

# The Legitimacy of Medical Treatment

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## What role for the medical exception

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## Chapter 6

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**Family perspectives on ‘proper medical treatment’ for people  
in prolonged vegetative and minimally conscious states**

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# 6 Family perspectives on ‘proper medical treatment’ for people in prolonged vegetative and minimally conscious states

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## Introduction

Proper medical treatment is routinely defined, in law and in practice, as requiring the consent of the patient. Patients with disorders of consciousness (long-term ‘coma’) are unable to give or withhold consent because they are completely unconscious (‘vegetative’) or have only fleeting and occasional moments of consciousness (‘minimally conscious’). They are completely (or largely) unaware of themselves and their environment.<sup>1</sup> They cannot understand the situation they are in or the treatments on offer; they cannot retain information relevant to a decision to accept or to refuse a particular medical treatment, nor can they weigh up the pros and cons of any treatment.<sup>2</sup> In England and Wales these patients, like others who lack the capacity to make some or all decisions because of learning disabilities or dementia, fall under the remit of section 5 of the Mental Capacity Act 2005, which is designed to ensure that proper medical treatment can be provided to people who lack the capacity to consent to it without putting doctors at risk of criminal prosecution.

The initial impetus for the 2005 Act is usually traced to the decision in *F v West Berkshire*,<sup>3</sup> commonly identified as ‘a turning point in English medical law’.<sup>4</sup> The House of Lords was asked to determine the legality of sterilising a 36-year-old woman with learning disabilities who was deemed incapable of giving consent

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1 Royal College of Physicians (RCP), *Prolonged Disorders of Consciousness: National Clinical Guidelines* (RCP, 2013), available at <https://www.rcplondon.ac.uk/resources/prolonged-disorders-consciousness-national-clinical-guidelines> (accessed 19 December 2014).

2 These are the criteria for determining whether a person has the capacity to make decisions for themselves: Mental Capacity Act (MCA) 2005, s. 3(1).

3 *F v West Berkshire Area Health Authority* [1990] 2 AC 1, HL.

4 A. Grubb, ‘Editorial: Who decides? Legislating for the incapacitated adult’ (1998) 5 *European Journal of Health Law* 231, 232.

for the surgery. They found that nobody, including next of kin and the courts,<sup>5</sup> had the legal power to consent to medical treatment on behalf of another adult. Any doctor who operated would do so without consent and, hence, would prima facie be guilty of offences of battery and/or trespass against the person. Both F's mother and her professional carers wanted to protect F against pregnancy, which, according to psychiatric evidence, would be 'disastrous' for her mental health,<sup>6</sup> but F's access to the service they believed she needed was impeded by her inability to consent and the inability for anyone to consent on her behalf. The House of Lords held that unless some solution could be found, then not just sterilisation but *any* medical treatment and, indeed, any day-to-day care (for example, 'dressing, feeding and so on'<sup>7</sup>) that involved touching a patient without their capacitous consent risked liability for tortious or criminal offences.<sup>8</sup> The remedy fashioned in *F v West Berkshire* was that their Lordships, while acknowledging that they could not consent to treatment on F's behalf, nonetheless granted the declaration that surgery would not be unlawful. They did so by invoking the 'doctrine of necessity',<sup>9</sup> holding that surgery was 'necessary' because it was in the patient's 'best interests' as defined by the *Bolam* test.<sup>10</sup>

Although providing a stopgap solution for this particular case, *F v West Berkshire* exposed a serious lacuna in the common law and the lack of any comprehensive framework to deal with it. Consequently, the Lord Chancellor asked the Law Commission to carry out a consultation exercise on decision-making for incapacitous adults, resulting in a series of publications<sup>11</sup> that culminated in the final report (and draft Bill) in 1995 and eventually the Mental Capacity Act 2005. The Act provides the legislative framework in England and Wales for determining capacity, appointing decision-makers, and establishing the basis on which decisions regarding those

5 Despite common public belief to the contrary, family members have never had the right (qua family members) to consent to medical treatments on behalf of an adult relative (and still do not). The courts had jurisdiction to consent to surgery under the common law principle of *parens patriae*, the Crown's ancient duty to protect 'imbeciles, lunatics and idiots', but lost this, more by accident than design, in 1960 with the coming in to force of the Mental Health Act 1959, leaving the lacuna in the law to which the House of Lords was now responding.

