested, be possible to set out clearly in the Code of Practice what each respective role entailed,[683] accommodating these duties within the role of the LPA would seem a more workable solution, enhancing the appointment process, take-up and execution of the role. Completing and registering an LPA is already administratively burdensome and costly, and appointing a supporter is likely to be similarly bureaucratic. To be able to appoint both at once would therefore streamline the process, reducing time and costs for both appointer and administrator. It might also facilitate take-up: as of 2014, there were only 261,331 live LPAs for health and welfare,[684] and it is reasonable to suppose that take-up of supporters will not be greater. Amalgamating the roles would not only reduce costs and effort, but would arguably make both more worthwhile, as the remit of the LPA would become greater. It would also seem more practical, given that many people would in any case appoint the same person for both roles, given the level of trust and confidence these positions demand.

Treating them as one role (or at least providing the option to do so), would also avoid tension and disagreement between different actors, and confusion about where

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[682] Law Commission, Consultation Analysis (n15), 14.49.

[683] ibid, 14.53.

[684] Ministry of Justice response to a Freedom of Information request. Available at <https://www.gov.uk/government/uploads/.../lasting-power-of-attorney-for-health.doc> accessed 30/09/18.

the role of supporter ends, and attorney begins (that is, the question of when the switch from attempting to support them to come to their own decision, to making a decision on their behalf, occurs). The role of the attorney is then to support the person as far as possible to come to their own decision, and then only if they cannot, to make an assessment of what is in their best interests, based on discussions with the person about the decision. In doing so, it also prevents a duplication of efforts by the attorney/ supporter, since they are not both required to familiarise themselves with the nature of the decision that has to be made, and the person's views in respect of it. This would surely help to assuage the concern that introducing another person into the process might slow down decisions yet further.

Often families already do this informally, helping the person (especially if elderly) to engage with the decision they have to make, and to express a view on it. There is nonetheless value in placing this duty on a particular person who takes responsibility for it (and on a person other than an already overstretched doctor), and in defining more clearly the duties incumbent on them. Its role in softening the capacity cliff-edge is necessarily limited: it does not provide a mechanism for overriding the decision that is made (with support). But it does recognise that there will be people who, while still able to make a decision, may nonetheless benefit from some support in making the decision which best reflects their essential values. This would seem to strike a more appropriate balance between empowering and protecting people in such decisions.

While according decision-makers greater power to interfere with the decisions of people who have capacity cannot then be supported, it must be remembered that section 5 MCA provides a defence for doctors who reasonably believe that the person lacks capacity and intervene accordingly, thus protecting them from liability for their actions should they (reasonably) intervene in such cases.

Fears about legal liability

While section 5 provides doctors with a broad defence to battery should they wrongly find the person to lack capacity, it does not offer any protection to doctors who wrongly regard the patient as *having* capacity and consequently respect their refusal of treatment. Consequently, evidence suggests that doctors, fearful of the legal consequences of failing to treat the patient, instead opt to deem the person incapacitous and treat them in their best interests (under the protections of section 5), rather than risk not treating them and facing a charge of negligence or gross negligence manslaughter. If doctors are to no longer operate a bias in favour of over- rather than under-treating therefore, it is important to consider whether the law in this area ought to be amended so as not to encourage doctors fearful of legal liability to find the person to lack capacity.

Despite doctors' concerns, the bar for showing that a healthcare professional was negligent is high. Following *Bolam v Friern HMC*,[685] a doctor will not be negligent providing 'he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular art.'[686] This was qualified to a small extent in *Bolitho* v. *City and Hackney H.A,*[687] to include that that body of

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[685] [1957] 1 WLR 582.

[686] ibid, 587.

[687] [1998] A.C. 232.

opinion must have a logical basis'.[688] Nevertheless, to show that the doctor did not breach their duty of care, they need only adduce evidence that other doctors would also not have deemed the evidence sufficient to rebut the presumption of capacity. Given the clear bias in favour of preventing harm, it is unlikely that a doctor would find a person to *have* capacity without having examined them in detail, or got a second opinion. Successful negligence suits will therefore be rare – even more so in the emergency context, where the standard of care is relaxed to take account of the exigencies of the circumstances.[689] It is only where no reasonable body of medical opinion would act as the doctor did, that they ought to be found guilty of negligence. Given this, greater protection for doctors would not be desirable. To lower the standard any more, would effectively insulate doctors from liability for anything short of sheer recklessness. This would demand an exceptionally low standard of care by doctors, with clear implications for public safety and confidence in the public health system.

Moreover as the spread of '*Bolam*' illustrates all too well, any changes to this area of law are unlikely to be restricted to capacity assessments alone. Despite the very particular context in which the standard articulated above was introduced (where a decision required specific technical expertise not shared by the judge[690]), it has since

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[688] ibid, 242.

[689] *Jones v Boyce* [[1816] 171 ER 540.

[690] *Bolam* concerned a patient who suffered a fracture as a result of not being given a relaxant drug while undergoing electro convulsive therapy. At the time, there was divided opinion among medical professionals about whether or not the drugs ought to be given to patients, given that they produced a small risk of death, which explained the decision of the House of Lords that a doctor should not be found to ne negligent *merely* because there was a body of medical opinion who would take a contrary view of what was clinically the best. The logic behind this was explained by the House of Lords in *Maynard v West Midlands Regional Health Authority* ([1985] 1 All ER 635): the nature of professional services involves the exercise of skill, and the possession of a body of knowledge, which is not shared by the public at large or by the judge, even more so where practice is evolving rapidly as in a new specialty, or where exceptionally complex scientific or technical issues are moot. A judge is therefore not in a position to choose between the view of competing medical expert opinions, and so as long as there is a

been applied far beyond that, including in the context of information disclosure[691] and best interest decision-making.[692] Changes to negligence law in the capacity context would thus likely percolate through medical negligence, to the dismay of those who already regard *Bolam* as indicative of courts 'abdicat[ing] responsibility for defining and enforcing patients' rights';[693] and going against the clear movement away from this towards a more patient-centred approach, illustrated in *Montgomery.*[694]

The bar for gross negligence manslaughter meanwhile, is even higher. While the recent case of Dr Hadiza Bawa-Garba[695] has provoked considerable concern amongst doctors about the possibility of such a conviction, in fact the attention and controversy it has generated demonstrates just how rare it is for a doctor acting within the normal course of their duties to be found guilty of this crime. Not only must the doctor be found to have breached their duty of care, causing the death of the victim, but that breach must be regarded by a jury as 'so gross as to justify a criminal

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competent school of thought that believed the defendant's actions were reasonable the judge will find the defendant not to have been negligent.

[691] *Sidaway v. Board of Governors of the Bethlem Royal Hospital* [1985] AC 871. This has now be rolled back on in *Montgomery v Lanarkshire Health Board* (2015) UKSC 11.

[692] *Re F* (n19).

[693] M. Brazier and J. Miola, 'Bye-Bye Bolam: A Medical Litigation Revolution' (2000) Medical Law Review 8, 85-114, 85.

[694] *Montgomery* (n103).

[695] Dr Hadiza Bawa-Garba was convicted of manslaughter by gross negligence in 2015, following the death of Jack Adcock. The appeal was recently rejected by the Court of Appeal: B*awa-Garba v R* [2016] EWCA Crim 1841. For an example of the reaction this case received within the medical community, see: https://www.independent.co.uk/news/health/hadiza-bawagarba-jack-adcock-death-gmc-junior-doctor-registrar-legal-case-a8184966.html <accessed 12th April 2018>.

conviction'.[696] In *R v Adomako* for example*,* an anaesthetist failed to notice for 6 minutes during an operation that the tube supplying oxygen to his patient had become disconnected, despite obvious signs of this.[697] In *R. v Misra and Srivastava* meanwhile,[698] two doctors failed to diagnose an infection in the wound of a post-operative patient despite visible signs, which over a series of *days* resulted in him suffering from toxic shock syndrome and dying. Both cases are a far cry from a doctor conscientiously assessing a person's capacity, but ultimately concluding that there is insufficient evidence to rebut the presumption.

This is clearly illustrated by the case of Kerrie Wooltorton,[699] who was admitted to hospital having taken a life-threatening dose of ethylene glycol (anti-freeze). She suffered from depression and had overdosed no fewer than nine times in the previous year (accepting treatment on each occasion). Three days previously she wrote a note refusing any life-saving treatment and explaining that if she drank poison and called an ambulance, it was only because she wished not to die alone and in pain. Having sought a second opinion and legal advice, the treating clinician assessed her to have capacity and respected her wishes, with the result that she died the following day. He later said of the decision:

> I would have been breaking the law and.,. I think she would have asked, 'What do I have to do to tell you what my wishes are?'…It's a horrible thing to have to do but I felt I had no alternative but to go with her wishes. Nobody wants to let a young lady die.

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[696] *R v Adomako* [1995] 1 AC 171.

[697] ibid.

[698] [2004] EWCA Crim 2375.

[699] See for example P. Szawarski, 'Classic cases revisited: the suicide of Kerrie Wooltorton' (2013) *The Intensive Care Society*, available at < http://journals.sagepub.com/doi/pdf/10.1177/175114371301400307> accessed 8th August.

That Dr Heaton was correct to act as he did was emphasised by the coroner at the inquest, who noted that ‘a deliberate decision to die may appear repugnant, but any treatment to have saved Kerrie's life in the absence of her consent would have been unlawful.’[700]

While this decision ought to give clinicians confidence that a carefully-considered capacity assessment is unlikely to lead to negligence charges, it also illustrates the width of the gap between the perceptions of doctors and legal reality. Three doctors raised this case during the interviews and expressed doubts over whether the doctor was correct to uphold her refusal. One said:

> With the benefit of hindsight, I think that most clinicians would not have made that decision because there's no way that just because someone has a piece of paper that doesn't mean that it was written in a capacitated state. So, I suspect that most doctors wouldn't make that same assessment of that case.[701]

While another suggested:

> Within the medical community, I think there are still divided opinions about what people would have done. I think the easiest option is always to treat because it's not just you're going down one pathway that everybody agrees with.[702]

The third, while not condemning Dr Heaton’s actions, nonetheless suggested that that ‘it was bold of them not to section’ Ms Wooltorton. Notwithstanding the coroner’s affirmation then, concerns remain about acting in this way. So even if, in reality, claims in negligence are likely to be rare, the fear of such claims clearly troubles clinicians.

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[700] See <http://news.bbc.co.uk/1/hi/england/norfolk/8284728.stm> accessed 8th August 2018.

[701] Interview [anonymised] (Oxford, March 2017).

[702] Interview [anonymised] (Oxford, March 2017).

One particular concern raised in response to the *Bawa-Garba* case — which formed part of her challenge before the Court of Appeal[703] — was the way in which the decision singled out the actions of the doctor, while minimising the role of the wider systemic problems that had contributed to the death. In allowing Bawa-Garba's appeal against the decision of the High Court to remove her from the Medical Register, the Court noted that:

> as was made clear in both the summing up and the sentencing remarks of Nicol J, systemic failures on the part of the Trust were only ever of peripheral relevance to the guilt or absence of guilt of Dr Bawa-Garba for gross negligence manslaughter.[704]

Given concerns in both the healthcare and social work context, that time-pressures, staff shortages and huge patient numbers are all culminating in less robust capacity assessments,[705] this only exacerbates fears. Greater clarification on the influence of broader systemic failures on medical negligence claims would therefore be welcomed. Beyond this, however, fears about negligence liability are better addressed through improving doctors' understanding of the high bar to proving negligence, than through any changes to the law.

IV Conclusions

A number of suggestions have been put forward in this and the preceding chapter, aimed at helping to improve the consistency with which the test for capacity is applied, and the accuracy with which it is able to assess whether or not a person is capable of

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[703] [2018] EWCA Civ 1879.

[704] ibid, [74].

[705] See Chapter I, Section II(b).

making an autonomous decision. These include far greater guidance for decision-makers on the nature of different types of impairment, on what the ‘relevant information’ is that the patient ought to understand for different treatments, and on the breadth of section 2 MCA. It has also been suggested that the Law Commission’s proposals to introduce ‘supporters’ ought to be adopted, albeit that this should form part of the role of the LPA.

However, given the nature of making decisions in this area, and the need to leave each decision-maker to determine whether the person’s impairment is severe enough to rebut the presumption of capacity, substantial discretion will inevitably be left in the hands of the decision-maker: no capacity assessments will ever be entirely robust, and there will always be some variation in the way that decision-makers accommodate the many different factors and considerations inherent in any assessment. There will also always be the risk that they will be influenced by the outcome of the decision, and the harm that may result from it. Given this, there is reason to question whether the current approach to people who lack capacity, which as seen in chapter 2, has been dominated by risk-aversion and a ‘doctor knows best’ mentality, can really be maintained. Chapter 5 will therefore consider how the law might be reformed to better reflect the inevitable ambiguity which surrounds assessments on the cusp of capacity.

V Softening the capacity 'cliff-edge'

The proposals put forward in the previous chapter could substantially improve the clarity, consistency and transparency with which capacity assessments are made, giving both decision-maker and patient more faith that they are accurately distinguishing those who are capable of autonomous decision-making from those who are not. However, any test that relies on a threshold will always face difficulties at the margins, and a substantial 'grey area' will remain on the cusp of capacity. This is heightened by the discretion that is left to the decision-maker to determine how 'grave' the impairment must be before it rebuts the presumption of capacity, especially since this is often exercised against the backdrop that the only way of preventing the person from causing harm to themselves is for the decision-maker to rebut the presumption and find them to lack capacity.

This inevitable ambiguity must then be reflected in the way that the law responds to a finding of incapacity: as Herring observes, the wishes of the incompetent person should not be treated as though they are 'no more than the grunts of an animal'.[706] There are many people with clearly and strongly held wishes and feelings, who are perfectly able to appreciate the effects of a decision on them, and to feel distress at having their wishes frustrated. Moreover, if it is accepted that there is a second dimension to autonomy concerned with the authenticity of the person's values and beliefs (and which exists independently of the person's capacity to reason in accordance with those values), it follows that there will be a number of people who, while not necessarily able to make decisions which protect their interests or which

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[706] J. Herring, 'Losing it? Losing What? The law and dementia' [2009] *Child and Family Law* Quarterly 3, 14.

reflect their beliefs and priorities, nonetheless still have deeply held values and beliefs that are profoundly important to them, which ought to continue to guide the decisions made about them when they lose capacity.

