

# Confronting Death in Legal Disputes About Treatment-Limitation in Children

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**Abstract** Most legal analyses of selective nontreatment of seriously ill children centre on the question of whether it is in a child's best interests to be kept alive in the face of extreme suffering and/or an intolerable quality of life. Courts have resisted any direct confrontation with the question of whether the child's death is in his or her best interests. Nevertheless, representations of death may have an important role to play in this field of jurisprudence. The prevailing philosophy is to configure death as a release from a futile or painful existence and/or as a dignified end in an objectively hopeless situation. However, there can be disagreement about the meaning of death in these settings. Some parents object that death would be premature or that it represents a culpable neglect of their child. A closer examination of these discordant interpretations allows for a better comprehension of the cultural understandings that underscore clinical and legal accounts of death following end-of-life decisions.

**Keywords** Death and dying · Treatment-limitation in children · Parental opposition · Good death · Legal responsibility for death · Personhood and disability

## Introduction

As anthropologist James Green has observed, contemporary death is “culturally shaped by available technology; decisions about its application and withdrawal; and the constraints of medical, legal, and moral standards” (2008, 47). This medicalisation of death and dying has brought law and medicine into close partnership as families and clinicians struggle anxiously with difficult questions about the lives of their patients and loved ones who “hover in the liminal zone between active living and cold death” (Green 2008, 48). As we come to understand death and dying as matters of social as well as clinical and legal judgment, we also inevitably are brought into the sphere of negotiation and contestation. It thus has become necessary for courts to grapple with questions such as: Should the treatment cease? Who will be responsible for the decision and its consequences? How will death occur? When? Will it be now or later?

When it serves the child's best interests, the law regards decisions not to continue with active treatment as choices not to avert, rather than choices to cause or hasten, death. Such deaths are characterised as “natural” and, therefore, outside the scope of the criminal law. But there is no escaping the fact that in these situations death follows a decision. Where there is agreement between parents, clinicians and law that treatment-limitation is in the best interests of a child, there will be mutual understanding that the child's death is an acceptable, if tragic, outcome. However,

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death is capable of sustaining multiple and competing interpretations in these settings. Although death might be framed as a natural event, providing relief from unremitting pain and suffering, or as a good and dignified end in an objectively hopeless situation, it might also be framed as the premature or even culpable outcome of discriminatory judgment.

This article will reflect critically on the discordant understandings of death that emerge from the legal disputes about treatment-limitation in children and how these can, in turn, support competing claims about legal responsibility for death. It will first examine the ways in which death is configured in clinical and legal accounts of treatment-limitation. It will then explore parental objections to these decisions in order to draw out the nature of their challenges and the very different understandings of death that underscore them. It is suggested that these treatment-limitation disputes are embedded in larger cultural contests over the meaning of death.

### Confronting Death

There has been a growing awareness within neonatology over the last few decades that preventing death does not always serve the best interests of children. The withdrawal of life-sustaining treatment has steadily grown as a cause of death in neonatal intensive care units (NICUs) in Australia and comparator jurisdictions. In 1986, a study conducted at Hammersmith Hospital in the United Kingdom reported that 30% of NICU deaths followed withdrawal of treatment (Whitelaw 1986). In 2001, that figure rose to around 70% for the United Kingdom (McHaffie et al. 2001), and Australian studies report even higher figures (Wilkinson et al. 2006). Doyal and Durbin argue that, prior to the development of sophisticated life-saving technologies, it was relatively unproblematic for the neonatologist to attempt to use all measures to save the lives of premature newborns because “most died, and medical intervention was usually unsuccessful for those who did not” (1998, 275). However, as neonatal intervention and care have improved, “we increasingly understand that though such treatment may save life, success can create a terrible burden for some children and their parents” (Doyal and Durbin 1998, 275). The survival of extremely impaired children has been credited with

forcing a rethinking of the manner in which technologies are deployed in neonatal care. More fundamentally, however, it has led to a search for a set of normative principles that can appropriately ground decisions to end active treatment, notwithstanding that so doing will result in death (Singer 1995). This reevaluation has seriously challenged, if not supplanted, the idea that life should always be saved, regardless of its quality.

The ethical withdrawal or withholding of medical treatment rests on a constellation of ideas and associations between the purpose of treatment and its likely effect. One influential attempt to systematise these ideas into policy guidance for clinicians can be found in the Royal College of Paediatrics and Child Health (RCPCH) publication *Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice* (hereafter RCPCH guidance) (Royal College of Paediatrics and Child Health 2004).<sup>1</sup> This identifies five situations in which treatment-limiting decisions might be taken. These include:

1. The “Brain Dead” Child. ...
2. The “Permanent Vegetative” State. ...
3. The “No Chance” Situation ... [where the] child has such severe disease that life-sustaining treatment simply delays death without significant alleviation of suffering. ...
4. The “No purpose” Situation ... [where although] the patient may be able to survive with treatment, the degree of physical or mental impairment will be so great that it is unreasonable to expect them to bear it.
5. The “Unbearable” Situation ... [where the] child and/or family feel that in the face of progressive and irreversible illness further treatment is more than can be borne (Royal College of Paediatrics and Child Health 2004, 10–11).

The guiding principle is that active treatment will be questionable if it merely prolongs the child’s suffering and offers no benefit. How “suffering” is to be understood is further refined

<sup>1</sup> Other guidelines on treatment-limiting decisions in children include the American Academy of Pediatrics Committee on Bioethics’ (1994) “Guidelines on Foregoing Life-Sustaining Medical Treatment and New South Wales Health’s (2005) *Guidelines for End-of-life Care and Decision-Making*.

by reference both to the condition of the child (brain dead, dying, permanently or severely disabled, or suffering progressive illness) and to the burdens of the treatment.

