Caring to the bitter end

In Brief

- **Disputes over medical treatment of sick children must be decided on the best interests principle**
- **The right to life does not require patients to be given treatment which is not in the best interests to be kept alive**

Introduction

A v MC (Care Proceedings) [2017] EWHC 370 (Fam) was one of those heart-breaking cases involving a seriously ill child. C was 13 1/4 and had multiple, significant disabilities. He had a limited life expectancy. The NHS Trust sought a declaration that it was lawful to withhold invasive treatment. His mother opposed the declaration.

C suffered from multiple disabilities. He had severe four limb involvement spastic quadriplegia with athetoid cerebral palsy, global developmental delay, no vocal communication, curvature of the spine, epilepsy, very limited swallowing reflex, and respiratory problems. His lungs were damaged by previous infections and he was he suffered chronic malnourishment. He did not have mental capacity to be involved in decisions about his care. C lived with his mother and have very occasional contact with his father, who played no part in these proceedings.

The breakdown of the relationships

The proceedings arose from a break down in the relationship between C's mother and the professionals involved in C's care. C was admitted to hospital in February 2016, although there had been chronic concerns about C's under nourishment and weight since 2012. A naso-gastic tube was fitted and some weight increased. It seems that it was at this point that the relationship between C's mother and the healthcare professionals and social workers became particularly strained. C's tube was removed and the mother refused to have it reinserted. She alsotook C to Romania, without informing the local authority. This led to the local authority's successful application for an interim care order.

In October 2016 C was described as "skeletal" and a tube was inserted into his gut to feed him that way. It was twice removed by the mother. She refused to consent to further invention feeding. The mother's refusal to cooperate with the care plan meant that she was prevented from unsupervised contact. The trust sought a care order and a declaration for a "ceiling of care". This would mean that all invasive treatment would be withheld and that the only treatment provided would be non-invasive interventions designed to improve C's quality of life. If the declaration was granted it would be to lead to a "redirection of management from life sustaining treatment to palliative". These applications were opposed by the mother.

The declaration

The key legal principles were clear. The court should make the declaration if doing so was in C's best interests. The parents' views were be heard but they did not carry weight. Indeed Russell J even rejected the view that the court would respect a parent's views unless they could be shown to be unreasonable, relying on *Re T (Wardship: Medical Treatment)* [1997] 1

WLR 242). Nothing was to detract the court from an objective assessment of the child's welfare.

The court referred to *Wyatt v Portsmouth NS Trust* [2005] EWCA Civ 1181 and *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67 and drew out the following key points:

• The welfare of the child is the court's paramount consideration;
• The court must look at the question from the point of view of the patient;
• There is a strong presumption in favour of action prolonging life, but the presumption can be rebutted
• The best interests assessments looks at medical, emotional and other welfare issues
• A balance sheet listing the benefits and disadvantages of alternative courses of action can help ensure all factors are weighed up properly.

Applying these to this case the court granted the declaration sought by the local authority, on an interim basis until the neurological assessment of C had been received. Rusell J explained that the treatment which could be withdrawn or withheld would have caused C considerable pain and discomfort and reduce his ability to enjoy the society of his mother and others. She concluded:

> "It is clear to the court that C seeks and wants to be close to his mother (and to the carers that he likes) and would not want to end his life without being able to do so. It is in his best interests, taking all aspects of his life, medical, social, familial and emotional into account, that the Trust is granted the declarations that it seeks."

and the interim care order was to remain in force. Russell J confirmed the Interim Care Order. There were "more than" sufficient and reasonable grounds to believe the s 31(2) criteria were made out. This was primarily based on the finding that the mother was responsible for the removal of the feeding tube on at least two occasions.

Discussion

It is important to emphasise this is not a case about active euthanasia. No one was suggesting the doctors should do an act which would cause C's death. That could be murder. The declaration was about whether the Trust could stop providing the treatment it had been giving or refrain from giving invasive treatment in the future. As the Trust no longer wanted to provide the treatment, the court had limited powers. It cannot require doctors to provide medical treatment against their professional judgement (as was recently confirmed by MacDonald J in *Re Y (No 1)* [2015] EWHC 1920 (Fam)).

The mother, unsurprisingly, relied on article 2 of the European Convention of Human Rights, which protects the right to life. Russell J confirmed that Article 2 does not require medical professionals to provide treatment which is futile nor treatment which is not in the best interests of the patient. She found that in this case the treatments which the hospital wished to withhold (particularly CPR) came with clear burdens, including continuous renal replacement therapy, which would require intubation. The treatments if provided would have meant C's decline towards death would be "all the more frightening, isolated and detached from the giving and receiving of human warmth, love and comfort" (para 66).

While there is no doubting the care Russell J gives to the case, the mother's perspective is somewhat lacking the judgement. While her struggle in caring for C with little, if any, personal support is acknowledged, her opposition to the professionals views is not really explained or examined. We are told she "finds it difficult to take accept or act on advice that she does not agree with", but we are not told the source of this disagreement. Indeed all we are really told about her views is that she did not agree with the experts. That may be because the mother failed to articulate objections. But the case sits somewhat uneasily with other cases of this kind, where there is a clear attempt to engage with the parents and understand their perspective.

Russell J seems to nearly indicate a wariness about placing weight on a parent's views, stating:

> The wishes of any parent may serve to inform and provide explanatory background as to the quality of the child's life, including that relationship with his parent but it is subjective, and not necessarily evidence which is relevant to an objective view of the best interests of the child.

Yet the relationship between a child and parent or primary carer; particularly a disabled child and their primary care is absolutely central to an assessment of the child's welfare. As Russell acknowledged in this case C had spent more time with his mother than anyone else and the mother knew C so well. The relationship between mother and child in such a case must be central to the assessment of welfare. This is not to say that the parent in such a case should determine what welfare means. But it should mean the child-mother relationship is a central factor in assessing welfare.

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