Chapter 2 suggested that this is not reflected in the way that the law on best interests is currently framed. By making the person's wishes just one factor among many that must be considered in any determination, doctors and care-workers are not provided with any guidance or support to make decisions which prioritise the person's wishes. The result is that the capacity cliff-edge is operating extremely harshly in some cases, most notably in some of the care decisions discussed in Chapter 2 where the wishes of the individual are frequently being overridden by decision-makers. Even in the courts, decisions such as in *A Local Authority v E*[707] suggest in the absence of guidance, the most clear and unequivocal wishes of a person on the cusp of capacity may be outweighed by other factors. Any reforms to the law must therefore provide both greater guidance on how to apply the best interests test; and greater support to enable practitioners to feel secure in prioritising the wishes and feelings of the individual even in the face of risks of harm.

This chapter will therefore consider ways to address these concerns. The starting point is that there ought to be a presumption that the person's wishes and feelings are determinative of what is in their best interests, except where giving effect to them will expose the person to a serious risk of significant harm. However, even where the harms are significant, it might still be right to prioritise the person's wishes and feelings in circumstances where they reflect deeply and strongly held beliefs, values or commitments. Accordingly, this chapter will propose an amendment which

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[707] *E* (n24).

captures the fact that the weight accorded to the person’s wishes ought to be proportionate to the strength of those wishes, given that this will affect the psychological and emotional harm of frustrating them. This will be supported by a non-exhaustive list of factors that will help to identify where these circumstances arise. These reforms will be augmented by an amendment to section 5 of the MCA so as to provide decision-makers with a defence to battery only in circumstances where the intervention was necessary to prevent significant harm. The hope is that through these reforms, decision-makers will have the flak jacket they need to feel able to withhold treatment or care from refusing patients.

I A rebuttable presumption in favour of giving effect to the person’s wishes and feelings

The idea of a ‘rebuttable presumption that the reasonably ascertainable will and preferences of [a] person should be given effect to’,[708] originated in the work of the Essex Autonomy Project (EAP). This, they considered, would stand in the ‘vast majority of cases’, but it would not be absolute, and ‘in some exceptional circumstances, a proportional and effective strategy for protecting the full range of the person’s fundamental rights, freedoms and interests may require action contrary to the person’s known will and preferences.’[709] In the consultation that followed, the EAP found there to be ‘considerable support’ for such a presumption, subject to concerns by some that it was unnecessary, and by others that it did not go far enough in articulating the standard under which the presumption would rebutted.

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[708] W. Martin et al, ‘Achieving CRPD Compliance’ Essex Autonomy Project (22/09/14), available at <https://autonomy.essex.ac.uk/wp-content/uploads/2017/01/EAP-Position-Paper-FINAL.pdf>, 41.

[709] ibid.

Similar problems afflicted the recent proposals put forward by the Law Commission. In its Consultation Paper, it likewise proposed 'an assumption that the person's wishes and feelings are determinative as to their best interests, although this assumption could be overridden where there are good reasons to do so'.[710] While this gained the support of the majority of people who responded to the consultation (of the 182 consultees who expressed a view on this proposal, 119 agreed, 35 disagreed and 28 held equivocal positions[711]), criticism remained, echoing concerns raised in the EAP consultation that section 4 was sufficient without the need to resort to any such presumption. Mr Justice Charles for example, suggested that the proposal was 'unnecessary and would cause considerable complications when [P's wishes and feelings] have varied over time or cannot be met in practice'[712] a view supported by the Bar Council[713] and Peter Jackson J, who in *Wye Valley* stated that:

> To elevate one important factor at the expense of others would certainly not have helped the parties, nor the court, in the present case. All that is needed to protect the rights of the individual is to properly apply the [Mental Capacity Act] as it stands.[714]

However, it is doubtful whether the MCA as it stands *is* sufficient, as Chapter 2 makes clear. The lack of guidance over how section 4 ought to be applied means that it is perfectly possible to 'properly apply' the MCA (at least on the face of the statute), while still giving very little weight to the person's wishes. This was picked up on by

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[710] Law Commission, Consultation Paper (n424), 12.45.

[711] Law Commission, Consultation Analysis (n15), 11.20.

[712] ibid, 11.34.

[713] ibid, 11.38.

[714] *Wye Valley* (n7), [17].

Lucy Series, who suggested that one could be 'diligently following the best interests checklist', and yet balance the person's interests in an entirely different way to Peter Jackson J.[715] The Law Commission agreed.[716]

Even if one accepts the need for reform, however, neither the Law Commission nor the EAP's proposals set out very clearly when the presumption will be displaced. As Peter Jackson J noted in *Wye Valley* (supported by other judges of the family division[717]):

> the Law Commission proposal would not lead to greater certainty, but to a debate about whether there was or was not *"good reason"* for a departure from the assumption.[718]

The Law Commission responded saying that while the proposal would prompt debate,

> this would not be a wholly undesirable outcome. Best interests determinations will inevitably provoke debate and this focus would be a step forward from the current focus of debate on whether *any* weight should be given to wishes and feelings at all (which the current wording of section 4 necessitates).[719]

A similar response had been given by the Essex Autonomy Project, when the same criticism was made of their proposals:

> Any just and reasonable system of law adequate to the practical challenges of this domain of practice will lead to debates. The aim should not be to avoid debate, but to

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[715] Law Commission, Consultation Analysis (n15), 11.37.

[716] Law Commission, Consultation Paper (n424)*,* 14.11.

[717] Law Commission, Consultation Analysis (n15), 11.35: this would 'simply lead to debate about whether there is 'good reason' to depart from the assumption and would not produce better outcomes in these difficult cases'.

[718] *Wye Valley* (n7).

[719] Law Commission, Consultation Paper (n424)*,* 14.13

> establish a framework for having the debate in terms that are respectful of the rights, will and preferences of persons with impaired capacity.[720]

A presumption would certainly move the debate on from one focussed on what *degree of weight* ought to be accorded to the person's wishes, to one instead centred on why it is *not possible* to give effect to a person's wishes. It would also enhance transparency, requiring the decision-maker to be explicit about exactly why it is that they are not prioritising the person's wishes, in a way that is markedly absent from some of the cases under the current law, such as *RB.*[721]

However, a presumption cannot be accepted in the form proposed either by the Law Commission or by the Essex Autonomy Project. From a practical perspective, neither would provide the clarity and support that decision-makers require in order to feel comfortable prioritising the person's wishes: they would be left guessing over how courts might interpret 'good reasons' or 'exceptional circumstances' in any challenge brought against them. After all, there is arguably 'good reason' to intervene wherever a person's welfare might be adversely affected by their decision, but if this were the case, the assumption would never hold.

Even without reference to these practical concerns however, the failure to elucidate what amounts to 'good reasons' fails to provide a clear normative basis for why the court is justified in overriding the individual's assessment of what is best for them in certain instances, but not in others. This ambiguity also raises doubts over whether this reform would improve compatibility with Article 8 ECHR, since whether

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[720] Essex Autonomy Project, Achieving CRPD Compliance (n676).

[721] *RB* (n407).

the intervention is ‘necessary and proportionate’ would depend entirely on how broadly ‘good reasons’ is construed.

Although the Law Commission dropped their proposal for a rebuttable presumption that the person’s wishes be given effect to in their final report, the reasons given for this focussed on their remit, rather than raising any principled objections to the idea:

> Whilst we were attracted by the idea of a rebuttable presumption, we do not consider this would fit into the structure of section 4. The requirements of section 4 are largely procedural. Logically, the introduction of a duty to make wishes and feelings generally determinative would require the amendment of section 1 (not section 4), in order to give them a higher status than best interests. However, we did not consult on this and such a reform would be far beyond our remit.[722]

Therefore, a rebuttable presumption may well remain the best way to address concerns over section 4, albeit that it would need to accommodate the objection that ‘good reasons’ does not provide sufficient clarity over when that presumption will be rebutted. This clearly needs to be addressed.

II Modifying the presumption: a serious risk of significant harm

When determining what is in a person’s best interests, it is not only their physical interests which must be taken into account, but also their psychological, emotional and relational interests.[723] As Hale LJ (as she then was) said in *R (Wilkinson) v Broadmoor Special Hospital Authority*,[724] ‘most people are able to appreciate that they are being

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[722] Law Commission, *Mental Capacity and Deprivation of Liberty* (Law Com No 372), 13th March 2017, 14.4.

[723] This was emphasised by Lady Hale in *Aintree v James* (n18).

[724] [2002] 1 W.L.R. 419.

forced to do something against their will even if they are not able to make the decision that it should or should not be done'.[725] Deciding contrary to a person's strongly held values or desires may not only result in a decision which arguably is not 'best' for them at all, but might also have huge psychological and emotional consequences for that person, causing them to feel profoundly disempowered and even objectified. This is especially so where the treatment in question is invasive, as in surgery, where the process of restraining, anaesthetising and then operating on a person constitutes the gravest of infringements to their bodily integrity, which as well as frustrating their autonomy, is likely to cause significant trauma and distress for the person involved.

This is acknowledged by judges and doctors, who have both suggested that they would be less likely to act contrary to the person's wishes where the proposed treatment was invasive. When listing factors which would influence the weight given to the individual's wishes in *M v Mrs N* for example, Hayden J referred to 'the nature of the contemplated treatment' and 'how intrusive such treatment might be',[726] a view he reiterated in *QZ* when he distinguished *Wye Valley* on the grounds of the 'relatively minor level of intrusion involved' in the case at hand.[727] In the interviews meanwhile, there was near consensus on this issue: where patients were objecting to surgery, it was very rarely regarded as being in their best interests to perform it regardless. This was especially so if the surgery was not being required in an emergency situation, or was not necessary to save the person's life. One doctor for example, described forcing

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[725] ibid, [79].

[726] *M v N* (n382), [28]

[727] *Q* (n400).

someone to have non-emergency, non-lifesaving treatment as ‘very hard to justify’;[728] while another suggested the situation would have to be ‘pretty extreme’ where ‘bodily integrity is compromised’.[729] Surgery can be particularly intrusive given that, as many doctors pointed out, the consequences may also be ongoing, as surgery often demands substantial aftercare and physiotherapy. This will therefore be even more of an affront to a patient who resisted the surgery in the first place.

As Feinberg observes, not all desires, if frustrated, give rise to harm: people are commonly left disappointed or dissatisfied without suffering harm, because generally the person’s interests is in securing (or avoiding) the outcome itself, rather than the consequential state of mind.[730] He explains that

> some of our most intense desires then are not of the appropriate kind to ground ulterior interests since (like a sudden craving for an ice cream cone) they are unlinked to our longer-range purposes, or they are insufficiently stable and durable to represent an investment of a stake.[731]

When then, will a desire for something give rise to an interest in some outcome? While being careful not to characterise these as necessary criteria, Feinberg identifies three common hallmarks of when a desire will amount to interest.[732] The first is that it is generally associated with a realistic hope or expectation:[733] one is not harmed by not being able to go to Mars or win the lottery, for example. The second is that the person

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[728] Interview [anonymised] (Oxford, May 2017).

[729] Interview [anonymised] (Oxford, July 2017).

[730] Feinberg (n661), 43.

[731] ibid.

[732] ibid, 44.

[733] ibid.

must want the outcome, at least in part, for its own sake, and not purely for the advancement of other, pre-existing interests (such as making money to further other desires that they have).[734] The third common hallmark is that if it is an ultimate interest, it ought to be capable of promotion by human efforts — there must be ways in which the person can help that goal to be achieved. It is this relationship with personal effort that in Feinberg's view 'converts a mere want into an objective',[735] by creating the necessary investment to give rise to a stake in the outcome.[736] The desire to refuse a treatment or care intervention — whether in pursuit of a good death, religious salvation or merely being free from excessive interference — clearly exhibits all three of these hallmarks. Clearly then, forcing treatment or care on a person in this way would be harmful, thwarting the person's interests in their bodily and psychological integrity, liberty, and freedom from coercion.

Given this, for any such treatment or care-decision to be regarded as in the 'best interests' of a patient, the harm to them that will result from giving effect to their wishes (whether to refuse treatment, or return to an unsafe lifestyle) must be *sufficient* to outweigh the clear emotional and psychological harms of frustrating them. In other words, to be the decision which best promotes a person's interests, it must be the least harmful of the options available. While there will be situations where the person may be ambivalent about what happens to them, usually, unless the harm of giving effect to a person's wishes is *significant*, this will be outweighed by the psychological harm of overriding their wishes. In the example given above of a woman refusing treatment for

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[734] ibid.

[735] ibid.

[736] ibid.

a tendon injury, while this may be a poor decision which she may well later regret, as the harm to her is not substantial (it will result only in slightly diminished function later in life), it cannot justify anaesthetising her and performing surgery against her will. The injury then, would have to be markedly more grave, for non-intervention to be more damaging that the psychological effects of belittling and frustrating the person in this way. This is also true of care decisions: the risk of an elderly person falling and suffering a physical injury must, for example, be weighed against the feelings that they have lost their independence, routine, home comforts, and the potential depression that could result from removing someone from their home.

Accordingly, it should be presumed that a person's wishes are determinative of what is in their best interests *unless* giving effect to these would result in the person suffering (or being exposed to a serious risk of) significant harm — understood as a serious setback to the person's interests. Where giving effect to their wishes would not expose the person to a serious risk of significant harm (such as in the tendon injury example, where the setback would be relatively minor), no further balancing exercise is required by the decision-maker: the person's wishes will be respected. It is only if the presumption is displaced (for example, the person would suffer serious injury or death if their wishes are respected), that the decision-maker will then have to engage in a balancing of the respective harms, weighing the consequences of giving effect to the person's wishes against the consequences of frustrating them. (This will be considered further in Section III.)

Of course, this presumption must be seen against the background position that there is no legal obligation for doctors to provide any treatment that they do not consider to be clinically indicated and so even if the person *requests* treatment which is not harmful to them, the doctor is under no duty to provide it — a position made clear in *NHS v VT & Anor*.[737] Therefore, in the medical context in practice this approach only changes the position in respect of treatment refusals.