### Inevitable Deaths

How *death* is to be understood relative to the purpose of the treatment in question is only explicit in categories 1 and 3. In category 1, death by medical and legal standards has already occurred, and so this represents a situation where treatment is not merely questionable but entirely without purpose. In category 3, the child is suffering and there is no chance of survival or, to put this differently, death is proximate and inevitable. Courts have been confronted with such situations, for example, *Re C (A Minor)(Medical Treatment)* [1998] 1 FLR 384, which concerned a 16-month-old child who suffered from a fatal and incurable disease, spinal muscular atrophy. She had only limited movement in her arms and legs and this would progressively worsen until she was completely paralysed. The child C needed artificial ventilation to breathe, and her life expectancy was estimated at not more than 9 months. The court explained her condition in the following terms:

There is no issue in this case that this is a fatal disease and that in real terms this little child is approaching death. She has a desperately tragic existence. She is emaciated. Although she is conscious, there is the prospect of increased suffering as the days go by. The doctors are all of the view that it would be in her best interests that she be removed from ventilation and that in the event of what they believe to be an inevitable respiratory arrest it would follow that she should not be replaced on ventilation which would of itself give rise to increased suffering and distress (*Re C (A Minor)(Medical Treatment)* [1998] 1 FLR 384, 388).

In addition to death's inevitability, the determination of best interests for a dying child will consider the burdens of the treatment itself. In *Re OT (A Child)* [2009] EWCA Civ 409, a case concerning a child suffering from a mitochondrial condition of genetic origin, the child required frequent suctioning to

prevent choking, which doctors believed was extremely distressing. The court accepted that "suctioning causes him extreme discomfort and probably pain" and that ventilation "raised the risk of complications, including of further strokes leading to further brain damage; ... a substantial risk of further infections and, over all, of multiple organ failure" (*Re OT* [2009] EWCA Civ 409, [2]). In this case, the court held that "it would be lawful, as being in OT's best interests, for the hospital ... to withdraw and withhold ventilatory support from him and to move to a regime of palliative care in order to lessen his discomfort, and respect his dignity, during the no doubt extremely brief period of his life thereafter" (*Re OT* [2009] EWCA Civ 409, [20]).

In situations such as *Re OT* and *Re C*, death is configured as a release from a short future that would, in any event, be eclipsed by pain and suffering. Significantly, death also is understood to be a natural event. In these cases, law regards technology as being the reason for the child's existence. This is implicit in the reasoning of Lord Donaldson who, in *Re J (A Minor)(Wardship: Medical Treatment)* [1991] Fam 33, observed of such cases that "no amount of medical skill or care could do more than achieve a brief postponement of the moment of death ... death is inevitable, not in the sense that it is inevitable for all of us, but in the sense that the child is actually dying. What is being balanced is not life against death, but a marginally longer life of pain against a marginally shorter life free from pain and ending in death with dignity" (*Re J* [1991] Fam 33, 42). The idea that treatment is merely postponing death frames the child's life as precarious and contingent. Hopkins makes this point in the specific context of artificial ventilation, when he observes that "once the patient's breathing is artificial ... his or her very existence is perceived as a novel phenomenon" (1997, 33). This is significant because, once the breathing machine is seen as the reason that the child is alive, the removal of that machine may be configured as returning to some "natural" state in which death will occur (Hopkins 1997, 33). This, too, is clearly articulated in the judgment of Lord Justice Taylor in *Re J* when he states that "the court ... has to decide, not whether to end life, but whether to prolong it by treatment without which death would ensue from natural causes" (*Re J* [1991] Fam 33, 54).

## Acceptable Deaths

In categories 2 and 4, death may not be inevitable in the sense described in *Re OT* and *Re C*. Nevertheless, it might be an acceptable outcome in light of the balance of benefits and burdens of treatment. The idea that treatment has “no purpose” is prefigured by certain understandings and beliefs about personhood and the qualities that make life meaningful such as “consciousness, the capacity for physical, social and mental interaction with other beings, having conscious preferences for continued life, and having enjoyable experiences” (Singer 1995, 192). It is also prefigured by certain beliefs about how medicine should be directed. Thus, Doyal and Durbin argue “the moral point of health care—what is beneficent and non-maleficent about it—is the optimisation of the potential for human flourishing through therapeutic intervention which is designed to minimise any mental or physical disability brought about by sickness or disease” (1998, 279). In their view, individuals who can neither engage in social interaction nor conceptualise such interactions have no need for life-sustaining treatment. They state that:

In such circumstances of extreme and untreatable neurological damage, there would be no reason to be alive as a human, because there would be no ability to do the things which ordinary humans do. Further, such profound disability would make it impossible intentionally to contribute to the potential flourishing of others—nothing to add to their personal or private lives, other than perhaps their own feelings of virtue in the exercise of their concern and charity (Doyal and Durbin 1998, 279).

Within this framework, cognitive impairment stands as a negation of the very qualities that are thought to be central to personhood. Indeed, there is evidence that cognitive impairments are assessed particularly negatively in practice. Wilkinson observes that in paediatric practice “the single most important factor in discussions on withdrawal of treatment is the presence (or predicted presence) of severe intellectual disability. ... On the other hand, where intellectual disability is not present (or predicted), even when the child’s prognosis is very grim, or includes substantial physical disabilities, there is often a reluctance to countenance anything less than

maximal treatment” (2006, 454–455). Disability studies theorist Tom Koch (1998) makes similar findings in his research on attitudes toward selective nontreatment of disabled individuals. He found that intellectual disability was assessed far less favourably than physical impairments in determinations about nontreatment. He notes that “[o]ne physician summed up the group’s sentiment when he said flatly, ‘No physical state should be a deterrent [to continued treatment] as long as they’re cognitively normal’” (Koch 1998, 113). In an effort to better understand these responses to cognitive impairment, Wilkinson argues that:

since the experience of many cognitively impaired individuals are inaccessible to us, the only option is to judge their quality of life according to their capacity to enjoy the goods that most people would regard as “objectively valuable” such as “knowledge, communication, the development of deep reciprocal relationships, or the achievement of goals or ambitions” (Wilkinson 2006, 458).

