

End of life care: how do we move forward?

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Death and dying are inevitable. High quality and accessible palliative and end of life care can help people who are facing progressive life-threatening and life-limiting illness, and those dear to them, by focusing on their quality of life and addressing the problems associated with their situation. This paper draws attention to the scale of the challenge, some of the key areas we could address and the shifts in culture, mindset and leadership approach that are needed.

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Background

Dying and death are inevitable. It is the final common pathway for us all. Those who suffer catastrophic events have little warning: days, hours or minutes at most. Others with one or more gradually deteriorating final illness may have months or years to prepare for it. For the bereaved there is a sense of loss and a need for readjustment to life without the dead person. The experience of the last hours, days, months or years of life is often etched in the memory of those who live on.

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. It aims to prevent and relieve suffering by means of early identification, assessment and treatment of pain and other problems: physical, psychosocial and spiritual.¹ It should be part of the core skill set of any health and care professional, regardless of where care is being provided or whatever the specialty. Some patients will require the additional expertise provided by specialists in palliative care, particularly if there are complex physical or psychological symptoms or complicated family, social or spiritual issues. Palliative care may be needed early in the course of an illness, in parallel with condition-specific interventions. Recognition of the potential benefit of palliative care should be based on need, not prognosis or life expectancy. Palliative medicine formally became a physician specialty in the UK in 1987.²

In the last decade, the term 'end of life care' has been added to the nomenclature in an attempt to define a cohort

of people for whom this care is particularly relevant, i.e. those who are likely to be in their last year of life. In its guidance on treatment and care towards the end of life, the UK General Medical Council defines this population as 'patients whose death is imminent (expected within a few hours or days) and those with: advanced progressive, incurable conditions; general frailty and co-existing conditions that mean they are expected to die within 12 months; existing conditions if they are at risk of dying from a sudden acute crisis in their condition; life-threatening acute conditions caused by sudden catastrophic events'.³

In 2008, the Scottish Government published its national action plan for palliative and end of life care,⁴ followed by a new strategic framework in 2015.⁵ Also in 2008, the Department of Health in England published a national strategy for end of life care for adults.⁶ Following the Health and Social Care Act 2012 in England and its increasing emphasis on local population-based commissioning of healthcare, the *Ambitions for Palliative and End of Life Care* was published in 2015.⁷ Although it built on the 2008 Strategy, its distinguishing features were that it covered the whole of life, not just adults; it was designed as a national framework for local action; it was co-produced and therefore jointly owned by an alliance of 27 national organisations across health and social care, and statutory and third sector communities; it had a set of six ambitions framed as person-centred outcomes, which were identified as the key themes from many publications, reports and recommendations for improving palliative and end of life care (Figure 1).

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Figure 1 Ambitions for Palliative and End of Life Care⁷

Along with these policy developments, there have been publications of guidelines and standards to support practice. In 2011, the National Institute for Health and Care Excellence (NICE) published a quality standard for *End of Life for Adults*.⁸ More recently, NICE has published clinical guidelines and quality standards focusing specifically on care of the dying adult^{9,10} and end of life care for children and young people.^{11,12} The General Medical Council published a generic professional capabilities framework which makes explicit reference to the need for doctors in training to 'demonstrate compassionate professional behaviour, clinical judgement and intervene appropriately to make sure patients have adequate...symptom control, pain management, end of life care...'.¹³ These are key publications which reflect the importance of this subject and aim to ensure that practitioners (whatever their specialty or setting), service providers and commissioners of health and social services, know what is required of them in the care of people approaching the end of their lives.

Scale of the challenge

The Global Atlas of Palliative Care¹⁴ estimates that over 20 million people each year require palliative care across the world, with almost 70% being adults over the age of 60 and 6% being children. In England and Wales, the number of deaths registered each year is on the rise from just over half a million in 2014, to 525,048 in 2016.¹⁵ This is projected to rise by over 25% by 2040. Based on these projections and current upward trends, the growth in the number of people requiring palliative care could range from 25 to 42.4%.¹⁶

Dementia and cancer are estimated to be the main drivers of need.¹⁶ Historically, the majority of people receiving palliative care had cancer, but there is growing recognition that people with non-malignant advanced progressive disease also benefit from palliative care. However, there appears to be a disparity in the proportion of people with cancer versus non-malignant conditions who are identified on the palliative care register.¹⁷

As medicine advances, more people are living longer but many more do so with multimorbidity. Some of these have

little impact on their lives, but others cause significant and multiplying effects in terms of discomfort, disability and frailty. All this points to a growing health and care need for the population as a whole. Age is clearly an important factor but it is not the whole story. Barnett et al.¹⁸ found that while the prevalence of multimorbidity was higher in older people, more than half of those with multimorbidity were younger than 65. They also found that multimorbidity started 10–15 years earlier in people living in the most deprived areas compared with the most affluent. Some of these conditions had particularly strong links to social deprivation and health inequalities, e.g. lung disease. About 115,000 people die from lung disease each year in the UK, with the top three lung diseases being lung cancer, chronic obstructive pulmonary disease and pneumonia.¹⁹ All those in the first two groups, and some in the latter, will benefit from palliative care.