A similar idea has been put forward by Emily Jackson in the context of refusing medical treatments. She suggests that there ought to be a presumption that 'if [the patient] wishes to refuse a medical intervention, [their] refusal should be respected, unless to do so would result in significant harm to [them].'[738] Jackson appears to suggest that the presumption should be rebuttable if the circumstances so justify, but it has been argued above that the presumption should be determinative (as it only applies when significant harm, or a serious risk thereof, is not at stake). Further, this presumption ought to apply to treatment and care decisions across the board however — albeit that it is certainly easier to apply to treatment refusals than to care decisions. In the medical context, the harms are often clear and immediate (i.e. if the person is not given treatment for their overdose or blood loss they will quickly die). In care decisions, by contrast, the harms are more speculative: the person who insists on living independently, even though she is frail, *could* fall over and break her hip, or leave the gas ring on, or forget to take her medication — but equally, none of these things might happen. For this reason, the question must be whether respecting the person's wishes would put them at a *serious risk of* significant harm. That means both that the risk of harm occurring should be substantial *and,* that if it does occur, that the harm will be significant. These changes would not act as a bar to people being placed into cared-for environment against their wishes, but they would place the onus on any care-worker or local authority who sought to do so, to provide strong evidence that the person was at

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[737] [2013] EWHC B26 (Fam).

[738] Jackson (n4), 257.

serious risk in their home, rather than merely asserting that leaving their home would be 'better for them'. This would make it very difficult for behaviour such as that seen in *Essex County Council v RF*[739] or *Hillingdon LB v Neary*[740] to be replicated.

One concern that may be raised is that this proposal nonetheless leaves it to each decision-maker to determine whether something is harmful, and whether that harm is 'significant'. This may be problematic in two respects: firstly, as Chapter 2 made clear, in order to feel empowered to make decisions which prioritise the person's wishes, decision-makers need clarity about when the presumption will be rebutted, and confidence in how courts will later interpret the provisions; and secondly because if this is understood and applied differently by different decision-makers, then this raises further concerns about the consistency with which the law is being applied.

Significant harm is an inherently relative concept: it must be significant relative to something. However it is possible to adopt a more objective understanding of significant harm if it is understood as being relative not to the opposing harms (i.e. the harms of not giving effect to a person's wishes), but relative to the person's previous condition. As noted above, Feinberg's test for when a person has suffered harm is whether their interest is in a worse condition than it would have been had the invasion not occurred at all.[741] For the harm to be significant therefore, the interest must be in a *substantially* worse condition, for example the person's prior capabilities must be seriously impaired. It is only *once the presumption has been displaced* (i.e. where the harm is thought to be significant), that the decision-maker must then weigh the harms

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[739] *RF* (n455).

[740] *Neary* (n450).

[741] Feinberg (n661), 34.

of giving effect to the person's wishes against harms of frustrating the person's wishes, in order to determine which course of action is in the person's best interests.

The relative harmfulness of doing or not doing what the person wants should not therefore be considered as part of determining whether giving effect to their wishes would cause 'significant' harm. Otherwise, far from helping to resolve the question of what is best for the person, applying the presumption would merely descend into a discussion about whether the person's wishes are rightly regarded as harmful at all, when seen relative to the consequences of not giving effect to them. Taking the example of a Jehovah's Witness refusing a blood transfusion, if the question of whether giving effect to their wishes amounted to 'significant harm' was answered relative to the harms of not doing so, then a dispute would instantly arise between the decision-maker (who would undoubtedly regard it as harmful — the person will die), and the individual (who would deem the opposing harm — eternal damnation — to outweigh this). This would introduce substantial subjectivity into the assessment, and undermine its conceptual clarity. If, by contrast it is only relative to the affect it has on the person's life, then agreement could be reached over whether it amounts to significant harm.

To facilitate greater consensus over this question, the Act could provide indicators of what might amount to significant harm, similar to in the Northern Ireland Act (see section 'IV' below). This might include actions which are likely to cause death; serious injury to, or deterioration in, the person's physical or mental health; or if it significantly reduces the options they will have available to them in the future. In many cases, there is likely to be a high degree of consensus over these issues: no-one would dispute that death, or something seriously and permanently disabling does not amount to significant harm.

However, there will undoubtedly be some borderline cases where disagreement will arise over whether something constitutes a 'serious' injury or deterioration in the person's health (as has been the case in other areas of the law where a disability or injury is required to be serious or significant[742]). This might be the case for example, where something is not life-threatening or grossly debilitating, but it would cause someone substantial pain (for example a large kidney stone), or reduce their future mobility (such as refusing a hip replacement). Even within this, while significant pain or suffering invariably amounts to significant harm,[743] there will be a grey area between this and say, refusing surgery for arthritic joints, which may cause some pain and discomfort, but we might not regard it as *significantly* harmful. While disputes will arise at the margins, this would at least make it incumbent upon the decision-maker to show why the person's wishes amounted to significant harm — a determination which would then be open to challenge if the patient disagreed.[744]

Although writing in the context of decisions about children, Douglas Diekema has further suggested that clinicians understand the concept of 'harm' much better than they understand 'best interests'.[745] While this was not explicitly examined in the

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[742] See for example *Jepson v The Chief Constable of West Mercia Police Constabulary* [2003] EWHC 3318, where a judicial review challenge was mounted against the decision of the police not to prosecute a doctor who carried out an abortion under s1(1)(d) of the Abortion Act 1967, which permits an abortion if there "is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped". It was argued by the appellants that a cleft palate and lip could not amount to a "serious handicap" under the act.

[743] As Joseph Feinberg notes (n661), 'when a given condition becomes extremely painful.. it does interfere with the pursuit of various goals and objectives, and that incapacitating effect renders it harmful' (p47).

[744] Where the issue is one of resources (as in *Re LC* [2015] EWCOP 25), this can also be accounted for in a significant harm framework: the question is whether *in light of the resources available to care* the person, they would be at risk of significant harm if, for example, left in their own home.

[745] D. Diekema, 'Parental refusals of medical treatment: the harm principle as threshold for state

interviews, doctors frequently cited what they saw as their fundamental responsibilities — 'avoiding harm', 'relieving suffering', or 'saving life', and there was a high degree of consensus when faced with the vignettes over what constituted a 'negative' or 'harmful' outcome. This suggests it might be easier to gain some consensus over whether something is 'harmful' (a negative value) than over what is best for a person (a positive). Doctors also appeared to intuitively grapple with the seriousness of the harm to the person, for example giving greater weight to the person's wishes where the psychological harms would be greater (such as where the treatment is incredibly invasive, such as surgery (above)), and less where the physical harms would be greater (as in life-saving situations).

Perhaps most importantly, the concept of significant harm is also used successfully in other contexts, and is something with which social and care workers are already familiar. Section 31 of the Children Act 1989 prevents a court from making a public law order placing a child in the care of, or under the supervision of, a local authority, unless the court is satisfied that the child is suffering or is likely to suffer significant harm. Social and care workers are thus used to applying this standard, in particular when determining whether a child should remain at home under the care of their family or instead be placed into care. It would not, therefore, seem to be a significant step to apply the same test in relation to whether a person with learning disabilities, brain damage or dementia should be permitted to remain in their own home or under the care of their family, or be moved into a cared-for environment: in both instances, their home environment presents various risks to the individual and the potential for sub-optimal (or neglectful) care, and the question is whether these are

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intervention' [2004] 25(4) Theoretical Medicine 243-64.

serious enough to justify moving them. Given that the Children Act was intended to stop the over-zealous actions of local authorities in too-readily removing children from their families, introducing similar requirements for other vulnerable individuals who require some measure of state supervision and support would seem appropriate. It would also mean that there is an existing body of jurisprudence which can be drawn upon by both doctors or social workers and the courts.[746] Notwithstanding the concerns raised above that harms are more speculative in the care context therefore, there is reason to believe that this concept is capable of being used in care decisions.

Differences, of course, remain between the two contexts. In the case of children, there are two prima facie decision-makers — the parents — who have responsibility for the child, and so the question is in what circumstances the state should be able to displace them as the decision-makers for the child. The bar for this is understandably high, since it dictates when the person who arguably has the most legitimate claim to make the decision about the child, ought to be prevented from doing so. The parents are default decision-makers due to the deeply personal role they have in the child's life and the wide and long-term responsibilities associated with parenthood: there are thus very good reasons why this position should not easily be usurped by other decision-makers. In the current context however, the decisions for an incapacitated adult fall straight to the doctor or carer (subject to there being an LPA) and the question is the basis on which they ought make the determination of what is best for the person, rather than when they ought to displace another decision-maker. This might not necessitate such a high threshold.

Far from being problematic however, this could provide a useful way of

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[746] MCA (NI), s22.

reconceptualising the role of the individual in decisions about their treatment and care. Rather than viewing incapacity as a ‘switch’ which permits the views of others to be substituted for those of the individual, this would instead conceive of that person as holding the strongest claim to know what decision is best for them (even if they lack capacity), which may be displaced *only* in so far as they are doing something which causes significant harm to themselves. A similar approach can be seen in the Irish Assisted Decision-Making (Capacity) Act 2015, under which the co-decision-maker can only refuse to ‘acquiesce with the wishes of the appointer’ if it is reasonably foreseeable that doing so would result in harm to the appointer (or another).[747] Their wishes must therefore be given effect to unless harm would result. (The benefits of adopting a threshold based on significant harm rather than merely harm is discussed below.)

Under these proposals for reform then, presumptive power is given to the person’s wishes, thus clearly signalling to decision-makers that it is these which ought to form the starting point in any assessment of what is in their best interests, and which must be respected, unless it can be shown that the harm that will result from doing so is sufficient to outweigh the emotional and psychological harms of frustrating their wishes. This in effect would mean that there is a zone in which people are free to make choices about what is best for them, and to prioritise the values and beliefs that *they* endorse, provided that in doing so, it does not expose them to significant harm. The decision-maker is thus provided with a flak jacket in these circumstances if they wish to uphold a person’s decision to refuse treatment; while if they wish to override it, the onus is on them to justify *why* the decision is so dangerous that it outweighs the

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[747] ADMC (Ireland) Act, s19(5).

presumption in favour of respecting their choice. And this debate, of course, results in greater transparency, which will tend to promote more considered and compassionate decisions.

In doing so, the law would strike a better balance under Article 8 ECHR, which as noted above, demands any interference with the person's wishes (even if they lack capacity) to be justified as both necessary and proportionate.[748] As the discussion in Chapter 2 makes clear, an intervention will only be 'necessary' (defined as there being a 'pressing social need' for it[749]) if it is a proportionate response to a legitimate aim. Given that the aim here is to protect vulnerable people from causing harm to themselves, intervening only where their decision exposes them to significant harm would seem then to be a more proportionate response.

While it might be contended that mere 'harm' ought to be a sufficient check on this freedom, whether 'significant' or not, the reality is that people make decisions all the time which are potentially harmful to them: not eating healthily, failing to exercise, drinking to excess or neglecting personal hygiene all set back certain interests that they have. It is only in the most extreme cases however, that we deem it legitimate to interfere: otherwise, as noted in Chapter 3, every self-regarding decision could be overridden on the basis that the person wrongly prioritised or balanced their own interests. A similar approach should be adopted for those who lack capacity. As Hedley J eloquently captured in *Re P (abortion)*, the role of the law in such decisions

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[748] *E* (n24).

[749] *Dudgeon* (n472).

> is not to dress an incapacitous person in forensic cotton wool but to allow them as far as possible to make the same mistakes that all other human beings are at liberty to make and not infrequently do.[750]

All people then, should be accorded some discretion to live according to their own conception of a good life, even where this involves making 'sub-optimal' decisions. This would better reflect the ambiguity on the cusp of capacity, and the fact that people may retain important elements of autonomy even if they formally lack capacity.

This presumption would also help to make the law more 'CRPD-compliant'. The Essex Autonomy Project for example, concluded that a rebuttable presumption in favour of giving effect to a person's wishes would strike an appropriate balance between merely 'taking account' of the person's wishes and feelings (under the current law), which they considered 'falls short of fulfilling a requirement of respect', and total deference to the person's will and preferences.[751] Similarly in response to the proposals put forward by the Law Commission (which arguably demanded less to rebut the presumption than significant harm), the Equality and Human Rights Commission,[752] Alzheimer's Society[753] and a number of academics[754] all commented that it would make the law more compatible with Art 12 CRPD.

This proposal would thus strike a better balance from a theoretical perspective, allowing for the discussion of what is in a person's best interests to take place in a way

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[750] (2013) EWHC 50 (COP), [10].

[751] Essex Autonomy Project, Three Jurisdictions (n482), 40.

[752] Law Commission, Consultation Analysis (n15), 11.21.

[753] ibid, 11.22.

[754] ibid, 11.26.

that is more respectful to the person as an individual, with their own values and priorities. But it would also go some way towards providing the guidance and support identified in Chapter 2 as lacking from the current law. Being required to base their decisions on such a clear-cut presumption would provide clinicians and care workers with greater support when making judgements which entail some element of risk. It would offer them effective protection from legal liability, as anyone challenging the decision would be obliged to adduce evidence that, contrary to what the decision-maker thought at the time, the person would have been exposed to significant harm. And it would have a huge impact on care decisions, where evidence suggests that aversion to risk is often the default position given the fear of litigation — the default position would instead become that a person's wishes ought to be given effect to.

That a person's wishes ought to be determinative of their best interests in the absence of a serious risk of significant harm does not, however, tell us how their interests ought to be balanced where there is significant harm. Or to put it another way, if the harm is not significant, it will invariably be outweighed by the psychological and emotional harms of overriding their wishes. It does not follow from this, however, that where the harm is significant, it will always outweigh those psychological harms: rather the harms must be weighed against each other to determine which course of action is the 'least harmful', or 'best' for the person. The following section will therefore consider when a person's wishes ought to prevail even in the face of 'significant harm'.

III Deeply held beliefs in the face of significant harm

The most taxing decisions are often those where a person resolves to do something deeply harmful to themselves. Yet it is precisely because the consequences are so grave, that the person is likely to care about these decisions most strongly. To decide whether to have stitches on a cut to avoid scarring, or a cast versus a splint on a fractured wrist will scarcely engage the emotions. It is quite another matter to decide where a person is allowed to live, or how the final moments of their life should play out. Nowhere is freedom of choice more important than where decisions relate to a person's fundamental sense of self. Munby J captures this point in *In the Matter of X (A Child)*,[755] concerning whether to terminate the pregnancy of a 13-year-old girl:

> A child or incapacitated adult may, in strict law, lack autonomy. But the court must surely attach very considerable weight indeed to the albeit qualified autonomy of a mother who in relation to a matter as personal, intimate and sensitive as pregnancy is expressing clear wishes and feelings, whichever way, as to whether or not she wants a termination.[756]

When confronted with the vignette of Lucy, meanwhile,[757] in which a decision had to be taken on whether to force contraception on a young woman with learning disabilities who expresses a wish to have a child, one doctor said:

> I don't know how you would make a best interest decision about a matter that's fundamental to a person's personhood…. for me to say whether it's in someone's best interest to have a child or not seems churlish.[758]

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[755] [2014] EWHC 1871 (Fam).