Wilkinson further acknowledges that the choice of these goods necessarily privileges intellectual over nonintellectual “goods,” but, he argues, this is consistent with the fact that “reason is a key distinguishing characteristic of humans” (Wilkinson 2006, 458).

These inverse associations between maximal treatment and severe impairment also find expression in law. It is now well established in law that continuing to provide life-sustaining medical treatment to a child with extremely limited cognitive functioning may not be in a child’s best interests. *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33 concerned a prematurely born child with very severe brain damage. Doctors predicted that he would develop a range of problems, including spastic quadriplegia, blindness, and deafness, but that he may nonetheless live into his teens with medical support. Doctors wanted to know whether they could lawfully withhold ventilation in the event of a future respiratory collapse. At first instance, the court decided that ventilation could be withheld in J’s best interests. On appeal, it was unsuccessfully argued that, as the child was not terminally ill, doctors were bound to provide treatment aimed at prolonging his life. As this was the first case in which an English

court held that it was in the best interests of a child who was not dying to withhold treatment, the court carefully explained the reasoning behind the decision. Lord Donaldson observed:

What is in issue in these cases is not a right to impose death, but a right to choose a course of conduct which will fail to avert death. ... The choice is that of the parents or court if, by reason of his age, the child cannot make the choice and it is a choice which must be made solely *on behalf of the child*" (*Re J* [1991] Fam 33, 44, *emphasis original*).

It was held that the child's actual and predicted quality of life did not justify the burden to him in prolonging his life. According to Lord Donaldson:

There is without doubt a very strong presumption in favour of a course of action that will prolong life. ... But in the end, there will be cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause increased suffering and produce no commensurate benefit (*Re J* [1991] Fam 33, 46–47).

It was, thus, not in J's best interests to be ventilated should the need arise and, in that event, his death would be an accepted outcome.

#### *Death as a Release From a Pitiful Existence*

Consistent with Wilkinson's observations, the vast majority of applications to English courts for orders to permit treatment-limitation concern children, like J, with cognitive impairment. Justice Hedley in *Portsmouth NHS Trust v Wyatt* [2004] EWHC 2247 (Fam), for instance, identified the key to the decision to withhold ventilation was "the quality of [Charlotte Wyatt's] sensory faculties" and concluded that the fact that she was deaf, blind, and without volition "substantially preclude[d] physical or emotional response to another human" (*Portsmouth NHS Trust v Wyatt* [2004] EWHC 2247 (Fam), [31]). In *Re C (A Minor)(Wardship: Medical Treatment)* [1990] Fam 26, doctors wished to withhold antibiotics, gastric feeding and intravenous fluids from a 4-month-old child born with severe hydrocephalus, because they considered it inconceivable that the baby would develop appreciable skills. The primary judge decided

that it was in C's best interests to allow the hospital to "treat [C] to die," although this wording was subsequently amended to state that the hospital was "at liberty to treat the child to allow her life to come to an end peacefully and with dignity" (*Re C (A Minor)(Wardship: Medical Treatment)* [1990] Fam 26, 35). The Court of Appeal approved the primary judge's statement that

any quality to life has already been denied to this child because it cannot flow from a brain incapable of even limited intellectual function. In as much as one judges, as I do, intellectual function to be a hallmark of our humanity, her functioning on that level is negligible if it exists at all. Coupled with her total physical handicap, the quality of her life will be demonstrably awful and intolerable (*Re C* [1990] Fam 26, 35).

In an attempt to better understand why cognitive impairments are assessed so negatively, Wilkinson identifies three possibilities. First, in very severe cases of cognitive impairment, the child may have no interests to speak of because he or she has no consciousness at all; second, that cognitive impairment is itself a form of suffering; and/or, third, that cognitive impairment diminishes the benefits derived from living (Wilkinson 2006, 456–458). The idea that cognitive impairment diminishes the benefits of living seems closest to the meaning used in the RCPCH guidance, which describes "intolerable disability" as occurring "when there is little or no prospect of meaningful interaction with others or the environment" (RCPCH 2004, 24). In this situation, the RCPCH guidance continues, "no reasonable person would want to lead such a life, nor impose on a doctor a duty actively to strive to bring it about" (RCPCH 2004, 24). Nevertheless, some slippage between these three possible bases is apparent in the case law, and it is reasonable to suggest that courts also have on occasion regarded cognitive impairment or reduced consciousness as a form of suffering in itself.

#### *Death as a Release From the Distressing, Invasive Activity Required to Sustain Life*

As we have already seen, where the treatment in question is artificial ventilation, the burdensome nature of the treatment is often cited as a significant

disbenefit (*Re OT* [2009] EWCA Civ 409, *Re B (A Child)* [2009] EWHC 3269 (Fam); *Re Winston-Jones (A Child)(Medical Treatment: Parent's Consent)* [2004] All ER 313). Courts have taken a broad view of suffering in this context. This may encompass the pain and distress caused by the intervention and its associated procedures (even if these would not be permanent) and also the suffering that might be said to arise from the limits that the interventions place on consciousness or other capacities. Thus, in *Royal Wolverhampton Hospitals NHS Trust v B* [2000] 2 FCR 76, it was noted that ventilation was distressing because it entailed “there being a sizeable tube down the patient’s throat ... [with the result] that a child of this age would need to be sedated so as not to be distressed. In other words, her consciousness would be altered or reduced, although she would not be unconscious” (*Royal Wolverhampton Hospitals NHS Trust v B* [2000] 2 FCR 76, 78). Similarly, in *Re Winston-Jones (A Child)(Medical Treatment: Parent's Consent)*, declarations were sought that it would be lawful not to ventilate a 9-month-old child who was born with trisomy 18, a genetic condition associated with heart defects, respiratory problems, developmental delay epilepsy, and hypertonia. The court was persuaded that being placed on a ventilator would not be in the child’s best interests because of the level of sedation needed to support him on the ventilator and the fact that he would be deprived of the physical closeness of his mother (*Re Winston-Jones* [2004] All ER 313, [25]).