The growing measurement of frailty has been enabled by the development of a frailty index which is electronically calculated using routine data in general practice. This electronic frailty index (eFI) has been found to have robust predictive validity for predicting outcomes in people aged between 65–95 years. For those with severe frailty, the 1 year adjusted hazard ratio is 4.52 for mortality and 4.73 for hospitalisation.²⁰ This gives us a real opportunity to identify this very vulnerable cohort of people so we can plan and offer proactive support for their end of life care.

Tackling some of the challenges

Identification

One of the key challenges in addressing the health and care needs of people approaching the end of their lives is to find them well before they present with a crisis. In some situations, recognising that someone is likely to be in their last year of life is obvious. In others, particularly those who have multimorbidity and frailty, recognising the 'tipping point' is much more difficult. To date, prognostic tools have been of limited value, particularly if more than one condition is involved. All of them require some degree of clinical judgement and skilled communication, particularly in order to understand the extent of symptoms and their impact on the patient's function and quality of life. This is particularly important for general practitioners, geratologists and condition-specific specialists, as they are best placed to recognise the change in trajectory and initiate these conversations with their patients. Trainees in these fields must learn to do so. The Supportive and Palliative Care Indicators Tool (SPICTTM), developed in Scotland, provides a useful approach to identifying people who may be at risk of deteriorating and therefore could benefit from proactive palliative and supportive care.^{21, 22}

Personalising care and decision making

In the interest of safety, there is a growing plethora of checklists: used well and wisely, these are helpful adjuncts to busy clinical practice. But there are too many instances in which these checklists become mindless tickboxes, and

risk depersonalising care, especially in situations where there is significant pressure on time and workload. There are increasing efforts to embed personalisation and shared decision-making within routine practice. Turning these intentions from rhetoric to reality is a challenge, especially as clinicians feel increasingly under pressure. Joseph-Williams et al.²³ describe a range of ways in which shared decision making can be implemented based on lessons learnt from the Making Good Decisions in Collaboration (MAGIC) programme, which had been commissioned by the Health Foundation to design, test and identify the best ways to embed shared decision making into routine primary and secondary care. The authors acknowledge the often claimed view that different patients want different levels of involvement but remind us that these preferences must be elicited rather than being based on the clinician's assumptions about the patient's desired level of involvement. They said '...skills trump tools, but attitudes trump skills'.

The range of therapeutic interventions that now exist are impressive but not always beneficial nor benign. They can bring adverse effects, burdens and risks that are not always known, defined or adequately acknowledged. Also, if patients are going to be able to truly participate in shared decision making, they need to have sufficient levels of health literacy. Health literacy skills are 'the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health'.²⁴ The challenge for doctors and other health professionals is that they need to adopt different styles and levels of communication for people with low versus high health literacy.²⁵ While this might seem obvious, it is important to recognise that this ability to adapt one's style to accommodate different levels of health literacy is also relevant to addressing health inequalities. There is evidence that low health literacy is associated with worse physical and mental health, and higher use of emergency services.²⁶ In the context of palliative and end of life care, where tensions often run high and emotions are fraught, the ability to recognise the pressure that this puts on pre-existing levels of health literacy and the need to rapidly and sensitively adapt one's communication style is even more critical. Communication skills training can help, though a recent systematic review showed that although generalist staff can improve their ability to show empathy and discuss emotions in simulated interactions in communication skills training situations, the effect of this training on their behaviour in real life and on patient-reported outcomes, was inconclusive.²⁷ It is therefore important we do not simply rely on communication skills training alone taking place, but that patient feedback is used to inform continuing professional development and quality improvements.

Measuring outcomes that matter

In recent years, the location of death has been used as one of the key measures, albeit a proxy one, for the quality of end of life care. This was based on the ease of collecting such data from death registration and systematic reviews which indicated that when people are asked for their preferred place

of death, over 60% of respondents had said they would prefer to die at home.²⁸ However, this could be misleading as the evidence came from a population based telephone survey, using a hypothetical scenario. This included people who did not have life threatening illness. A later systematic review found more varied figures for the preference for dying at home: 31–87% for patients, 25–64% for caregivers and 49–70% for the general public.²⁹ A more recent systematic review found that, once missing data were excluded from these studies, the median known preference for dying at home for patients dropped to 40% and 27% for caregivers.³⁰ The assumption that dying at home is a proxy measure of a good outcome in end of life care is therefore called into question. Many clinicians know that patients do change their minds as their condition deteriorates or circumstances change. Families and carers, however loving and willing, can also run out of steam. Moreover, the home becomes a place where healthcare provision takes place and this can lead to changes in home and family relationships for family carers who feel their personal space is diminished.³¹ This demonstrates why it is important to constantly re-examine policy and practice in the light of emerging evidence.