[756] ibid, [10].

[757] Lucy has a mild learning disability. She is able to carry out basic day-to-day tasks and volunteers once a week in a charity shop, but she struggles with financial and administrative matters and so has to receive assistance with these. She stops taking contraception because she would like to have a baby. Lucy's family are concerned that she does not fully understand the physical and emotional effects of pregnancy. They also think she will not be able to care for a child, which will either have to be raised by them, or taken into care, a view supported by the local social services who also think she would not be able to manage. This would cause Lucy great emotional distress. Lucy disputes this, saying she has read numerous books on pregnancy and motherhood, and understands the demands it places on her. When questioned by the doctors, she demonstrates a clear knowledge of the basic day-to-day needs of a baby, including feeding, changing nappies, sleep routines etc. Doctors suspect however, that she doesn't fully appreciate the impact that a baby will have on her life. She says that she wants the chance to experience motherhood and that if she cannot have a baby, she would rather not live at all.

[758] Interview [anonymous], Oxford, March 2017.

As Chapter 4 considered in relation to people *with* capacity, it would seem perverse for the law to deny people any say over those decisions which are of such profound importance to them, while giving them substantial say over those in which the consequences are relatively unimportant. That a person lacks capacity does not render such intensely personal and emotionally significant choices any less salient. Significant harm cannot then act as a trump card in all such decisions. Rather 'the psychological harm that is done to someone by imposing treatment upon her, where to do so goes against beliefs that are profoundly important to her, should be *put in the balance* with the physical harm that might be caused if she does not receive the treatment [or care] in question.'[759] The question is therefore in what circumstances the harm that results from frustrating a person's wishes may be sufficiently grave as to outweigh the harm of giving effect to them.

There are a number of circumstances in which a person's wish may be of such 'profound importance' to them, that frustrating it becomes especially harmful: when it reflects a particular belief which is of huge personal significance to the person; when it embodies a set of values, priorities or characteristics to which the person attaches primary importance; or when it represents a direct and considered response to their current circumstances, and thus to frustrate it will cause them unendurable suffering. Each of these will be discussed in turn.

(a) Frustrating deeply held beliefs

Sometimes a person will hold beliefs which they deem incompatible with the treatment or care intervention proposed. This might be because it is expressly prohibited within that belief-system, as where a Jehovah's Witness refuses a blood transfusion, a Muslim

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[759] Jackson (n4), 266.

refuses food during the daylight hours of Ramadan or a Jew refuses porcine-derived medication or foods. Or it might be that although the intervention is not specifically prohibited by their beliefs, they hold certain values on account of those beliefs which lead them to feel that the intervention would violate them (as where a Catholic woman refuses to terminate a pregnancy even where the foetus carries risks to her for example, or a Muslim woman not wanting to be examined or intimately cared for by a male nurse). While decisions to refuse treatment often involve a religious element, religious beliefs are by no means the only reason: in *St George* for example,[760] the woman's refusal was apparently based on her belief that nature should be allowed to 'take its course'; while there are examples of vegetarian patients refusing treatments because they contain animal products (clotting disorders for example, are often treated with low molecular weight heparin which is prepared from mucosa taken from porcine intestine).

The fact that a person may not have the cognitive abilities to make a decision independently does not simply extinguish these beliefs, or make them irrelevant. As argued in Chapter 2, to act in a way that is contrary to the person's most deeply held beliefs and values merely on the basis that the person now lacked the legal authority to make a binding decision, would be to deny respect for the person as an individual and to undermine our commitment to value pluralism and religious freedom. This is especially so given that it is often the very circumstances that render some intervention necessary (say, a blood transfusion) that are causing the person to lack capacity (perhaps due to a severe injury and blood loss). A person would therefore be denied the

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[760] *St George* (n141).

opportunity to adhere to their beliefs in the very circumstances where that belief has most relevance.

The more strongly a belief is held, the more it can be expected that setting it at nought will cause psychological or emotional harm. For a devout Muslim woman to be forced to expose herself in front of a man could be profoundly shaming. For a Jehovah's Witness to have a blood transfusion forced upon them would be to act contrary to God's will. One can scarcely underestimate the emotional damage that would ensue from terminating the foetus of any woman against her will — but this would surely be compounded where a woman held life to be a sacred gift from God, and that saving her own life had made her complicit in the murder of her child. Just because a person is unable to formulate a capacitous decision does not necessarily make them unaware — either at the time of decision or subsequently — that these actions contravene their most fundamental beliefs about what is right and wrong. Nor then, should it justify denying them any control over matters of such profound importance to them.

(b) Overriding the person's wishes and priorities

Even where there is no one particular belief which is implicated by a decision, a person's wish may nonetheless embody values, priorities, or characteristics which are deeply important to them, and which would be frustrated if their wishes were overridden. This seems to underpin many recent judgments, where notwithstanding the possible harm that might result, the decision was thought to proceed from values and priorities that had been of huge personal importance to the person throughout their life, and which continued to resonate. In *Re D* for example, it was D's character as a 'very private man' which led the judge to conclude he would not have wanted his current existence;[761] in *Wye Valley* Peter Jackson J was motivated by Mr B's 'core quality' of 'fierce independence' which was now under threat;[762] while Manuela Sykes was thought to continue to 'appreciate and express the value of being at liberty and being allowed autonomy.'[763]

In all of these cases then, the judge recognised that to force a decision on a person which ran contrary to those things that mattered most to them — be that their liberty, independence or privacy — would be hugely distressing for them. In *Wye Valley*, Justice Peter Jackson was clear that it could not be in Mr B's best interests to take away his remaining independence and dignity by forcing an amputation on him that he would then have to live with for the rest of his life;[764] while in *Sykes,* District Judge Eldergill noted that the fundamental importance to many people of being able to live out the final moments of their life in their own home, even if that caused some distress.[765] To force a person to endure the consequences of decisions which deprive them of those things they value most, particularly where they relate to things of such fundamental importance as where they should live, or how they should die, represents a very grave invasion of their liberty and autonomy. Indeed as Dworkin captures in relation to the latter, 'making someone die in a way that others approve, but he believes

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[761] [2012] EWHC 885 (COP).

[762] *Wye Valley* (n7), [43].

[763] A. Ruck Keene et al, *Court of Protection Handbook: A User's Guide* (2014), 3.79.

[764] *Wye Valley* (n7), [45].

[765] *Sykes* (n183).

a horrifying contradiction to his life, is a devastating, odious form of tyranny'.[766]

Even where a person is incapable of experiencing distress (as in a persistent vegetative state), the infringement of their autonomy (and for some commentators, dignity) involved in forcing treatment on them which they would not want, has been recognised in the case law. In *M v N* for example, Justice Hayden was left in 'no doubt' that Mrs N would have been 'appalled' by her current existence and would want all further treatment to be withdrawn.[767] In *Re D,*[768] Peter Jackson J highlighted that the patient had been a 'very private man before his incapacity' and thus 'would have been horrified at the prospect of being kept alive in this condition with the total loss of privacy that his dependency entails'.[769] Indeed David Feldman even suggests that it may be incumbent on the state to act in this way, given its obligations under Article 8:

> In life-and-death situations, positive obligations on the state to assist those who are incapable of giving effect to choices could involve a duty to respect the dignity and moral integrity of a person who is comatose or in a persistent vegetative state *by giving great weight to a previously expressed wish to be allowed to die in such circumstances* [emphasis added].[770]

(c) Recognising the person's own assessment of their quality of life

Finally, a person may refuse an intervention because they regard their quality of life to be unbearably low and have no wish to prolong their life further. We readily accept

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[766] R. Dworkin, *Life's dominion: an argument about abortion, euthanasia, and individual freedom* (New York: Alfred A Knopf, 1993), 217.

[767] *M v N* (n382), [60].

[768] *Re D* (n761)

[769] ibid, [17].

[770] D. Feldman, 'The Developing Scope of Article 8 of the European Convention on Human Rights' (1997) 3 *European Human Rights Law Review* 265, 270.

that people *with* capacity can experience their life as unacceptable and refuse treatment on this basis. Yet as *A Local Authority v E*[771] illustrates all too clearly, that a person does not have decision-making capacity does not preclude them from experiencing pain, discomfort, distress, loneliness (indeed the condition causing incapacity may itself trigger these feelings). There may, therefore, be circumstances in which the person considers these to outweigh any enjoyment they gain from life, and so have no desire to evade death. This need not be dramatic: as little as refusing antibiotics can prove fatal for the elderly. *E* may seem an extreme example of this, given her young age and possibility of recovery (albeit low). There will be other people however, particularly those with degenerative illnesses such as Parkinson's disease, who when faced with interminable decline, may well take the decision to refuse life-saving treatment at the point at which their life becomes threatened. Given that they may be able to experience suffering no less keenly, it cannot be right to deny person any say over what happens to them in such cases simply because they have lost decision-making capacity. Indeed given that, as explained in Chapter 3, people's perspective can often change when they find themselves ill, dependent and nearing the end of their lives, listening to the person's perspective and their wishes about how they wish for their life to end in such cases, is essential.

That a person's wishes reflect their deeply held beliefs, core values and characteristics, or an appraisal of their quality of life, are all reasons therefore, why those wishes or interests may be particularly strongly and deeply held, and thus generate significant psychological harm and distress if frustrated. In these circumstances, the harm in overriding their wishes could outweigh the physical harm to

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[771] *E* (n24).

which giving effect to them would expose the person, and thus it might be in a person's best interests to have their wishes respected, even if that leads to significant harm.

But the strength and conviction with which these wishes are held also makes it more difficult to justify interfering with these choices. It was suggested above that even if a person lacks capacity, they may still retain important elements of autonomy, including strongly held values, beliefs, priorities which are authentic to them. It follows then that wishes that reflect these beliefs and values demand great respect, as these enable the person to pursue their own conception of a good and valuable life — certainly more so than impulsive, erratic or whimsical choices which do not further the person's beliefs or values. This was recognised by Feinberg, who noted that desires that are stable, durable and linked to longer-term goals and priorities are more likely to be ulterior interests which, if frustrated, generate harm.[772]

The Law Commission acknowledged this in their final report: 'the stronger and clearer the ascertainable wishes and feelings, the greater the weight that should be given to them — due to the greater infringement on the person's autonomy under Article 8(1) of the ECHR if they are not followed.'[773] This has also been recognised by some of the judges, who have noted that it is harder to justify overriding a person's wishes where they are more strongly held. In *Re M*, Munby J was clear for example, that the weight he accorded to them in the best interest assessment would be influenced by 'the strength and consistency of the views being expressed by P',[774] while Hayden J in *TH* noted that the 'clarity, cogency and force' that the person's views are found to

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[772] Feinberg (n661), 43.

[773] Law Commission, 'Final Report' (n722), 14.17.

[774] *Re M* (n33).

have would have a direct 'impact on the weight they are to be given.'[775] Indeed this may explain the difference of approach between Hayden J in *QZ* and Peter Jackson J in *Wye Valley.* While Peter Jackson emphasised the profound importance of Mr B's beliefs to him, which were 'his faith and an intrinsic part of who he is',[776] and did not warrant the term 'delusions', Hayden J portrayed QZ's beliefs as 'delusional beliefs' which 'must not be permitted' to eclipse the other 'facets of her personality'.[777] This suggests that her wishes were not regarded as clear and consistent desires which reflected important aspects of character, but rather the product of an illness, from which she must be protected.

Doctors also seemed to attribute greater weight to views which were deemed to be more 'authentic', 'strongly held' or 'consistent'.[778] And as Johnston *et al* observe, various tools that had been created to help doctors elicit such information about the values and priorities that are important to the individual, including the King's Psychosocial Assessment and Communication Evaluation (K-PACE), which includes a checklist for information about *inter alia* the person's values, religious beliefs, previously expressed treatment preferences;[779] and the 'Life Story Book' devised by

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[775] *TH* (n389), [55].

[776] *Wye Valley* (n7), [43].

[777] *Q* (n400).

[778] See the examples given above of doctors regarding best interests as almost a form of substituted-decision-making at n423-427.

[779] Johnston et al (n377), 260.

Dementia UK.[780] It is clear, therefore, that where the person's wishes, values or beliefs are strongly and deeply held, they may experience them being frustrated as profoundly harmful. This harm might then outweigh the physical harm of giving effect to them, such that it is in a person's best interests that they be respected.

(d) Capturing this in the law

While a person's deeply held beliefs and values ought to take on great weight in the best interests determination, the question remains how exactly this should be reflected in the law. Emily Jackson has suggested that the initial presumption that the person's wishes ought to be decisive should be supplemented by a second presumption which allows for the person's refusal of treatment to be respected even where it would cause significant harm 'if it is grounded in her core values and beliefs, that is, in views that are, or were, of profound importance to [the person].'[781]

While this suggestion has normative appeal for the reasons set out above, it can be difficult to differentiate a person's core from their non-core beliefs. In situations like that of the Jehovah's Witness, it might be easy to identify the belief in question, assess its importance to the person, and apply it to the situation at hand (in a decision over a blood transfusion). Treatment and care decisions however, will rarely be this clear-cut, and most values or beliefs will be far less prescriptive or precise than this. As Johnston *et al* explain:

> A common value expressed by individuals who witness the decline and mental deterioration of elderly relatives is the desire for dignity towards the end of life, something that many often do not see as compatible with living in a nursing home, being incontinent and requiring assistance with personal care. What this reflects is something about the kind of person one is, what one values, and how one wishes to

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[780] Available at <https://www.dementiauk.org/for-professionals/free-resources/life-story-work/> accessed 18th September 2018.

[781] Jackson (n4), 279.

> live one’s life. Such values may also provide insight into what would give a person a good death. Such expressions do not provide evidence for particular healthcare/end of life choices in specific (usually unforeseeable) circumstances, but they do provide a rich seam of context in which to make some judgement about what kinds of treatment, or non-treatment, the person would be likely to want in a given situation… They are not individual preferences specific to particular circumstances but general, broad instantiations of the kind of person one is and wants to be, with or without capacity.[782]

The person’s previous sentiments are therefore important in helping to formulate a narrative about the person, which together provides evidence about what the person would want in their current situation, even if this cannot be explained by reference to any particular value or belief.