The argument that treatment causes significant distress and suffering is clearest when the treatment in question is artificial ventilation. However, the withholding of tracheostomy surgery and the withdrawal of artificial feeding also have been assessed as being in a child’s best interests (*Re B (A Child)* [2009] EWHC 3269 (Fam); *Re Baby D (No 2)* [2011] FamCA 176; *Re K (A Child)(Withdrawal of Treatment)* [2006] EWHC 1007 (Fam)). In the case of these treatments, distinguishing between the futility of existence and the pain and distress inflicted by the treatments may be even more complex. In *Re B (A Child)*, RB was born with congenital myasthenic syndrome, a rare neuromuscular condition that severely limited RB’s ability to breathe and move his limbs. RB’s father argued that he should have a tracheostomy operation, though his mother disagreed. In any event, doctors refused to perform the operation on the belief that, even if this could enable RB to go home, his life would nonetheless be

too burdensome. Dr. F, a paediatric intensive care consultant, gave evidence that Baby RB was “severely limited in his ability to reach any sort of potential” and observed that “his disabilities would become more and more marked as he grew older” (BBC News 2009, ¶7 under “On a Knife Edge”). The doctor concluded that his “heartfelt feeling is that his existence is impoverished” (BBC News 2009, ¶8 under “On a Knife Edge”). The clinical view was that the tracheostomy, “rather than being a panacea, would simply open up the potential for him to have to endure a further range of procedures and operations. The very living of life itself, day by day, hour by hour, is likely to be at best uncomfortable and, more probably, regularly painful for him” (*Re B (A Child)* [2009] EWHC 3269 (Fam), [7]). After hearing 6 days of evidence, RB’s father withdrew his opposition to the proposed treatment withdrawal. As a result, the court did not have to rule on whether the withdrawal of ventilation was in RB’s best interests. Nevertheless, Justice MacFarlane concurred with the decision reached (*Re B (A Child)* [2009] EWHC 3269 (Fam), [10]).

Similarly, in *Re Baby D (No 2)* [2011] FamCA 176, the court was asked to determine whether an endotracheal tube could be withdrawn in circumstances where the child was profoundly neurologically impaired but not ventilator dependent (she was, however, dependent on the tube to keep her airway open). Baby D had suffered a tracheal obstruction when extubated on a prior occasion, and it was not known whether she would develop an airway obstruction when the tube was withdrawn a second time. However, the doctors and her parents felt that, if she did, it would be best to accept her death and not attempt to address the obstruction. The unique feature of Baby D’s case was that she had “no underlying irrecoverable life-threatening problem” (*Re Baby D (No 2)* [2011] FamCA 176, [65]). Her support was limited to the tube that was keeping her airway open—she did not require the machine to breathe and her other major organ systems (excepting her brain) were not compromised. Like Baby RB, tracheostomy was, at least theoretically, a treatment option for Baby D. The independent medical expert, Dr. W, explained:

In this situation the much more difficult calculation which must be made is whether the immediate burden of care is so great that it is not justified by what the child can gain from it,

to whether the ongoing quality of life for the child is so demonstrably awful that it is legitimate to accept the death of the child concerned. ... [S]uch balancing requires the humility needed to understand that we cannot cure everything and that just because a medical intervention is possible does not necessarily mean it is good medical practice to offer it (*Re Baby D (No 2)* [2011] FamCA 176, [136]).

On this view, it would not be good practice to offer the intervention because, though it could fix the airway problem, Baby D's neurological damage was so extensive and irreversible that her impairments could never be "cured." This is a case in which it seems to have been accepted that the treatment would cause increased suffering, both because of the procedures associated with a tracheostomy and, perhaps as importantly, because it was thought that her life would hold little meaning for her (*Re Baby D (No 2)* [2011] FamCA 176, [147]–[151]). Within this framework, death is configured as a release from a pitiful existence *as well as* from the persistent, distressing, and invasive activity required to sustain fragile and vulnerable life.

### Contested Deaths—Parental Opposition to Treatment-Limitation

The ethical and legal basis for lawful treatment-limitation configures death as a release from an intolerable life that is being prolonged without benefit. As mentioned previously, this understanding about treatment and its burdens rests on a particular construction of individuated personhood that values "consciousness, the capacity for physical, social and mental interaction with other beings, having conscious preferences for continued life, and having enjoyable experiences" (Singer 1995, 192). Where a child's quality of life is judged to be very poor relative to these measures, the ideal is that families and physicians will agree that death is inevitable or acceptable and the treatment should be withdrawn to allow the child to die. However, a number of recent cases demonstrate that this consensus is not always possible. An examination of these disputes shows three crucial points of departure. The first concerns the characterisation of death as "good" in circum-

stances where parents do not accept that it should occur at all. Second, some of these parents have rejected the framing of death as a natural event and have instead regarded death as being causally related to the acts or omissions of doctors. Third, some parents have posed a more fundamental challenge to the negative assessment of cognitive impairment and the understanding of personhood upon which it is based.

### A Good and Dignified Death

The first challenge posed by dissenting families is to the construction of a "good death" as a real benefit to their child. The idea of a "good" death is tied to the issue of how precisely death is to occur once the decision has been made to stop active treatment. The idea that a planned and controlled death can provide a benefit to the child might seem to sit a little uneasily within the legal framework for determining best interests. Courts have been emphatic that the best-interests assessment is not an assessment of whether death is best for the child but rather whether the treatment is offering benefit. In *Airedale NHS Trust v Bland*, Lord Goff observed:

The question is not whether it is in the best interests of the patient that he should die. The question is whether it is in the best interests of the patient that his life should be prolonged by the continuance of this form of medical treatment or care (*Airedale NHS Trust v Bland* [1993] All ER 860, 869).