6 *F* (n 3) 34, *per* Butler-Sloss LJ; 53, *per* Lord Brandon.

7 *F* (n 3) 72, *per* Goff LJ.

8 Emergency treatment was recognised as an exception (*Wilson v Pringle* [1986] 2 All ER 440, CA), as were mental health treatments delivered to patients detained under the Mental Health Act 1983.

9 This doctrine is traced back to *R v Dudley & Stephens* (1884) 14 QBD 273; see AWB Simpson, *Cannibalism and the Common Law* (University of Chicago Press, 1984).

10 This test is widely used in the law of medical negligence and requires doctors to act in accordance with a practice accepted as proper by a responsible and competent body of relevant professional opinion: *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582.

11 Law Commission, *Mentally Incapacitated Adults and Decision-Making: An Overview. Consultation Paper No. 119* (HMSO, 1991); Law Commission, *Mentally Incapacitated Adults and Decision-Making: A New Jurisdiction. Consultation Paper No. 128* (HMSO, 1993); Law Commission, *Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research, Consultation Paper No. 129* (HMSO, 1993); Law Commission, *Mentally Incapacitated Adults and other Vulnerable Adults: Public Law Protection, Consultation Paper No. 130* (HMSO, 1993); Law Commission, *Mental Incapacity, Consultation Paper No. 231* (HMSO, 1995).

who lack capacity should be made: ‘best interests’. For people with disorders of consciousness then, best interests supplants consent as a key criterion on the basis of which an otherwise tortious or criminal act against the person becomes an appropriate and legitimate medical intervention.<sup>12</sup>

People with disorders of consciousness typically receive a wide range of different medical treatments from the moment of the injury onwards. The vast majority of these treatments are now commonplace and well-established treatments for patients generally (for example, ventilators and feeding tubes), rather than newer and more controversial treatments discussed elsewhere in this collection. The controversy, if there is one, lies only in the application of these life-prolonging medical treatments to this *particular* group of patients rather than involving a controversy about the treatments per se. The question that generates fierce debate is should we be prolonging, for years or even decades, the lives of people who have little or no consciousness and who are highly unlikely ever to regain it? This is a question that is addressed, and evaded, by law and social policy, by media coverage, by professional codes of practice, by practitioners, and by family members.

For treatment of an unconscious patient to be lawful (at least after the emergency stage), each treatment should be delivered only if a decision has been made (in accordance with the guidelines laid out in the 2005 Act and its associated Code of Practice) that it is in the patient’s best interests to receive it. Best interests is not defined in the Act, but a non-exhaustive checklist (section 4) requires the decision-maker to ‘consider all the relevant circumstances’ (section 4(2)), including, in addition to clinical concerns, the person’s past and present wishes, feelings, beliefs, values, and ‘any other factors he would be likely to consider if he were able to do so’ (section 4(6)). Alongside this, there is a requirement for the decision-maker to consult widely to discover what these wishes, feelings, beliefs, and so on are (section 4(7)), and the need for such consultation is also highlighted in professional guidelines.<sup>13</sup>

Consultation with those who knew the patient before they were rendered unable to speak for themselves is crucial for best interests decision-making as a route to try to access what the patient might have wanted, and recent case law has emphasised that:

[I]nsofar 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.<sup>14</sup>

12 The only exception is when the person has a valid and applicable advance decision to refuse treatment (under the MCA 2005, ss 24–26), in which case best interests gives way to the decisions made by the individual. As with a contemporaneous refusal by a person with capacity, these prospective decisions can be binding even if those caring for the person believe them to be counter to the person’s current best interests: Department for Constitutional Affairs, *Mental Capacity Act Code of Practice* (TSO, 2007) paras 5.4, 5.34. Best interests also does not apply, in certain circumstances, to participation in research (para. 5.4).