Trying to distinguish ‘core’ from ‘non-core’ beliefs may be particularly difficult in the medical context, since many beliefs or values which would not have been regarded as ‘core’ — in the sense that they did not guide the person’s behaviour throughout their lives — may take on new significance in the circumstances now in question. There is a risk, therefore, that such an approach would also privilege certain beliefs, namely those from organised religions. As Jackson herself acknowledges, ‘untangling what matters most to the patient, and identifying what might be said to be her core values and beliefs will not always be straightforward.’[783] Where the person is able to articulate strong and deeply held beliefs however, it would seem wrong to dismiss these purely on the basis that they are not regarded as of ‘core’ significance to the person. Rather, it ought to be enough simply that the value being expressed is both authentic to them, and deeply held, since this alone will make the invasion of the person’s autonomy, and psychological harm greater. This has the value of not being relative: the belief or value does not have to be *more* important, or more deeply or

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[782] Johnston et al (n377), 252.

[783] Jackson (n4), 270.

consistently held, nor does it have to be of *fundamental* importance to the person. Rather it is sufficient provided that it has these qualities at all.

Even if ‘core beliefs’ is replaced with ‘strongly and deeply held beliefs’ however, there remain difficulties both with this formulation, and with its operation as a rebuttable presumption as Jackson suggests. The formulation still creates a threshold of significance, above which beliefs are decisive, and below which they are just one factor in the best interests determination. This binary distinction does not reflect that, in reality, a person’s beliefs occupy a spectrum of significance for them. It would also invite manipulation by decision-makers, who would surely be tempted to determine that a particular belief of the person fell just above or below the ‘strongly and deeply held’ threshold in order to achieve the decision-maker’s preferred outcome.

Furthermore, presumptions work in all-or-nothing terms: either the presumption stands, or it is displaced. This can be helpful when used in situations such as that suggested above (that the person’s wishes are determinative of their best interests unless these would expose the person to a serious risk of significant harm), in that it generates a clear ‘yes’ or ‘no’ answer which dictates how the decision-maker should then respond. If giving effect to the person’s wishes would not cause them significant harm, then the presumption stands and the person’s wishes ought to be given effect to. If it would, then the presumption does not apply and those harms must then be weighed against the harm of frustrating their wishes in the best interests determination. In the context of this determination, however, to produce the same clarity, the second presumption would have to treat the categorisation of a belief as ‘core’ (or ‘strongly or deeply held’) as determinative of how we ought to then respond to it — providing a belief or value is ‘core’ or ‘strongly held’, giving effect to it will *always* outweigh the opposing harm, and thus be in the person’s best interests. A presumption that made the strongly or deeply held belief less than determinative — for example, a presumption that such beliefs should carry more weight — would provide no clear guidance (how much more?). However, both the determinative and 'significant weight' approaches are too simplistic. Whether the psychological and emotional harm of overriding a person's wishes outweighs the physical harm of giving effect to them will depend both on the strength of that person's wish (which operates as a spectrum and not a threshold) *and* on the degree of harm that will result (clearly even within 'significant harm' there will be different degrees of severity, death being the most 'significant'). It is not the case therefore, that wherever a belief is regarded as strong and deeply held, it ought necessarily to be given effect to at all costs. Rather the strength, consistency, and authenticity of that belief must all be weighed in the balance, as must the likely effects of frustrating the person's wishes on them, and how important the belief is in the context of this particular decision, to determine whether this outweighs the opposing harms.

Rather than a second presumption therefore, the law must be amended in a way that is capable of capturing the fact that the weight accorded to different wishes, feelings, beliefs and values ought to reflect the level of importance that the person attached or attaches to those wishes, feelings beliefs and values, since this will dictate the level of harm that the person will suffer as a result of their being frustrated. When determining what is in the person's best interests, the decision-maker must, under section 4(6) MCA, take into account the person's past and present wishes and feelings, and the values and beliefs which would be likely to influence his decision if he had capacity. This could therefore be supplemented by a provision that the weight given by the decision-maker to those wishes, feelings, beliefs, and values 'must be proportionate to the strength with which they were held'.

Of course one can never determine the strength with which a wish, belief or value was held by another with exactitude. However, it may still be possible to identify a series of hallmarks which might be present where they are held more strongly, which could form a non-exhaustive list of factors to be taken into account when determining their strength. This idea has been used elsewhere in the law. Until 2013 for example, *Reynolds v Times Newspaper*[784] provided a defence to defamation where the defendant acted as a 'responsible journalist' in publishing the statement. Rather than defining 'responsible journalism' however, Lord Nicholls instead set out a non-exhaustive list of factors that ought to be taken into account when determining whether or not the journalist behaved responsibly. These included for example, the seriousness of the allegation, the nature and source of the information, steps taken to verify the information, urgency etc.[785] A similar idea could usefully be developed in this context, identifying factors which might be taken into account when determining the extent to which something constitutes a strongly held wish, feeling, belief or value. This might include, for example, looking for evidence of dedication or commitment to that value or belief (for example through attendance at a religious ceremony, or through vocalising or espousing the values or beliefs in any social context); whether it was long-standing; whether it had been held consistently (or had fluctuated in importance or been subject to change); and whether it was held prior to the loss of capacity. It might also inquire about how, if at all, that belief or value had affected the way that the person had made previous decisions, and what the effect on the person of frustrating

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[784] [2001] 2 AC 127.

[785] While this defence was abolished by section 4(6) Defamation Act 2013, the list of factors effectively remains via section 4(2), which requires the court to have regard to all the circumstances of the case.

that belief is thought to be. Notably, many of these factors have already been identified in the case law, cited as influencing the weight to be accorded to the person's wishes — this reform would help to ensure that these factors are given weight in all best interest determinations. This provision would be bolstered by section 4(7) MCA which requires the decision-maker to consult with the person's family, friends and carers about what would be in their best interests, in particular with a view to ascertaining the person's wishes, feelings, values and beliefs.

While this might not always provide definitive answers, it would at least provide a framework within which to think about and weigh up the evidence available about that person. In *Re T* for example,[786] the fact that the woman had not been a practising Jehovah's Witness for some time, and that she had provided no explanation as to exactly why she was refusing the blood transfusion, while her partner and father presented evidence that it did not reflect her genuinely held beliefs would all, under this approach, be factors which would be taken into account when concluding that this was *not* a strongly held wish which ought to be respected even in the face of her death. Less weight would therefore be accorded to these wishes, with the result that they will likely be outweighed by the significant harm of allowing her to refuse life-sustaining treatment when determining what is in her best interests. Indeed this was precisely the approach of Ward J, who having reviewed the evidence, concluded that:

> I do not find that the refusal as made evinced a settled intention on her part to persist in that refusal even if it is injurious to her health and when the best interests for her health require that blood be transfused to her.[787]

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[786] *Re T* (n16).

[787] ibid, [19].

In *LM,*[788] by contrast*,* the patient had been a Jehovah's Witness for thirty years, and had, since the point of admission to hospital, repeatedly made it clear that she did not wish to have a blood transfusion. Mr Peter Jackson adduced evidence from someone who had known her throughout that time that she was an 'active member of the congregation who fully subscribed to the tenets of the faith (including its opposition to blood transfusion) and had taught them to others'.[789] Accordingly, he found that her 'wishes and feelings and her long-standing beliefs and values carried determinative weight',[790] a view that would also be endorsed under this approach. Given the profound psychological and emotional harm that would result from forcing her to contravene her deeply held religious beliefs, her best interests would be served by permitting her to refuse treatment.

The same can be true even if those beliefs have their source in an illness, as in *Wye Valley,* if those beliefs are of huge importance to the person. In this case, his religious beliefs (even if caused by hallucinations) were 'deeply meaningful' to Mr B, his 'faith' an 'intrinsic' and 'inextricable' part of who he is.[791] Moreover the effect of overriding his wishes would have been profound, condemning him to have to spend the rest of his life having to adjust to life without his leg. His wishes were therefore deserving of the greatest respect when determining what was best for him, notwithstanding their origins. In this sense, this provision does not mirror exactly the

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[788] *LM* (n352).

[789] ibid, [17].

[790] ibid, [23].

[791] *Wye Valley* (n7), [43] and [13].

authenticity criterion proposed above, as a person's wish could reflect disordered beliefs, while still being sufficiently important to the person that they ought to be given great weight in any best interest assessments.

While all of the above cases would have been decided in the same way under this approach, it is hoped that it might have resulted in a different outcome in *A Local Authority v E.*[792] Although giving effect to her wishes would undoubtedly have resulted in significant harm to E (sufficient to rebut the initial presumption), the psychological harm of frustrating her wishes in this case could scarcely be greater. Not only was her wish to die long standing and consistently expressed (she had even attempted to encapsulate it in an advance directive), but the intervention required would be hugely invasive and traumatic for her. In this case therefore, the clarity and strength of her wishes — founded on years of suffering — ought to have carried very significant weight, which would, under the new approach, have resulted in treatment not being deemed in her best interests.[793]

In the context of care decisions meanwhile, giving proportionate weight to wishes, feelings, beliefs and values would likely have changed the outcomes of *Neary*[794] and *RF.*[795] In cases such as the latter, which concerned the decision to move an elderly man out of his home and into a care-for environment, this provision might

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[792] *E* (n24).

[793] By way of contrast, in the vignette of Cara (the young woman with anorexia who was brought into A&E having taken a paracetamol overdose), given that none of this information was available to the doctors (who had only the information being provided by Cara at that time), it would be right not to attach this extra significance to her wishes.

[794] *Neary* (n450).

[795] *RF* (n455).

be particularly important. The fact that a person greatly valued their independence, was strongly attached to their family home, and had made it clear throughout their life that they would not wish to move into a cared-for environment, even at the expense of their safety, would all lean in favour of allowing the person to remain in their home, even though that exposed them to some risk of harm. The best interests calculation would therefore likely have fallen down in favour of acceding to his wishes. Since these wishes demonstrably survive the loss of capacity, it would seem right to put them on an equal footing with the beliefs and values of someone who retains capacity.

As the evidence suggests that doctors and judges are more inclined to give greater weight to wishes which reflect long-standing, consistent and deeply held beliefs, these reforms will be unlikely to necessitate a wholesale change of approach on the part of clinicians. It will however provide greater support for those charged with making these decisions, giving them some guidance on how to reconcile situations in which a person strongly resists an intervention, by according greater weight to more strongly held wishes. Providing the decision-maker can then show that they have engaged with the factors on the list, and have evidence to support their findings in respect of each, this would provide decision-makers with a degree of security that they will not face legal liability merely because a harm or risk materialised. On the other hand, if a decision-maker fails to give sufficient weight to the person’s wishes, this would provide an avenue for challenging the decision, enabling the court to impugn a best interests assessment where it is felt that the weight accorded to the person’s wishes as part of it was disproportionate to their strength. While it is likely that such a finding will be relatively rare, it would nonetheless represent a step forward from the current law, according to which a decision can only be impugned where the decision-maker does not take account of the person’s views at all.

While the examples given above are of decisions in which the factors seem to weigh heavily in one direction (i.e. that the wish is or is not strongly held), there will of course be cases in which these factors are not mutually supportive, but rather pull in different directions. While conflicts of this kind are inevitable, this approach provides a means of navigating them, by creating a list of factors which can be used to evaluate the evidence presented, in order to resolve such conflicts. Where someone appears to have competing or inconsistent wishes or values, the factors provide a means of appraising the strength and consistency of these, in order to discern whether the conflict is as problematic as first thought. For example, although at first glance, a belief might appear to be strongly held because of its religious content, when one examines that belief further, and the way that it had previously guided the person's decision-making, it may not seem as important as first thought.

Where the evidence suggests either that the wish is not one which the person would want to be upheld in the face of significant harm, or where it is unclear what they truly want, the law must step in to protect the person from the harm. Here the value in protecting the person clearly outweighs the value of empowering them, since if the wish is not strongly and authentically held, it cannot truly be said to express the person's autonomy. These reforms would therefore strike a better balance between the empowerment and protection of those who lack capacity.

IV Amending the defence to battery

These proposals for reform aim to ensure that even if a person is deemed to lack capacity, their wishes continue to guide the decisions made about them, and are less vulnerable to be overridden on the basis of another's conception of what is best for the person. This would be undermined however, if doctors could evade this by treating them regardless, and then relying on the defence in Section 5. This section will therefore briefly set out necessary amendments to this provision, mirroring those already seen in the Northern Ireland Act, to ensure greater consistency between this and the changes to best interest determinations proposed above.

As noted above, section 5 provides a defence for anyone acting in connection with the care or treatment of a person, where they reasonably believe the person to lack capacity and where they act according to what they regard as being in the person's best interests. The bar for succeeding under the defence is low. The doctor need only show that they had *reasonable grounds* for believing that the person lacked capacity, not that they in fact did believe it. They will not have to adduce much evidence, therefore, to gain its protections. It is also broadly framed, applying to *any* action taken in the patient's best interests where there are any concerns about the person's capacity, irrespective of whether, for example, the intervention was necessary to prevent serious or immediate harm. In this sense, it ought to be sufficient to counteract the concerns by doctors raised in Chapter 1, that they are at risk of being guilty of battery. This is especially so given the inherent difficulties with assessing the patient's capacity *ex post facto*, which means it will not be easy for a judge to substantiate a finding that there were *not* reasonable grounds for believing that the person lacked capacity, in the face of contemporaneous evidence from the treating clinician.

While the relatively unqualified provisions of section 5 have clear advantages for doctors called upon to make difficult assessments, they do allow the defence to be invoked in a broad set of circumstances, with a risk that it undermines the presumption of capacity and erodes patient autonomy. Notably, the equivalent statutory defence provided for by the recent Northern Ireland MCA is significantly more circumscribed than that in English law. While it also provides a defence for a doctor who reasonably believes that the person lacks capacity and that treatment is in their best interests,[796] this is subject to additional safeguards set out elsewhere in the Act.[797] Section 13 qualifies section 9 where the intervention is categorised as 'serious', according to section 63. This will be the case wherever the intervention involves any 'major surgery';[798] causes the patient 'serious pain, serious distress, or serious side-effects';[799] seriously affects the options they have available to them in the future or has a large impact on their day-to-day life;[800] or otherwise has a serious consequence for the patient, be that physical or non-physical.[801] It will also encompass any situation where the person is deprived of their liberty.[802] In these situations a formal capacity assessment must be performed[803] and a statement of incapacity made for the person detailing why it is that the assessor considers them to lack capacity,[804] and what help or support has been given to the patient, without success, to enable them to make the

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[796] Mental Capacity Act (Northern Ireland) 2016, section 9(2).