Nevertheless, it is implicit in the cases considered above that death will not always be regarded as a wrong or harm to be avoided and that some forms of dying are preferable to others. Since *Bland*, the law has been increasingly drawn into discussions around what constitutes a "good" death. In *Portsmouth NHS Trust v Wyatt*, Justice Hedley remarked that "any consideration of best interests in a person at risk of imminent death is that of securing a 'good death'" (*Portsmouth NHS Trust v Wyatt* [2004] EWHC 2247 (Fam), [28]). In this case, the hospital argued that ventilation should be withheld in the event of inevitable deterioration so that the child "should be allowed to die peacefully in her parents arms if that is the natural course" (*Portsmouth NHS Trust v Wyatt*

[2004] EWHC 2247 (Fam), [27]). The court then offered the following observation:

Given that death is the one experience (other than birth) that all humanity must share, no view of life that does not include a contemplation of the place of death, even in a child, can be complete. As a society we fight shy of pondering on death yet inherent in each of us is a deep desire for both oneself and for those we love for a “good” death (*Portsmouth NHS Trust v Wyatt* [2004] EWHC 2247 (Fam), [28]).

Although a good death may be open to differing interpretation, there are hints at what the courts mean by this term. A good death is defined in part by the absence or minimisation of technology, by appropriate levels of pain relief and sedation, and by its speed and predictable timing. In the case of *An NHS Trust v MB* [2006] EWHC 507 (Fam), for example, doctors wished to effect immediate withdrawal of ventilation so that the patient’s death would be “carefully planned and agreed” (*An NHS Trust v MB* [2006] EWHC 507 (Fam), [55]). This was described as follows:

Appropriate sedation would be given to dull pain and distress but not, of itself, to cause death; and M would die rapidly and peacefully, disconnected from all equipment, and in the arms of his parents if they wish. ... [This would] enable M to have a peaceful and dignified death, or as Dr SI called it “a good death,” which the doctors regard as a real benefit to M (*An NHS Trust v MB* [2006] EWHC 507 (Fam), [55]).

This good death was contrasted with an alternative scenario in which “the time of death would be unpredictable” (*An NHS Trust v MB* [2006] EWHC 507 (Fam), [56]).

This conceptualisation of “good death” is an emerging theme in the case law, where it has been implied on more than one occasion that a dignified and/or peaceful death is a death without the presence of technology. Another example of this can be found in *Re K (A Child)(Withdrawal of Treatment)* [2006] EWHC 1007 (Fam), where the court held that treatment withdrawal “would not only be a mercy” but that it was “in her best interests to cease to provide TPN (total parenteral nutrition) while she is still clinically stable, so that she may die in peace and

over a comparatively short space of time, relieved by the palliative treatment contemplated ... [which] will enable her to live out her short life in relative peace in the close care of her parents who love her” (*Re K (A Child)(Withdrawal of Treatment)* [2006] EWHC 1007 (Fam), [57]). This understandable concern to ensure that a bad death is avoided will serve those families, like Baby K’s and Baby D’s, who are reconciled to the death of their child. But where there is no such acceptance, this approach raises the question: What benefit does a “good” death offer when there is fundamental disagreement about whether death should occur at all?

### Responsibility for Death

These questions lead directly to the second challenge issued by parents who oppose treatment-limitation for their children; namely, that treatment-limitation is, or will be, the cause of their child’s death. This challenge has taken two forms: Where parents accept that the child will die, they might nonetheless object that the planned treatment withdrawal is premature and, thus, hastening their child’s death. Alternatively (or in addition), parents may not accept that their child is dying, or should be allowed to die, but claim that treatment is being wrongly withheld or withdrawn because doctors hold distorted views about their child’s current or predicted quality of life.

### *Death is Premature*

Dissenting parental accounts differ significantly from clinical accounts in the emphasis they place on the potential and “fighting spirit” of their child. They implicitly reject medical understandings of futility by claiming the value of the additional time accorded to them with their dying or severely impaired children. Kellehear’s understanding of dying as a social relationship may help to clarify what is at stake for these families. He argues that dying is a social relationship and, thus, necessarily involves a broader web of relationships in which social attachment and disengagement occur and which delimit “particular moral and social functions during bodily decline” (Kellehear 2004, 1540). From this sociological viewpoint, these disputes can be read as disagreements about the nature of these obligations to the dying

patient. In the case of religious families, the relationship to their kin might underscore a religious obligation to ensure that life is protected to the greatest extent possible. But even where religious obligation is not the basis for the family's opposition, family members might understand themselves to be bound by a continuing obligation of care. *Re Winston-Jones (A Child)(Medical Treatment: Parent's Consent)* [2004] All ER 313 provides a good illustration of this point. The agreed medical position in this case was that the condition was incurable and that L had only a very short life expectancy. The court described the family's view as follows:

The strongly held view of the mother is that L has not deteriorated to the extent that is set out in the medical reports. ... L has clung to life and is a fighter, and has already defied the odds by staying alive. ... She [the mother] naturally wants to give him [L] every opportunity to be as fulfilled as is possible in his life. She accepts the medical reality that this is a question of management of his shortened life and the most appropriate palliative arrangements for his needs. She would want him to be dignified and comfortable, to end his life with dignity and peacefully, but in his time (*Re Winston-Jones (A Child)(Medical Treatment: Parent's Consent)* [2004] All ER 313, [8]).

L's mother did not dispute that her child might die, but she wanted to know that he had been given "every chance at life" (BBC News 2004a, ¶2 under "Ethical Dilemma"). Thus, she did not want cardiac massage withheld should the need arise, nor did she want ventilation to be automatically ruled out. Her belief was that, since L had not given up, nor should she (BBC News 2004b). In her words:

I cannot even begin to put into words how it feels as a mother to be facing this complete and utter nightmare. I cannot just stand by and allow my baby to die, they have all given up, but I will not. They want to play God with my son's life but I will not allow it. I am his mother and I will do what comes naturally to me, which is to protect him from any harm (BBC News 2004b, ¶10).