Societal

The final challenge I wish to raise is that of society and the environment. We live in a society where there is increased expectation of what can be achieved through medical advances and of access to health and care at all times of day and night. There is decreasing tolerance of failure. In recent years, there has been an emphasis on raising public awareness and encouraging people to talk about death and dying. This is certainly helpful and healthy for society at large. However, for the individual, it is even more important they are confident that if they initiate conversations about their illness or anticipated death, family, friends and professionals alike will be willing to discuss this. A recent survey carried out by the Malnutrition Task Force and Age UK reported (from that survey and other research) that older people found it difficult to talk to their family and professionals, but more easily to peers, about death and dying, and about wanting to stop treatment.³²

Digital transformation brings with it enormous potential and risks. Social media has great capacity for disseminating information but also misinformation. The role of big data and artificial intelligence bring exciting opportunities and create a paradigm shift. To ensure that this is a force for good, we must carefully think through what are the problems we need to solve, then use technology to achieve that, rather than be driven simply by the possibilities that technology brings.

How do we move forward?

The changes that are needed are three-fold: at the level of individual professionals; across the whole system of health and social care and, importantly, in society. In his book *Black Box Thinking*, Syed explores some of the changes that are needed.³³ He argues that there has to be a shift in our mindset so we recognise that failure represents opportunity to learn



Figure 2 Key elements of a culture of innovation³⁷. Reproduced with permission from The Kings Fund

and do better, not simply get stuck on finding scapegoats when things go wrong. It requires a willingness to take risks and experiment, which is vital for innovation. This will only work if our managers and the system share that mindset. A culture that makes it safe to admit and report on failure will encourage and facilitate higher standards, whereas if society stigmatises mistakes, professionals are more likely to feel the need to hide, or justify, these mistakes.

One way to break this vicious cycle is through the adoption of improvement science and building this capability across our health service. Individuals who develop the habits of improvement will be able to develop and enhance their own practice and, by building a community of like-minded individuals, will be much more likely to make quality improvements happen. The Health Foundation has published a thought-provoking paper in which it articulates five dimensions of improvement (Table 1).³⁴ There is already a growing emphasis on quality improvement, but there is now a need to rapidly grow the critical mass of clinicians, professionals and managers for whom quality improvement behaviour is simply a way of life.

Leadership is, of course, the crucial ingredient which will enable all this to flourish or flounder. Complex systems, such as healthcare, require system leaders who think beyond their organisational boundaries and see themselves as part of the wider system, one which puts the patient and their ‘whole person needs’ at the centre of everything they do. Bevan and Fairman describe how they see a tension between two kinds of power in today’s healthcare environment: the ‘old power’ which is based on positional authority and hierarchy, and the ‘new power’ which is based on networks, social movements and communities.³⁵ They argue that although both will continue to be needed, the emphasis of new power is on shared purpose, and it is this that can enable truly transformational change to happen. Dominant, hierarchical and top-down approaches to leadership are the most ineffective ways of managing healthcare organisations.³⁶ West et al.³⁷ identify the key elements of leadership that are most effective in promoting a culture of innovation (Figure 2). It is clear that the complex and inter-related world in which we all

Table 1 Dimensions of improvement³⁴

Learning	Questioning with curiosity
	Identifying the problem
	Reflection: need to understand whether changes are improvements or not
Influencing	Empathic
	Facilitative
	Being comfortable with conflict
Resilience	Optimistic
	Willingness to take calculated risk
	Tolerate uncertainty
Creativity	Generate ideas
	Critical thinking
	Team playing
Systems thinking	Connection making, e.g. using metaphors
	Synthesising – creates order out of chaos
	Accept change

live in today and in the future requires such compassionate and transformational leadership.

Conclusion

The Ambitions for Palliative and End of Life Care Framework (Figure 1) explicitly recognises these challenges through its six ambitions, i.e. each person is seen as an individual, each person has fair access to care, maximising comfort and wellbeing, care is coordinated, staff are prepared to care, and each community is prepared to help. It acknowledges that achieving this whole-system approach of ‘what good looks like’ in palliative and end of life care requires every individual, organisation and society as a whole to work together, so that the goal of the best possible end of life care can be achieved. ❶

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