[797] ibid, s9(3). The relevant sections are set out in s9(4).

[798] ibid, s63(1)(a).

[799] ibid, s63(1)(b).

[800] ibid, s63(1)(c).

[801] ibid, s63(1)(d).

[802] ibid, s63(2)(a).

[803] Under s14(2), this must be conducted by 'a suitably qualified person'.

[804] ibid, s14(3)(a)-(c).

decision in question.[805] The Act further provides that, except in situations of emergency, a nominated person must be put in place and consulted in determining whether the intervention is in the person's best interests.[806] If the question of what is in the person's best interests is finely balanced and the consequences serious, a second opinion must be sought.[807] Only if these extra stipulations are met, may the doctor avail themselves of the defence in section 9.[808]

Where the treatment proposed has serious consequences for the patient (which is defined in the same way as a 'serious intervention' above[809]), and their nominated person reasonably objects to it,[810] the patient resists it,[811] or the act amounts to a deprivation of the person's liberty,[812] the intervention must also satisfy the 'serious harm' condition. For the purposes of these sections, this requires that the doctor reasonably believes that a failure to provide the treatment would create a risk of serious harm to the patient or others;[813] and that the treatment is a proportionate response to the

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[805] ibid, s14(3)(d).

[806] ibid, s15(3)(a)-(b).

[807] ibid, s16.

[808] ibid, s13(2).

[809] ibid, s21.

[810] ibid, s19.

[811] ibid, s20(1)(c)(i).

[812] ibid, s24.

[813] ibid, s22(1)(a).

likelihood and severity of that harm.[814] In this sense, the Northern Ireland Act introduces a more complex and nuanced harm threshold for intervention: where the person resists the treatment, it may only be provided where there is otherwise a risk of serious harm to them and the treatment is proportionate to the likelihood and severity of that harm. More broadly, the Act demands greater steps to be taken by the doctor to avail themselves of the defence, depending on the severity of the consequences of the decision for the person.

In its recent review of the MCA, the Law Commission supported putting in place greater safeguards to limit when section 5 could be relied on by doctors, suggesting that this might improve the quality of decisions in this area:

> Our intention is to provide safeguards for people not by way of affording them express rights, but rather by focusing upon the liabilities that would attach to decision-makers if they do not take the additional steps required in any given case...restriction of the section 5 defence in this way would help to ensure better quality decision-making in relation to people who lack or may lack the requisite capacity.[815]

In particular, the Law Commission suggested that where the decision was of a particular nature (including serious medical treatment, or treatment known to be against the person's wishes[816]), the doctor would be unable to rely on the defence *unless* they had provided a written record (or reviewed a written record produced by someone else and believed it to be accurate).[817] This written record must contain the following information:

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[814] ibid, ss22(1)(b)(i)-(ii).

[815] Law Commission, Consultation Paper (n424), 14.35.

[816] ibid, 14.37.

[817] ibid, 14.36.

1) a description of the steps which have been taken to establish whether the person lacks capacity in relation to the matter in question;
2) a description of the steps which have been taken to help the person to make the decision or an explanation as to why it was not practicable to take such steps;
3) an explanation of why it is believed that the person lacks capacity in relation to the matter in question, including:
    a. identification of the impairment or disturbance in the functioning of the person's brain; and
    b. an explanation, by reference to section 3 of the Mental Capacity Act, of why the person is unable to make the decision;
4) a description of the steps which have been taken to establish whether or not it is in the person's best interests for the act to be done;
5) a description of any ascertained wishes, feelings, beliefs or values for the purposes of a best interests determination and, if the best interests decision conflicts with the person's ascertained wishes, feelings, beliefs or values, an explanation of the reason for that decision;
6) confirmation that any duty to provide an advocate has been complied with; and
7) confirmation that the act would not be contrary to an advance decision.[818]

While this remains less comprehensive and demanding than the system provided for in Northern Ireland, it would have been a welcome step forward. Although it does not place any restrictions on the way in which a doctor can act (for example limiting interventions in the absence of significant harm), it does nonetheless require that the doctor provides clear evidence of the reasons for their decisions, thus improving the transparency of decisions. It also provides a framework for approaching such cases, breaking down the many different steps involved in these assessments. By requiring doctors to write down exactly how the impairment is causing the person's inability to make a decision, and in what way their decision-making ability is impaired, this may also direct their minds to these particular issues, enhancing the specificity of decisions and addressing the problems identified above, that decision-makers were all too frequently failing to engage with the causative nexus at all.

It might be suggested that such a requirement would place too onerous a burden

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[818] ibid, 14.38.

on decision-makers, which, even if possible, is disproportionate to the benefits expected to be gained from such an approach. However all of the mandated steps are already required under the current law: the person ought to be supported to make a decision by themselves; deemed to lack capacity only if they have an impairment in the functioning of the mind or brain which renders them to be unable to make a decision according to the criteria in the test for capacity; and their wishes and feelings ought to be taken into account when later assessing what is in their best interests. Such changes would not therefore mandate a different approach by decision-makers, but merely requires them to document their findings in relation to each of these steps — documentation which, even if not legally required, is already regarded as good medical practice. In the Code of Practice for example, it states that

> it is good practice for professionals to carry out a proper assessment of a person's capacity to make particular decisions and to record the findings in the relevant professional records.[819]

Later meanwhile, when discussing best interest assessments, the Code is explicit that decision-makers

> should record their decision, how they reached it and the reasons for it in the person's clinical notes. As long as they have recorded objective reasons to show that the decision is in the person's best interests, and the other requirements of section 5 of the Act are met, all healthcare staff taking actions in connection with the particular treatment will be protected from liability.[820]

The requirement that doctors record the basis on which they deemed the person to lack capacity, and why they consider the treatment or care intervention to be in their best interests, is not, therefore, new. Nor is it unwarranted: should the decision later be challenged, this contemporaneous evidence is essential if the court is to be able to

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[819] Code of Practice (n266), 4.61.

[820] ibid, 6.17.

assess in any meaningful way whether the defence in section 5 ought to apply or not. In its absence, it is difficult both for the patient to challenge the decision and, importantly, for the doctor to later justify their actions. Indeed for this reason, evidence from the interviews suggested at least some doctors are vociferous in their production of notes wherever they deem a person to lack capacity. Given the benefits that such an approach would bring, and the lack of additional burden this would place on doctors, it is disappointing that in the recent Bill put before Parliament, all proposed changes to section 5 have been omitted.[821]

Nonetheless a provision closer to that of the Northern Ireland Act, demanding that when the patient or their next of kin resists the intervention, the doctor may only have a defence where there was otherwise a risk of significant harm to the patient (and the treatment is proportionate to the likelihood and severity of that harm), would strike a better balance between respecting autonomy and protecting doctors, and introduce greater consistency given the above proposals. While this would continue to leave doctors some room to manoeuvre in ambiguous cases, it would create a much more limited exception to the general presumption of capacity. Given the invasion of bodily integrity that treating a person against their will involves, and the huge psychological and emotional consequences of doing so, it is, as noted above, difficult to deem treating them to be in their 'best interests' in the absence of significant harm to the person. While there would once again be some debate over whether the harm in question is rightly regarded as 'serious'; this is more easily answered in this context than in relation to the presumption, as the question is not whether the harm is significant, but only whether or not the doctor could reasonably have believed it to be significant,

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[821] Available at <https://publications.parliament.uk/pa/bills/lbill/2017-2019/0117/18117.pdf> accessed 24/08/2018.

which provides an important degree of objectivity. This would introduce a welcome degree of consistency in the Act over when a doctor is justified in treating a person against their wishes.

Even absent these changes, the fact that the doctor must ‘reasonably believe’ that they are acting in the best interests of the patient to avail themselves of the defence may indirectly bring the defence in line with the changes proposed above. Currently, in assessing what is in the patient’s best interests, the decision-maker must, under section 4, take into account the person’s current wishes and feelings.[822] Arguably then, if the doctor overrides the patient’s decision *without* having due regard for the requirements of s4, their assessment of what is in the patient’s best interests could not be said to be ‘reasonable’, and thus they would not have the protection of the defence.[823] Certainly in *Winspear v City Hospitals Sunderland NHS Foundation Trust*,[824] a failure to consult the mother of an incapacitated patient before placing a ‘do not resuscitate’ order in their records, where that consultation was both practicable and appropriate, was sufficient to bar the NHS Trust from relying on section 5 in a claim for a breach of the patient’s Article 8 rights. Arguably therefore, if the patient is objecting to the treatment *and* they are unlikely to suffer any serious harm as a result of acceding to their wishes, it will be harder to show that the doctor reasonably believed themselves to be acting in their patient’s best interests for the purposes of section 5, especially if the proposals put

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[822] MCA, s4(6)(a).

[823] This point was argued by counsel Mr Coppel in *ZH v Commissioner of Police for the Metropolis* [2012] EWHC 604 (QB), [41]. Notably, in the equivalent provision in the Mental Capacity Act (Northern Ireland) 2016, it is explicitly stated that the provisions relating to determining best interests in the Act apply for the “purposes of determining whether a belief mentioned in subsection (1)(d) is reasonable” (s9(5)).

[824] [2015] EWHC 3250 (QB).

forward for reforming best interests are adopted. Reforming the defence so that it applies only where the intervention was necessary to prevent significant harm on the face of the statute, would nonetheless be welcome.

V Are more radical reforms needed?

Any law premised on capacity operating a threshold will inevitably face difficulties at the margins. So while suggestions have been made to improve the robustness of the capacity test and, in this chapter, to mitigate the starkness of the cliff-edge approach, a more radical reconceptualisation of capacity law is needed if these concerns are going to be eliminated altogether. It is in recognition of this, that some have advocated more wholesale changes to the law in this area, abandoning the threshold approach entirely and replacing it with a system that acknowledges that people's decision-making ability may be impaired to different degrees, requiring different levels of support or intervention. It is this idea which underpins supported decision-making schemes (SMD). Supported decision-making typically refers to a process whereby a person with impaired capacity appoints a 'supporter' in order to help them make decisions for themselves. The central premise is that a person should never have a decision taken for them, if they could, with support, take it for themselves. It also recognises that even those who might, under a threshold approach, be found to have capacity, may still benefit from some support in those decisions. Rather than an all-or-nothing threshold with stark consequences in either direction, it therefore recognises different 'grades' of capacity, warranting different levels of support.

It is not inconceivable that England and Wales could move to such a scheme: formal supported decision-making procedures have been implemented by a number of common law jurisdictions across Canada and parts of Australia, and most recently, by the Republic of Ireland. As noted above, in Ireland,[825] there are now three different levels of intervention depending on the person's degree of capacity: a decision-making assistant; a co-decision-maker and a decision-making representative. Only in the latter category must the person lack decision-making capacity. The exact provisions differ however, between jurisdictions. In Alberta for example,[826] similar to the 'decision-making assistant' in Ireland, an adult who 'understands the nature and effect' of the agreement can appoint a person of their choice as supporter, but the decision remains the person's own. Saskatchewan, Quebec and Alberta meanwhile have stand-alone co-decision making (like the middle 'grade' in Ireland), whereby the adult only has decision-making capacity for specified decisions when the co-decision-maker is involved.[827] There are also hybrid provisions in some jurisdictions, such as British Columbia's Representation Agreement, which authorises a third party to act on a person's behalf, but the representative must consult with the person, and the person creating the Agreement can revoke the Agreement at any time.[828]

Such schemes have been advocated by the United Nations Convention on the Rights of Persons with Disabilities (CRPD). According to 12(2), parties 'shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life'. Read literally, any legislation imposing substituted decision-making (as in the MCA) would thus fail to comply, and in its General

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[825] Assisted Decision-Making (Ireland) Act 2015.

[826] Adult Guardianship and Trusteeship Act, Alberta 2008, Chapter A-4.2.

[827] ibid; The Adult Guardianship and Co-decision-making Act, Saskatchewan 2000, Chapter A-5.3; Civil Code of Quebec (C.C.Q.), S.Q. 1991, c. 64, Art. 291.

[828] Representation Agreement Act, British Columbia 1996, c 405.

Comment, the Committee on the Rights of Persons with Disabilities was clear that many States had failed to appreciate that the CRPD necessitated 'a shift from the substitute decision-making paradigm to one that is based on supported decision-making'.[829] Such models certainly put the individual at the centre of decisions about their treatment and care, ensuring that people with disabilities or impairments are the 'subject of rights rather than objects of welfare'.[830] In doing so, they also mitigate some of the harshest effects of the cliff-edge approach to capacity.

It is not however, without its problems. There will always be people who, no matter how much support is offered, will not be able to make a decision for themselves (those in a coma, for example). Some degree of substituted decision-making is therefore inevitable — as Ireland recognised when they provided for a 'decision-making representative' for anyone unable to make decisions even with support. While they may lower the threshold for capacity, SDM schemes do not remove it altogether: there will always be a point at which a person cannot decide and someone else must make that decision for them, so the question still arises of when this point ought to be, and how that decision ought to be made – reintroducing the difficulties identified at the start of this thesis. Indeed, it may cause even greater confusion, giving rise to disputes about categorisation at the margins of each 'grade' of capacity.

A number of issues would need to be resolved before England and Wales could adopt any such model. For example, how does this approach apply in situations where the person wants mutually exclusive things (not to eat, but to continue to live, for

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[829] CRPD Committee, General Comment (n461), [3].

[830] G. Richardson "Mental disabilities and the law: from substitute to supported decision making" (2012) 65(1) *Current Legal Problems* 333-354, 347.

example), and a decision must be made about which to prioritise. Current frameworks do not provide any basis for distinguishing inauthentic or disordered values or wishes from genuinely held beliefs. Such models also leave vulnerable people open to abuse. Supporters will, particularly in co-decision-making regimes, wield significant power over a person with impaired autonomy, as they must be consulted in any decision and are entrusted with 'supporting' that person to form a decision. This gives them substantial scope to influence and pressure the individual, yet because the role of the supporter is more opaque than that of a best interests decision-maker under the current law, it is much harder to know exactly what influence they might have had over the decision. Any system for England and Wales would thus require substantial safeguards to protect people in such situations.