These statements reveal just how discordant were the meanings ascribed to these interventions by L's mother and his doctors. As we saw earlier, the agreed medical position was that L was dying and that

neither cardiac massage nor ventilation was in his best interests. In contrast, L's mother understood these as life-saving interventions, the withholding of which would signal an abandonment of him. Within her frame of reference, death is not only configured as a harm to L (because it would be premature) but also as an outcome for which doctors would be morally, if not legally, responsible. The clinicians and, ultimately, the court rejected this understanding of ventilation. However, the court was more troubled by the prospect of withholding cardiac massage from L:

I recognise that all the treating doctors and almost all the experts oppose the idea of cardiac massage, but as I have said, it has been used twice and whatever part it may have played in resuscitation on 8 October, that cannot have been negative. I consider it should remain an option. It is in the best interests of L that it remain an option (*Re Winston-Jones (A Child)(Medical Treatment: Parent's Consent)* [2004] All ER 313, [29]).

The court undertook a very careful and finely balanced weighing process, with the result that it was able to reason to different conclusions about withholding of the types of treatment under consideration. This capacity for sensitivity to highly contextual factors is one of the great strengths of the best-interests test. But the other point to notice is that the court shared the mother's ambivalence about L's death. Whilst it was settled in its view that permanent ventilation in a haze of semiconsciousness was not best for L, it was unsettled by the prospect of withholding a low-tech intervention such as cardiac massage.

#### *Death is Culpable*

This suggests that the nature of the technology or treatment in question may have a role in shaping the interplay between notions of the "artificial" and the "natural," which seem to underpin law's understanding of culpability in these settings. As we have seen above, Hopkins argues that framing technology as "artificial" has the effect of "plac[ing] the body in question into a neutral area of naturalness where its fate ... simply happens, without the direct, discomfoting involvement of medical personnel" (1997, 31). On this reasoning, when technology is removed (or

withheld) and death occurs, no one's rights are violated and no culpability arises (Hopkins 1997, 32). But as Hopkins also points out, once "deaths come in different ethical (and ontological) sorts, then the category to which particular deaths properly belong will be in dispute" (1997, 31). It follows that locating the child in a struggle in which she is actively aspiring to live, rather than succumb, shift the manner in which the acts and omissions of others are interpreted. To give a clear example of this, in *Re OT* [2009] EWCA Civ 409, when the sick child's condition deteriorated and medical personnel did not respond with life-saving interventions, the father exclaimed "this is murder" (*Re OT* [2009] EWCA Civ 409, [61]). Similarly, L's mother did not accept that his death was natural, and this necessitated a coronial inquiry into L's death (BBC News 2005).

Perhaps the best known example of a parent challenging how doctors understand the meaning of their child's predicted death is *R v Portsmouth Hospitals NHS Trust, Ex parte Glass* [1999] 2 FLR 905. The case concerned David Glass, a 12-year-old boy with hydrocephalus and severe cognitive and physical disabilities. He was admitted to the hospital with a respiratory infection and was administered diamorphine to relieve his pain and ease his inevitable death. Without consulting his mother, the hospital also applied a DNR order to his notes. Ms. Glass became increasingly concerned that the diamorphine was depressing her son's respiration and compromising his chance of recovery, but the hospital continued to administer palliative measures over her objections. As her concern turned to alarm, Ms. Glass, with the help of other family members, "pulled out the diamorphine drip, rubbed his chest and shouted in his ears to bring him back to consciousness" (Day 2004, ¶3). The family members were successful in reviving David and he did not die as predicted. He was discharged from hospital the following day.

Ms. Glass suspected that the doctors had misunderstood or mischaracterised her son's quality of life, and this led them to the mistaken belief that he *should not be saved* in his own best interests. Ms. Glass applied for judicial review of the hospital's actions, but the Court refused the application (*R v Portsmouth Hospitals NHS Trust, Ex parte Glass* [1999] 2 FLR 905). She then successfully appealed to the European Court of Human Rights, which found that David's Article 8 rights had been infringed and held that the

decision to give morphine against Carol Glass' wishes and without court authorisation amounted to an unwarranted interference with David's right to respect for personal integrity (*Glass and Anor v United Kingdom* [2004] 1 FLR 1019). In a separate decision, Judge Casadevall expressed concerns about the hospital's decision to apply the DNR, noting that the subsequent events have proven that "in the particular circumstances of the present case, maternal instinct has had more weight than medical opinion" (*Glass and Anor v United Kingdom* [2004] 1 FLR 1019 separate opinion, [2]).

The *Glass* case demonstrates that the construction of medical care as either "life-saving" or "life-prolonging," (with the very different ethical connotations that each of these constructions carry) bears a complex relationship to judgments about the value of life with cognitive disability. Disability rights scholars have called attention to these complexities and the dilemmas to which they give rise. Adrienne Asch argues that many doctors and bioethicists hold distorted views about the lives of people with disabilities because their experiences are "based solely on encounters with people in crisis" (Asch 1998, 78). French and Kayess make the related point that "in the case of persons with disability, the assessment of what treatment is futile is sometimes heavily influenced by factors extraneous to the specific condition being treated" (2008, 69). Negative or overly pessimistic assessments about quality of life may make the difference between understanding the child's medical needs as a "period of health vulnerability" from which he or she will emerge with treatment (French and Kayess 2008, 69) and an alternative understanding in which the child is dying and should be supported to enable that process to occur peacefully and with dignity. This latter understanding contributes to a vastly different reading of the child's situation and the appropriate response, as the following account given by one of David Glass' doctors demonstrates:

In normal circumstances, Dr Ashton said, hospital staff would advise the family to hold their dying child and calm him down while he was allowed to die peacefully. Instead, women members of the family started "blowing raspberries in his ears, banging his chest and rubbing his arms and legs very vigorously, despite being asked not to." One relative pulled

the child from bed, not to comfort him, but to stimulate him to breathe. Dr Ashton said: “In my own view this was extremely cruel. David should have been allowed to pass away peacefully and with dignity.” He said David “looked distressed” and it was not in his best interests “simply to keep him alive” (BBC News 1999, ¶3–7 under “Women Blew Raspberries”).