13 RCP (n 1) para. 3.5.

14 *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, para. 45, *per* Lady Hale.

However, as the government acknowledges, the 2005 Act has ‘suffered from a lack of awareness and a lack of understanding’ and ‘[t]oo many people who may lack capacity may be missing out on the legal rights that the [Mental Capacity Act] gives them’.<sup>15</sup> Our research regarding people in chronic disorders of consciousness<sup>16</sup> suggests that they miss out on the legal right (under section 4(6) of the Act) to have their values, wishes, and beliefs represented in decision-making about their medical treatments because family members are frequently not consulted, as they normally should be (under section 4(7)) about what those values wishes and beliefs were. One reason for this is, undoubtedly, because the patient’s own (presumed or reported) views are not determinative of treatment (as they are in some US jurisdictions which rely on ‘substituted judgement’), but are subsumed by the broader category of best interests as a criterion for legitimate treatment.<sup>17</sup>

This chapter is based on interviews with 65 family members of people with chronic disorders of consciousness (such as in vegetative or minimally conscious states), and explores how people understand proper medical treatment in this context. In-depth narrative interviews (on average around three hours in duration) were carried out by one or the other of the two co-authors, and included questions about how medical decisions were made, who made them, the process of decision-making, and whether the interviewee considered particular treatments to be in the patient’s best interests, as well as their view about whether or not the patient would have wanted them.<sup>18</sup> Here we present family accounts in relation to emergency treatments, life-prolonging but non-restorative treatments, and the special case

15 The Government’s Response to the House of Lords Select Committee Report on the Mental Capacity Act 2005, *Valuing Every Voice: Making the Case for the Mental Capacity Act* (HM Government, 2014), Foreword by the Minister of State for Care Services and the Minister of State for Justice and Civil Liberties, available at [www.gov.uk/government/publications](http://www.gov.uk/government/publications) (accessed 19 December 2014).

16 L. Clements, C. Kitzinger, J. Kitzinger, ‘Serious medical decisions and the Mental Capacity Act: Giving and withholding treatment for patients in prolonged disorders of consciousness’ (work in progress).

17 See *W Healthcare NHS Trust v KH and Others* [2004] EWCA Civ 1324, and *P (Statutory Will)*, *Re* [2009] EWHC 163 (Ch), for judicial discussion of the distinction between best interests and substituted judgement. The distinction was also made in the Law Commission’s 1991 consultation paper (n 11). By the second round of consultation in 1993, the Commission had arrived at the view that they ‘doubt[ed] that the two tests need be mutually exclusive, and favour[ed] a compromise whereby a best interests test is modified by a requirement that the substitute decision-maker first goes through an exercise in substituted judgment’, a position they confirmed in their final report on the grounds of the agreement of those they had consulted, Law Commission, *Consultation Paper No 128* (1993) (n 11) para. 2.14, leading to ss 4(6) and 4(7) of the 2005 Act.

18 For more information about families we interviewed, the interview questions, and our anonymising procedure see C. Kitzinger, J. Kitzinger, ‘Withdrawing artificial nutrition and hydration from minimally conscious and vegetative patients: Family perspectives’ (2015) 41 *Journal of Medical Ethics* 157; B. Saunders, J. Kitzinger, C. Kitzinger, ‘Anonymising interview data: Challenges and compromise in practice’ (2014) *Qualitative Research* (online advance access, DOI: 10.1177/1468794114550439), available at <http://qrj.sagepub.com/content/early/2014/09/23/1468794114550439>. refs (accessed 19 December 2014). Filmed extracts from many of our interviews can be viewed on our online module on ‘Family experiences of the vegetative and minimally conscious states’, available at <http://www.healthtalk.org> (accessed 19 December 2014).

of clinically assisted nutrition and hydration. We show that there was a diversity of views as to what constitutes appropriate or proper medical treatment for these profoundly brain-injured patients, but that, for most of them, the patients' own views (as families understood them) were crucially important. We set these family accounts in the context of contemporary law and medical practice relating to the treatment of people in chronic disorders of consciousness which (at least in theory) uses best interests, rather than the patient's reported views, as the criterion for determining treatment options.