As Gavin Davidson *et al* captured, 'the evidence suggests that implementing SDM is not a simple process, it takes time and resources, and may require a shift in attitudes of some care providers and in some service users themselves.'[831] It is doubtful therefore that there is the time, resources or appetite for this at present. Indeed, Genevra Richardson describes the prospect of such a scheme being accepted in the 'reasonably near future' as 'vanishingly slim';[832] even more, one that extends to people with psychiatric illnesses. For this reason the Law Commission did not engage with the possibility of such a shift, noting that the

> abandonment of best interest decision-making would raise many unresolved issues, and would be highly politically and ethically contentious at this stage. It is also not

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[831] G Davidson and others, "Supported Decision Making: A Review of the International Literature" (2015) 38 *International Journal of Law and Psychiatry* 61, 73.

[832] Richardson (n484), 351.

> within the remit of our review to initiate a complete reconfiguration of decision-making under the Mental Capacity Act.[833]

The same concerns apply here. While this thesis has highlighted some of the difficulties generated by a threshold approach to capacity, suggesting that there may be benefits to reconceiving of our approach to capacity in England and Wales, such radical and wholesale changes to this area of law warrant detailed consideration which is not within the scope of this thesis.

VI Conclusions

This section has proposed three changes to the MCA in order to provide greater guidance and support for doctors and local authorities, with a view to enabling them to make decisions which better empower the individual to live in accordance with their authentic values and beliefs. In doing so, it is hoped that the MCA will better meet the demands of Article 8 ECHR, and Article 12 CRPD, and strike a more appropriate balance between empowerment and protection than is currently being reached in practice.

The first proposal is to create a rebuttable presumption that, in so far as they are reasonably capable of being ascertained, the person’s wishes and feelings are determinative of their best interests, *unless* giving effect to them would expose the person to a serious risk of significant harm.

Where giving effect to the person’s wishes and feelings *would* expose them to a serious risk of significant harm, the decision-maker must then determine what is in the person’s best interests (i.e. whether the harm of frustrating the person’s wishes outweighs the significant harm of giving effect to them). When making this assessment

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[833] Law Commission, Consultation Paper (n424), 12.44.

then, the weight accorded to the person's wishes and feelings ought to be proportionate to the strength of those wishes. In these situations, the psychological and emotional harms of frustrating the person's wishes and imposing treatment or care decisions on them against their will are sufficiently grave that they may well outweigh the opposing harms, and thus giving effect to the person's wishes may be in their best interests.

These amendments are supported by a third amendment, to the defence in section 5, to ensure consistency in the MCA over when a doctor or care-worker might lawfully intervene in the decisions of someone found to have capacity.

The effect of these changes would be to substantially soften the capacity cliff-edge, ensuring that where a person is found to lack capacity, they still retain substantial say over the decisions made about them. This better reflects the fact that there are many people on the cusp of capacity, who while formally lacking capacity, nonetheless retain important elements of autonomy, which warrant respect.

Conclusion

The consequences of being found either to have, or to lack capacity, are immense. Those who have capacity may take any decision, irrespective of their reasons, or of its consequences. Those who lack capacity may not make their own decisions: instead, decisions are made for them, based on what others regard as being in their best interests. The test for capacity under the MCA is therefore instrumental in ensuring that while those who are able to make autonomous decisions are given the freedom to do so, those who are unable to make such decisions are provided with the support necessary to protect their interests and further their values.

Given the life-changing consequences of the capacity test, it might be presumed that it operates consistently and transparently, and is able to distinguish reliably between those who are capable of autonomous decision-making and those who are not. This thesis suggests that this is not the case — that the capacity test is currently not being applied accurately and consistently, and that as a result, disagreements are arising over the capacity of individuals on the 'cusp' of the threshold. It therefore puts forward a number of suggestions to address the shortcomings in the Act.

In part, the problems with the Act derive from a fundamental flaw in the conception of autonomy on which it relies. The Act takes far too a narrow an understanding of autonomy, focussing solely, and somewhat myopically, on the *process* by which a decision is made, in order to determine whether a person is acting autonomously. In doing so, the MCA fails to account for situations in which it is not the person's decision-making process which is impaired, but rather the content or substance of the values or beliefs underpinning their decision. In order to mitigate the effects of this, decision-makers have manipulated the test for capacity, adopting a strained interpretation of when a person is unable to 'use or weigh' the relevant information. Not only has this undermined the clarity, consistency and transparency with which the test for capacity is applied, but cases have occurred in which doctors have faced charges of battery for acting in this way.

Accordingly, this thesis has proposed that the 'use or weigh' criterion should be applied only to impairments in *process.* At the same time, a new limb of the capacity test should be introduced which focuses on the *content* of the person's values or beliefs. A person would thus be deemed unable to make a decision if the content of the wishes, feelings, values or beliefs being expressed by them are thought to have originated from or to have been altered as a result of a disease, illness or disorder. In this way, doctors could continue to intervene to protect the person, but rather than their decisions being opaque and unaccountable, their decisions would now be made in a clear and transparent fashion.

Even were the law to adopt a more demanding conception of autonomy, however, a further difficulty afflicts the way that capacity operates in practice. While capacity is, at law, a threshold concept, autonomy is not all-or-nothing, but admits of degrees, and is capable of being impaired in different ways and to different extents. This means there will often be a 'grey area' on the cusp of capacity, where a person's autonomy is uncertain. This inherent ambiguity places the doctors in the unenviable position of having to make sometimes very complex and multi-layered assessments about capacity, often under substantial time pressure and with access to only limited information. These challenges are then compounded by a lack of expertise on the part of the decision-maker in some cases, about the nature of the specific impairment from which the person is suffering.

Such decisions are made against the backdrop that if the person is found to have capacity, they will be permitted to refuse any intervention, even where that results in them suffering significant harm; on the other hand, a finding of incapacity will enable the clinician or care-giver to protect the person from themselves. It is no surprise, then, that where doctors perceive the person to be at risk, they are more inclined to opt for the latter, manipulating the threshold for capacity by more readily rebutting the presumption of capacity, in order to find the person to lack capacity. There are two problems with this. First, the test is being applied inconsistently as between decision-makers, so that different decision-makers might draw different conclusions about the same case, leaving the individual's rights and liberties vulnerable to the idiosyncrasies of the particular decision-maker. Second, the test is being driven by the outcome of the decision rather than the person's ability to make it. It is not the job of the doctor or care-giver to *agree* with the decision, but only to decide whether it is autonomously made.

Given the intensely subjective nature of autonomy, some degree of discretion when it comes to assessing capacity is unavoidable, and given that these are decisions made by individuals about other individuals, there will inevitably be some inconsistency in the way this discretion is exercised. In particular, it is impossible to set out prescriptively in advance how much autonomy a person must exhibit in order to be found capacitous, so this will always remain within the discretion of the decision-maker. However greater guidance would help to temper this discretion, and reduce the inconsistency that arises as a result of it. This guidance should include setting out what the 'relevant information' is that must be understood in respect of different treatment or care decisions; and detailing the ways in which different types of impairments or conditions might affect the person's decision-making, addressing concerns that non-experts must conduct these assessments.

When combined with the narrowing of the 'use or weigh' criterion, this would limit some of the discretion available to doctors to make outcome-orientated decisions. However to tackle this bias comprehensively, the law must remove the incentive to find the person to lack capacity so as to be able to prevent them from doing something that is harmful to themselves. This can only be done through allowing doctors some powers to intervene in the decisions of people who have capacity in order to protect them from themselves, something that could not be achieved without reconceptualising the boundaries of legitimate state authority.

Capacity assessments will never be entirely robust in operation — a substantial 'grey area' will necessarily remain on the cusp of capacity. If this is the case however, then the cliff-edge approach adopted by the law — permitting a large degree of interference with those who lack capacity — cannot be justified. While steps have been taken to mitigate the harshness of this through section 4(6) MCA, the failure to provide any guidance in the Act or Code of Practice on how to weigh the various factors in section 4, has resulted in paternalism and risk-aversion dominating best interest decisions on the ground. A more nuanced way of dealing with people on the cusp of capacity must therefore be adopted.

In order to address this, various reforms have been proposed. The first is a presumption that, in so far as they are reasonably capable of being ascertained, the person's wishes and feelings are determinative of their best interests, *unless* giving effect to them would expose the person to a serious risk of significant harm. Where giving effect to the person's wishes and feelings *would* expose them to a serious risk of significant harm, a best interest assessment must be conducted. When determining what is in the person's best interests, the weight accorded to their wishes and feelings ought to be proportionate to the strength of those wishes, with a view to decision-makers giving particular weight to those wishes which reflect deeply held values and beliefs. What these reforms do is to take account of the psychological harm that results from frustrating the person's wishes and imposing an unwanted decision on them, particularly where that is contrary to a strongly and deeply held wish which is of profound importance to the person. This harm can and should be considered as carefully as any physical harms. Indeed, it can be considered to be so damaging in some situations, that to occasion such harm cannot be said to be in the person's best interests, even where it would result in substantial harm, even death.

That a person lacks capacity does not make their wishes and feelings any less important, nor the experience of having their choices overridden and a treatment or care intervention forced upon them any less distressing. Neither is this an unusual scenario in the context of an ageing population, and increasing numbers of people suffering from mental illness. By 2037 it is expected that one in four of us will be over 65, and at least 3% of the population over 85.[834] 1 in 4 people each year meanwhile, suffer from a mental illness.[835] As old age and infirmity inevitably circumscribe people's choices, the areas in which they can still exercise their autonomy become all the more important to them. Adopting a more nuanced way of dealing with people on the cusp of capacity is therefore essential.

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[834] Office of National Statistics, *Overview of the UK Population: November 2018* (1st November 2018), available at: < https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/november2018> accessed 12th November 2018.

[835] S. McManus et al, *Adult psychiatric morbidity in England, 2007: results of a household survey* (2009) The NHS Information Centre for health and social care.

Appendices

Appendix A: General Questions put to Consultants

1. When assessing whether a person has capacity, what do you think you are you testing for?
    a. *Follow up questions (depending on answer):*
        i. What information are they required to understand?
        ii. What exactly do you think that 'use and weigh' is asking? How do you test for it?
2. Do you often come across cases in which you would regard the person's capacity to be on the cusp or borderline?
    a. What is it that indicates the cusp of capacity?
    b. What sorts of things makes a capacity assessment hard?
    c. Is there a particular limb of the capacity test under the MCA, which you are more often uncertain about whether they meet its requirements?
    d. Are there particular conditions where this problem arises more frequently?
    e. Are there particular treatment decisions where this problem arises more frequently?
3. Where a person is found to lack capacity, what factors do you usually weigh up when deciding what is in the best interests?
4. How frequently do you perceive a tension arising between what the person lacking capacity wishes, and what you consider to be in their best interests?
    a. Are there particular healthcare decisions in which this situation is more likely to arise?

5. When considering how much weight to give to the patient's views, what factors do you usually consider important when making this assessment?
6. [Show participant the Law Commission proposals to change section 4 best interests assessment]
    a. Do you think these changes are going to have an affect on how best interests are made in practice?
    b. Do you think these changes are welcome? Why/ why not?
7. [Explain Law Commission discussion on the supported decision-making, in which people who lack capacity would be able to formally appoint a trusted person ("a supporter"), to assist with decision-making.]
    a. What are your initial thoughts on whether or not this would be a helpful change?

Appendix B: Vignettes

Isobel

Isobel is 70 and has been diagnosed as suffering early stage dementia. She has a problem with her hip, which, due to stiffness and pain, makes it hard for her to get up the stairs to her bedroom and bathroom. Her family and doctors think it is advisable that she has a hip replacement however Isobel strongly objects to this. Although she understands the medical evidence in favour of having the replacement, she is scared of having an anaesthetic. Despite being in otherwise good health, and a low anaesthetic risk, she fears she will never wake up again. The doctors are concerned that if she does not have the hip replacement, Isobel will soon become unable to live in her home, and may have to move to a care home. Isobel is deeply opposed to moving from her home, but continues to refuse the operation.

Follow up questions:

1. Would your answer be different if the operation Isobel required was a heart bypass which would extend her life significantly, rather than a hip replacement?
2. What about if her reasons for refusal were not a fear of the anaesthesia, but because she doesn't want to live to an age where she becomes infirm and a burden on her family?

<u>Lucy</u>

Lucy has a mild learning disability. She is able to carry out basic day-to-day tasks and volunteers once a week in a charity shop, but she struggles with financial and administrative matters and so has to receive assistance with these. She stops taking contraception because she would like to have a baby. Lucy’s family are concerned that she does not fully understand the physical and emotional effects of pregnancy. They also think she will not be able to care for a child, which will either have to be raised by them, or taken into care, a view supported by the local social services who also think she would not be able to manage. This would cause Lucy great emotional distress. Lucy disputes this, saying she has read numerous books on pregnancy and motherhood, and understands the demands it places on her. When questioned by the doctors, she demonstrates a clear knowledge of the basic day-to-day needs of a baby, including feeding, changing nappies, sleep routines etc. Doctors suspect however, that she doesn't fully appreciate the impact that a baby will have on her life. She says that she wants the chance to experience motherhood and that if she cannot have a baby, she would rather not live at all.

Follow up questions:

1. What information would you expect Lucy to be able to understand to capacity to decide whether or not to take contraception?
2. Do you think her family's wishes on the matter are important here?

<u>Max</u>

Max suffers from schizophrenia, and experiences persecutory delusions. He has a bladder stone, which is causing him some abdominal pain, and he requires an operation to remove it. He understands the medical evidence in favour of having the operation, and the consequences of not having it, but is refusing it because he believes the pain is God's punishment for the sins he has committed during his life. He thinks doctors should not interfere with the actions of God, and that it is only God that will decide his fate. As a devout Christian throughout his life, he believes God will not let him die.

Follow up question:

1. If Max didn't have schizophrenia but still refused, for the same reasons (i.e. a belief that God will not let him die), would you then think he had capacity?

<u>Cara</u>

Cara is 26. She has suffered from anorexia nervosa since she was 14, and has been detained under the Mental Health Act a number of times in those years. She is admitted to hospital after taking an overdose of paracetamol. She says that she doesn't want to receive any treatment. She explains that her life has, for over 10 years, been plagued by her anorexia, and despite trying everything, she cannot get better. She says that she gains no pleasure from her life anymore, and wants to be left to die.