This illustrates perfectly the dilemma that arises when death becomes a matter of social judgment and those judgments differ. For the doctor, it was “cruel” to revive David because “simply keeping him alive” was not a sufficient reason to work toward saving his life. There is also a suggestion that death might provide David with the dignity he cannot obtain in life. But from his mother’s point of view, this could not have been more wrong. For her, David “was not a handicapped child but a child with handicaps” who needed life-saving rather than palliative care (quoted in Day 2004, ¶4). She says: “I have known David all his life. ... I know when he is happy, when he is sad or when he is in pain. I thought it was disgusting that these doctors did not take that into account” (quoted in Day 2004, ¶15).

This case also illustrates how these discordant perspectives on dying lead to radically different conclusions about responsibility for death. Although the medical staff understood their actions as relieving David’s distress and allowing him to succumb to his illness, the family construed the provision of palliative measures as “killing”. Thus, when the doctors left the room, believing nothing more could be done, a family member exclaimed: “You are not going. I want you to witness the death of a child you have killed” (quoted in Morris 2000, ¶9).

Once we appreciate that the law’s construction of death as natural in these cases is in part contingent on the quality-of-life judgment, it should not come as a surprise that this sort of challenge will arise. Thus, where there is disagreement about the quality-of-life assessment, it follows that there may be disagreement about whether or not the death is a culpable one.

### Relational Personhood

The courts have acknowledged that where quality-of-life assessments form part of the deliberations about

treatment, particular care must be taken. In *Re J*, for instance, Lord Donaldson agreed that it was “not appropriate for an external decision-maker to apply his standards of what constitutes a liveable life. ... [T]he decision can only be made in the context of the disabled person viewing the worthwhileness or otherwise of his life in its own context as a disabled person” (*Re J* [1991] Fam 33, 44). This approach, he continues, “gives effect, as it should, to the fact that very severely handicapped people find a quality of life rewarding which to the unhandicapped may seem manifestly intolerable” (*Re J* [1991] Fam 33, 46–47). Similarly, the RCPCH guidance acknowledges that the impact of disability on a person’s quality of life may be difficult to judge, noting that these impacts will be contingent on “individual perception” so that “what is tolerable for one person might well be intolerable for another” (RCPCH 2004, 25). The guidance is also conscious that negative evaluations of the quality of life associated with an impairment may not be shared by all—including those who live with those impairments. The guidance states:

some people with severe impairment describe a life of high quality and say they are happy to be living it. Impairment is not incompatible with a life of quality. Children and adults may not view their residual disability as negatively as some able-bodied people do, provided adequate support is available. It is important that society does not devalue disabled people or those living with severe impairments (RCPCH 2004, 24–25).

However, these observations serve to reinforce the point that the able-bodied majority are inclined to judge severe impairment particularly negatively. Koch laments, “if the difference [in functioning] is sufficiently severe, the person is assumed to be diminished, lessened both existentially and as a member of the social constituency we share” (Koch 2005, 123). Indeed, some philosophers judge serious deficits in cognition as posing a barrier to moral personhood (McMahan 2003). Nevertheless, this emphasis on psychological capacities has been challenged. Kittay, for instance, asks us to consider

an individual whose rational capacities are difficult to determine because she lacks speech but who has the capacity to enjoy life, to share her joy through her smiles and laughter. To embrace those who show her love and care, and to bring joy to all whose lives she touches—an

individual who, through her warmth, her serene and harmonious spirit, and her infectious love of life enriches the lives of others and who has never acted maliciously or tried to harm anyone. Whether or not she would know what it means to determine her own good may be in doubt, but the good she brings to the world is not. Such a person, profoundly mentally retarded as she is, fails to demonstrate the psychological capacities deemed requisite for philosophical conceptions of personhood. If we can imagine such an individual, can we not doubt the significance of the capacities of rationality and autonomy for the moral status of personhood? (Kittay 2008, 151).

Kittay also cavils with the assumption, attributed to McMahon, that people with severe cognitive impairment are “unresponsive,” claiming that “even profoundly retarded individuals are far from being unresponsive to their environment and other people” (2008, 153). Kittay does not seem to deny the existence of unresponsive individuals. Rather, she seems concerned to enlarge the scope of what counts as responsive (and, therefore, ethically relevant). Families who object to treatment-limitation make similar arguments about their children, rhetorically deploying the language of agency and purpose to provide rival accounts of their child’s capacities. For example, Derek Wyatt, the father of Charlotte Wyatt, described his daughter as follows:

Since September we have noticed Charlotte getting better and now she reaches out for things, she smiles she knows who her parents are, her oxygen has come down and there are great signs that she can see, hear and does have a quality of life. That is why we will battle on, as we believe the hospital maybe have given up on her but we have not (Wyatt 2005, ¶7).

The references to recognition and smiling convey the sense that Charlotte is part of and feels herself to be part of a family, that she can communicate pleasure through her smiles and that her pleasure is registered by her parents and family members. These statements implicitly repudiate the dominant construction of her capacities, to repeat Justice Hedley’s words, as “substantially preclud[ing] physical or emotional response to another human” (Wyatt [2004] EWHC 2247 (Fam), [31]). The parents in *An NHS Trust v D*

[2000] 2 FCR 577 also argued that their child was responsive. In that case, there was evidence that the child was “becoming more alert and responsive to the environment around him,” “greeted familiar people with recognition,” and was able to wave “goodbye in response to someone waving to him” (*An NHS Trust v D* [2000] 2 FCR 577, 586). Nevertheless, Justice Cazalet remarked, “I have to bear in mind that on any view the advances that [the child] has made are minimal advances for a boy over a period of 10 months. One is starting from a very limited base indeed, with [the child] having only a minimal awareness of what is going on around him” (*An NHS Trust v D* [2000] 2 FCR 577, 586).