Becky

Becky has been in labour for 46 hours. She is very insistent that she wants a natural birth, and is refusing any painkillers. She is weepy, exhausted, and clearly struggling to cope with the pain. Becky is diagnosed with a placental abruption, and the doctor tells her she requires a caesarean section, and that if she doesn't, she is likely to lose the baby. Becky’s mother, Josie, is against her having a c-section. She is a hypnotherapist who believes strongly that women can avoid pain during childbirth via self-hypnosis, and that natural birthing is best for both mother and child. She encourages Becky to resist any offers of painkillers, telling her to focus on her mental state instead. Becky refuses the c-section. Although she appears to understand the potential consequences, she tells doctors that it is important to her that she gives birth naturally, whatever the consequences.

Oscar

Oscar is an 85 year-old man. He is brought into hospital having taken a paracetamol overdose. When asked, he says that the suicide attempt had been planned for some time, and that he does not want any treatment as he would like to end his life. He explains to the doctors, that his wife of 60 years died over a year ago, and that, although he is not depressed, he continues to miss her. He tells the doctors that he has had a good life, with a fulfilled career and a happy marriage, but that, without any children or grandchildren, there is nothing left to give meaning to his life, and so he believes this is the ‘right time to go’.

Appendix C: Participant information

Practice area	Number of Participants	NHS Trusts	Interview window
Psychiatry - Liason psychiatry - Old age psychiatry - Emergency psychiatry - General psychiatry	**9** 4 3 1 1	Oxford University Health, Oxfordshire Oxford Health, Oxfordshire	March 2017 – July 2017
Geriatrics	**3**	Oxford University Health, Oxfordshire	March 2017 – April 2017
Emergency Medicine	**3**	Oxford University Health, Oxford Barts Health, London	March 2017 – July 2017
General Practice	**1**	Oxfordshire	July 2017
Intensive Care	**1**	Oxford University Health, Oxfordshire	March 2017

Demographic Information

Total Participants	No. of pps at Consultant level	Gender distribution	No. of pps known to be BME	Place of work
17	16	Male: 11 pps Female: 6 pps	1	Oxfordshire: 15 pps London: 2 pps

Appendix D: Themes deriving from empirical research

Capacity assessments

The interviews involved both general open-ended questions and a discussion of a series of vignettes. The main themes derived from the empirical data centre around two different questions: the first related to how doctors understood the test for capacity and the second to how they applied the test, and what factors influenced whether or not a person was found to have capacity.

(a) How the test for capacity is being understood

When asked what doctors regarded themselves as testing for when they were assessing capacity, the responses largely centred around three common themes:

1. A legalistic response reiterating the limbs of the test for capacity in section 3 Mental Capacity Act 2005.
2. Whether the person can apply the information to themselves and understand how it would affect them specifically.
3. Whether the person can make a decision which reflects their values or beliefs.

One issue that frequently arose in the interviews was the precise meaning of the 'use or weigh' limb of the capacity test. The responses indicated four possible meanings were being attributed to this limb:

1. The person's ability to reason or to provide adequate reasons for deciding in the way that they have.
2. The person's ability to weigh up the risks and benefits of having the treatment (or the 'pros and cons' of it).
3. The person's ability to put the information in their own context and appreciate how it applies to them.
4. The person's ability to understand and appraise the information in light of their values or beliefs.

Further themes that commonly arose in interviews included:

1. That capacity operates on a spectrum (and is not all-or-nothing)

2. That people sit on the cusp of borderline of capacity (albeit different doctors gave different explanations for why a person might be said to be on the ‘cusp’ of capacity)
3. That the test for capacity was subjective (though again, doctors focussed on different limb’s of the test as examples of the test being subjective).

(b) Factors affecting capacity assessments

The factors affecting capacity assessments could broadly be divided into two different categories. The first of these are factors which affect the person’s actual capacity (albeit that they might be accommodated different as between different doctors in different specialisms). The key factors that commonly arose in interviews were:

1. Delirium
2. Pain
3. Effects of drugs or medication
4. Capacity fluctuating as between days
5. Capacity fluctuating within days.

The second category are factors which might affect the conclusion reached about whether or not the person has capacity, but which don't necessarily affect the person’s *actual* capacity. These included:

1. High patient numbers (and in particular the large numbers of older patients)
2. Staff shortages

3. A lack of information about the patient to enable capacity to be robustly assessed, either due to doctors having insufficient time or resources to acquire that information, or due to a lack of engagement on the part of the patient.
4. An awareness of the outcome of the assessment of capacity – either for the patient themselves (i.e. if found to have capacity, will they be permitted to do something which is seriously harmful to themselves?); or for the other staff members who have to abide by the doctor's decision.
5. A fear of litigation being brought by or on behalf of the patient.

Best interests assessments

The NVivo analysis suggested that a number of factors were commonly affecting how doctor's were making best interest assessments. These often also reflected factors that had been noted in the case law. The most commonly-cited of these included:

1. The invasiveness of the proposed treatment (physically or psychologically)
2. The outcome of the treatment:
    a. The prospect of the patient recovering or returning to a 'reasonable' quality of life
    b. Whether the treatment was life-sustaining
    c. What the perceived risks were of the person refusing the treatment or care intervention
3. The circumstances of the patient:
    a. Their degree of incapacity
    b. Their age

    c. The distress experienced by the patient of having their wishes overridden
4. The reasons given by the patient for deciding as they have:
    a. The perceived authenticity of their reasons
    b. Whether there was a religious dimension to their reasoning
5. The decision-maker themselves:
    a. Their own values and beliefs
    b. Their age
    c. Their specialism
    d. The resources available to the decision-maker
    e. Their understanding of the legal requirements.

Broadly, the empirical evidence suggested the following factors would lend support for greater (or less) weight being placed on the person's wishes.

Factors supporting greater weight being placed on the patients' wishes	**Factors supporting less weight being placed on the patients' wishes**
The nature of the treatment	
The treatment sought is invasive e.g. surgery	The treatment is necessary to save P's life
There is more time to acquire collateral information about	It is an emergency situation
The outcome of the treatment for the patient	
There is no reasonable prospect of recovery or achieving an acceptable quality of life	There is a reasonable prospect of recovery or achieving an acceptable quality of life
The risk-benefit analysis of the value of treatment is finely balanced	The risk-benefit analysis of the value of the treatment is not finely balanced
The risks associated with the treatment or care decision are lower	The risks associated with the treatment or care decision are high
The circumstances of the patient	

The patient's capacity is closer to meeting the capacity threshold	The patient's capacity is further from meeting the capacity threshold
The patient is older	The patient is younger
The patient is less vulnerable	The patient is more vulnerable
The patient is likely to experience substantial distress as a result of the treatment	The patient is less likely to be aware of or feel distress at the treatment
Reasons given by patient	
The patient's views have been consistently expressed throughout life	There is a lack of evidence that the patient's views have been consistently held
The patient's beliefs have a religious dimension	The beliefs or values are outside of a recognised belief structure
The decision-maker	
The patient's reasons accord with the decision-makers beliefs or values	The patient's reasons do not accord with the decision-makers beliefs or values
The decision-maker has a good understanding of their legal obligations	
The accountability structure for the decision-maker is clear.	

Appendix E: Research Ethics Committee Approval Letter

SOCIAL SCIENCES & HUMANITIES
INTER-DIVISIONAL RESEARCH ETHICS COMMITTEE

Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD
Tel: +44(0)1865 616576 Fax: +44(0)1865 280467
ethics@socsci.ox.ac.uk

UNIVERSITY OF
OXFORD

11 June 2019

Cressida Auckland
Department of Law Faculty

Dear Cressida Auckland,

Research Ethics Approval (CUREC 1A)
Ref No: R39750/RE001

Title: How should the law resolve the tension between empowering and protecting those lacking capacity when making decisions about treatment and care?

The above application has been considered on behalf of the Social Sciences and Humanities Inter-divisional Research Ethics Committee (IDREC) in accordance with the procedures laid down by the University for ethical approval of all research involving human participants.

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and accordingly approval has been granted.

Should there be any subsequent changes to the project, which raise ethical issues not covered in the original application, you should submit details to the IDREC for consideration.

Yours sincerely,

Claudia Kozeny-Pelling

Claudia Kozeny-Pelling
Research Ethics Manager and Secretary SSH IDREC

cc: Dr Imogen Goold, Professor Jonathan Herring, Geraldine Malloy

Appendix F: Participant Information Sheet

Participant Information Sheet

The Cusp of Capacity: empowering and protecting people lacking capacity in decisions about treatment and care

CUREC Ref No: R39750/RE001

Details of the Researcher

Cressida Auckland
(Doctoral Student in Law, University of Oxford)

Contact details:
cressida.auckland@law.ox.ac.uk
07770 517749

The Faculty of Law
St Cross Building
St Cross Road
University of Oxford
OX1 3UL

Why have you been invited to take part?

The research considers the robustness of the concept of capacity in law, and the appropriate legal treatment of patients lacking capacity when making decisions about their treatment and care.

Whether a person lacks the legal capacity to make decisions for themselves depends on whether they meet the test for capacity set out in the Mental Capacity Act 2005 (MCA).[836] There will be some people however, for whom making this assessment will prove difficult, those who may be said to fall on the 'cusp' or 'borderline' of capacity. The first part of the research will be considering in what circumstances, and for what reasons, a person might be deemed on the cusp of capacity.

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[836] Mental Capacity Act 2005, ss 2 and 3.

Where the person is found to lack capacity, the MCA requires that a decision must be made on their behalf in their 'best interests'.[837] In making this assessment, the decision-maker is required to 'permit and encourage the person to participate' in the decision (MCA s4(4)) and to consider inter alia, their 'past and present wishes and feelings' (s4(6)(a)) and the beliefs and values that might have influenced it if he had capacity (s4(6)(b)). The second part of the project is therefore determining how the provisions in s4(4) and 4(6) of the MCA are being interpreted both on the ground by clinicians, and in the courts.

While published case law will be analysed to see if any patterns or themes are emerging in the way that the courts are applying these provisions, it is only where resolution by doctors or other health care professionals proves problematic that cases come before the courts. It is essential therefore that the day-to-day decision-making of doctors be examined through semi-structured interviews, to see how they apply the provisions of the MCA in difficult cases, and the factors that are influencing the way that they apply them.

Do you have to take part?

You are free to refuse to participate in the study, or to ask questions about the study before deciding whether to participate. If you do agree to participate, you may withdraw both yourself, and any data collected from the study without penalty at any time, and without giving reason, by advising the researchers of this decision.

What will happen in the study?

You will be asked to complete an interview of approximately one hour in length. Questions will be of a general nature (and will not ask for any confidential information), considering the sorts of cases you commonly confront in day-to-day practice, and how such cases are usually handled. Questions may include:

- Do you often come across cases in which you would regard the person's capacity to be on the cusp? What is it that might indicate that this is a difficult or borderline case?
- How frequently is there tension between what the patient wishes and what you consider to be in their objective best interests?
- Are there particular healthcare decisions in which this situation is more likely to arise?
- When considering how much weight to give to the patient's views, what factors do you usually consider important when making this assessment?

In addition to the questions outlined above, you will be given a number of hypothetical scenarios in which a decision has to be made, both as to whether the person has capacity or not, and, if they do not have capacity, what would be in their best interests. You will be asked how you would respond if faced with this scenario, what further information you may want to know, what factors you consider to be important in determining the outcome of it, and what decision you would ultimately make in the circumstances.

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[837] Mental Capacity Act 2005, ss 1(5) and 4.

Interviews will take place at a location convenient for you, where you feel comfortable discussing these issues whilst maintaining confidentiality.

Are there any potential risks in taking part?

Given the nature of the study, concerns may be raised about confidentiality. All interviews will be anonymous, and pseudonyms will be used in any records. Care will also be taken to ensure that contextual information does not reveal the identity of the participants.

What happens to the research data provided?

Only the researcher (Cressida Auckland) will have access to personal data provided. It will be stored in accordance with the University of Oxford Policy on the Management of Research Data and Records, in an encoded form on the University HSF Server (Hierarchical File Server), which is stored within the IT Services at the University. At the end of the project, the data will be deposited in anonymised form in the HSF archive.[838]

Will the research be published?

The results of this study will form part of my DPhil thesis. The University of Oxford is committed to the dissemination of its research for the benefit of society and the economy and, in support of this commitment, has established an online archive of research materials. This archive includes digital copies of student theses successfully submitted as part of a University of Oxford postgraduate degree programme. Holding the archive online gives easy access for researchers to the full text of freely available theses, thereby increasing the likely impact and use of that research.

If you agree to participate in this project, the research will be written up as a thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives, to facilitate its use in future research. The thesis will be published with open access. Aspects of the research may also be published separately in peer-reviewed journals or books.

If you have a concern about any aspect of this project, please speak to the relevant researcher, Cressida Auckland (07770 517749; cressida.auckland@law.ox.ac.uk), who will do her best to answer your query. The researcher should acknowledge your concern within 10 working days and give you an indication of how she intends to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the chair of the Research Ethics Committee at the University of Oxford (Chair, Social Sciences & Humanities Inter-Divisional Research Ethics Committee; Email: ethics@socsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD). The chair will seek to resolve the matter in a reasonably expeditious manner.

Who has reviewed this project?

This project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee.

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[838] Please note, in line with the University Research Data Storage Policy, the minimum retention period for research data and records is three years after publication or public release of the work of the research.

Who do I contact if I have a concern about the study or I wish to complain?
If you have a concern about any aspect of this project, please speak to the relevant researcher (07770 517749) or their supervisor (01865 271491) who will do their best to answer your query. The researcher should acknowledge your concern within 10 working days and give you an indication of how she intends to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the chair of the Research Ethics Committee at the University of Oxford (using the contact details below) who will seek to resolve the matter in a reasonably expeditious manner:

> **Social Sciences & Humanities Inter-Divisional Research Ethics Committee**
> Email: ethics@socsci.ox.ac.uk;
> Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD)

If a participant in University-sponsored research is ever considered to have suffered harm through their participation, the University has arrangements in place to provide for compensation. If you have a concern about any aspect of this project, please speak to the researcher Cressida Auckland or the Principal Investigator, Professor Jonathan Herring who will do their best to answer your query. The researcher should acknowledge your concern within 10 working days and give you an indication of how she intends to deal with it.

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