It is possible that the parents in these situations were overly optimistic about their children’s capacities to respond to them and to experience pleasure. It is also possible that they had insights borne out of their particular relationship to and experience with their children. There are two aspects to this claim: First, that through their experiences, family members have a deeper or different appreciation of the capacities and pleasures experienced by their children; and, second, that looking only to intrinsic psychological qualities (or predictions about them) as the basis of a quality-of-life assessment may not adequately account for the contribution that familial relationships and commitments can make to a child’s quality of life (Bridgeman 2007, 35). Bridgeman contends that any account of the child that does not encompass these familial contributions is inadequate. She argues instead for a conceptual framework of relational responsibility that pays careful attention to all the particularities of context. Such a framework does not look

to the psychological development of the child, their [*sic*] decision-making capacities, cognitive skills or thought processes, but to the child as a living and interdependent individual, the particular personality, character, spirit and experiences of whom, when very young, will be best articulated by those most intimately involved and closely concerned with them (Bridgeman 2007, 35).

From this perspective, an important dimension to any discussion about life’s quality concerns the place of relationships and, in particular, family relationships. These are the relationships that generally

sustain and nurture “when we are dependent, as in early childhood, during acute and chronic illness, with serious chronic conditions including disability, and in frail old age” (Kittay 2008, 152).

The relational thesis cannot escape the fact that relationships depend on the presence of some capacity to relate or to show pleasure, even if not through language. Nevertheless, scholars such as Bridgeman and Kittay are, in their respective ways, attempting to shift the focus away from diminished cognitive capacities of the child toward a broader or perhaps differently framed understanding of personhood that is more open to accepting a range of ethically relevant characteristics as significant and, importantly, to vulnerability and impairment as part of the human condition.

There is clearly scope within the best-interests test to embrace a more relational sensibility, as the decision in *An NHS Trust v MB* [2006] EWHC 507 (Fam) illustrates. This case concerned an 18-month-old child with type 1 spinal muscular atrophy, who was almost completely paralysed and was ventilator dependent. Doctors wished to remove the ventilator because they felt that he had “an intolerably poor quality of life” that “would only get worse” (*An NHS Trust v MB* [2006] EWHC 507 (Fam), [26]). The parents wished for ventilation to continue, while the doctors wanted “an early and dignified death” (*An NHS Trust v MB* [2006] EWHC 507 (Fam), [57]). In assessing the child’s best interests, the court identified, in careful detail, the benefits and burdens of treatment for MB, noting that these factors “cannot be weighed mathematically” (*An NHS Trust v MB* [2006] EWHC 507 (Fam), [62]). Importantly, and consistently with the presumption in favour of life, the court began with the benefits of treatment. The court noted that MB’s cognitive capacities were normal, that he had acquired some language and could hear and still see. These laid the groundwork for the court’s emphasis on MB’s capacity to experience the pleasures of social belonging. Thus, Justice Holman observed:

He is blessed with parents, especially his mother ... who have time and ability, and also the willingness and commitment to spend long periods of time with him so the pleasure which I assume he gains from the relationship is not

short lived or occasional (*An NHS Trust v MB* [2006] EWHC 507 (Fam), [67]).

In the result, the court was not persuaded that ventilation should cease at that time but, rather, should continue for as long as possible so that MB could “achieve and value” all that “life [could] give to him” (*An NHS Trust v MB* [2006] EWHC 507 (Fam), [108]).

*An NHS Trust v MB* [2006] EWHC 507 (Fam) seems to be something of an anomaly in the jurisprudence relating to selective nontreatment of children. It is possible that this is so because MB was not cognitively impaired and because he had lived long enough to develop social relationships that could be the subject of evidence. These are factors that may not be demonstrable in very young and/or brain-damaged babies. Nevertheless, the striking feature of *An NHS Trust v MB* [2006] EWHC 507 (Fam) is that despite the “formidable body of medical evidence” (*An NHS Trust v MB* [2006] EWHC 507 (Fam), [30]) that treatment was not in MB’s best interests, the court was reluctant to make assumptions about the quality of MB’s obviously fragile life. As Bridgeman concludes, it is open for courts to adopt a similarly nuanced approach to the best interests of cognitively impaired children who are not dying and whose parents are committed to their care and development (Bridgeman 2007, 181).

## Conclusion

In contemporary Western cultures, medical experts enjoy a secure position of authority in the sphere of death and dying (Timmerman 2005, 1001). This authority often exceeds the physiological managements of dying, to encompass the cultural authority to define reality and to make judgments about meaning and value where death and dying are concerned (Timmerman 2005, 994). Although there is no doubt that medicine wields considerable power in shaping prevailing accounts of death’s meaning, its authority to do this is not without challenge. On occasion, families resist these authoritative accounts of death following treatment-limitation.

This essay has explored discordant understandings of death in the intensive care setting. The prevailing philosophy is to configure death as the natural outcome of a child’s poor physiological condition

and, thus, a release from suffering or an otherwise intolerable existence. As we have seen, this in part depends upon a consensus about the limits of technology and a child's condition and prognosis. However, as the cases in which parents have disputed treatment-limitation attest, consensus can be fragile or impossible to achieve. Objecting parents provide a rival account of death's meaning, which stems in part from their rejection of cultural understandings that inform the authoritative account. Because they can comprehend a future for their child, they are unable to accept his or her death. Instead, they regard death as either premature or culpable or both. In this sense, these disputes call attention to the inadequacy of the language and logic of medicine and law to foreclose the generation of meanings around death, of suffering, and of imagined futures.

Where death is a matter of social as well as clinical and legal judgment, negotiation and contestation about its desirability and timing may well be inevitable. However, a more informed understanding of the contested nature of the cultural understandings that underscore the authoritative account of death may assist in crafting responses to these disputes.

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