### **Emergency treatments**

Prolonged disorders of consciousness are caused by severe brain damage in combination with subsequent medical interventions that prevent the person from dying as a result of that damage. Brain damage is the result of traumatic injury (typically a road traffic accident, sporting injury, or assault), anoxic injury (loss of oxygen to the brain such as is caused by a stroke, cardiac arrest, or near-drowning), or brain disease (for example, viral encephalitis). In the emergency phase, the hours and days after the precipitating event when death is a likely outcome of non-treatment, patients are likely to receive at least some of the following treatments: cardio-pulmonary resuscitation (CPR), tracheotomy, mechanical ventilation, clinically-delivered nutrition and hydration, a brain shunt, and surgery to remove blood clots in the brain and/or a decompressive craniectomy (removal of part of the skull to relieve pressure on a swelling brain).

Legally, some emergency interventions without consent can be justified under the doctrine of necessity; that is, in the absence of any information that the patient would object to treatment, it is considered that doctors who carry out interventions in order to save life should not have criminal or civil liability imposed upon them because the good effect they are seeking to bring about 'outweighs the value of adhering strictly to the law'.<sup>19</sup> The extent and severity of a person's brain damage is very often not apparent at the point of emergency intervention, and when a patient ends up in a permanent disorder of consciousness this usually could not have been accurately predicted at the point of the initial medical intervention. Indeed, if a clinician had known this would be the outcome she might have deemed intervention futile in the first place. Intensivists and neurosurgeons intervening at this stage may have different clinical judgements about the likely outcome, and also different attitudes towards what risks should be taken of a poor outcome balanced against the chances of meaningful recovery. Some clinicians may judge intervention to be justified, while others are increasingly concerned at the future harm their interventions can cause, which leads them to become more conservative in their practice.<sup>20</sup>

19 J. K. Mason, G. T. Laurie, *Law and Medical Ethics* (8th edn, Oxford University Press, 2011) 66.

20 See H. Marsh, untitled video, available at <http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/professor-henry-marsh/#ixzz3KdrZdq2p> (accessed 19 December 2014).

How, then, against this background, do families talk about what is proper treatment? In our research, many family members accepted that, initially, medical treatments were justified, 'It's all about keeping someone alive . . . and you do whatever has to be done' (Kate). But, in retrospect, most expressed some concern about the decision to intervene to keep the patient alive, often based on the assumption that medical professionals must have known (or should have known) what the eventual outcome would be. Belinda, whose son was in a vegetative state eight months after being assaulted, describes her initial belief (reinforced by medical professionals) that her son 'was going to be okay'. It was this belief that, for her, justified doing surgeries:

They took him right up for his first operation on his brain. The right side of his head was completely caved in and they haven't rebuilt it. Then he had to have another operation, swelling on the other side of the brain. They were very good there but they still assured us [he] was going to be okay. We knew he might have some disability like maybe a speech thing, or maybe not being able to walk straight off, you know the normal things that you'd think of . . . We really, really thought that he would come out of it.

Proper medical treatment in the early stages meant, for most family members, whatever doctors said it was. This is a position they have since re-evaluated. In retrospect, many thought they were too 'innocent', or that doctors 'never told us' important information:

When we started this, I was such an innocent and if somebody had said to me 'Right, do we operate or don't we? Do we put him into intensive care or don't we?' . . . I wouldn't have actually known. I was very much in the hands of the professionals. (Dawn)

*We* can't help him. We can't treat him. We can't look after him. So we're handing him over to somebody who has the skills, the knowledge, the experience, to take him through this stage and bring him out the other side and go, 'There we are. There's Patrick back!' They never told us they couldn't bring Patrick back. (Thomas)

Tania, interviewed jointly with her husband, Ian, describes how two different surgeons expressed contrasting views about the proper medical treatment of her son Charles:

We were actually sitting up to the early hours, planning Charles's funeral. We went back the next day, we saw the *other* surgeon, with the optimistic air, and *he* didn't mention anything about us saying goodbye to Charles. It was a *completely* different track. He started talking about fitting a tracheostomy. And we were *absolutely staggered* . . . And so we'd got a complete *rollercoaster* of you know, pretty much 'say goodbye to Charles, go home, come back the next

day', and we came back the next day I suppose expecting to *be* asked about having the life machine turned off. But we *weren't*. It was this *other* man wasn't it, and he uhm (*Ian interjects*: gave us a bit of hope) Yeah! And he just said you know, 'he's *young*', and he just had this feeling . . . And you *want* everything to be okay. You want to believe the *good* things, and *we* didn't want to lose Charles, we were in total shock, so we agreed to the decision to have the trachy fitted . . . Would that I *hadn't* given permission to do the surgery. Would that they hadn't got to Charlie in time to resuscitate him – knowing *now* what I didn't know then.

Only a few families considered, at the time, that life-prolonging medical treatments in the early days or weeks might *not* be appropriate, and in every case family members said that this was because they knew that life with profound brain injuries (whatever the eventual diagnosis/prognosis) was not something the patient would have wanted, and that the patient would not have wanted to take the risk of such an outcome. For these family members the doctrine of necessity that would otherwise have justified emergency treatment to save life, was trumped by their belief that the patient herself would have refused treatment under these circumstances:

They [other family members] said that this is a woman who loved country life, loved family, very, very active, don't operate on her if she is not going to have a quality of life that she – you know, if she's not going – if she's going to be very, very profoundly brain damaged . . . Exactly as she is now, we didn't want – because we knew that she wouldn't have wanted that at all. And they continued operating another two or three times to take blood clots. I think she had a massive swelling and they were taking blood clots out . . . I don't know why they went on operating on her, knowing how profound her brain damage was, why they didn't just let her go, why they didn't just stop. (Diana)

In sum, in the immediate aftermath of the emergency, life-prolonging treatment is often initiated and continued in order to keep people alive and prevent further damage occurring, so that once stabilized they can be properly assessed. For many people this is proper treatment, and many family members we interviewed believed that their relatives would have been willing to receive emergency treatments in such circumstances. But a few reported that their relative would never want to run even a small risk of ending up in such a condition and would want to refuse treatment early on.

It was also striking in our research that reporting on their *own* wishes, as opposed to what they believed their injured relatives' wishes would have been at the time of their injury, many interviewees had come to narrow their definition of proper medical treatment for themselves. Some family members, including those who supported or fought for treatments to keep their relative alive, had themselves made advance decisions refusing treatment in emergency situations like these,<sup>21</sup>

21 Advance decisions to refuse treatment now have statutory support: MCA 2005, ss 24–26.



'I don't want anything if my brain is damaged in any way. I'm really quite strict about it. I'm not that scared about death' (Daisy). For Daisy, and others like her, the only proper treatment after brain injury is palliative care permitting death.<sup>22</sup>

### **Life-prolonging but non-restorative treatments in 'continuing' and 'permanent' disorders of consciousness**

Prognosis for patients in disorders of consciousness becomes more accurate over time. The longer a brain-injured patient remains unconscious, the less good their eventual recovery is likely to be. At four weeks post-injury, a patient who is still unconscious, or virtually so, is said to be in a 'prolonged' or 'continuing' disorder of consciousness.<sup>23</sup> This is not a 'permanent' diagnosis; recovery can and does continue for at least some months, and often for some years. A permanent vegetative state (PVS) cannot be diagnosed until several months after non-traumatic injury, three months in the US and six months in the UK.<sup>24</sup> It takes even longer for a PVS diagnosis if the injury is the result of a traumatic injury; in that case a permanent diagnosis is not appropriate until at least one year.<sup>25</sup> The time span is extended again if the patient is minimally conscious, rather than completely unconscious; only after five years can the 'minimally conscious state' (MCS) be formally diagnosed as permanent.<sup>26</sup> In practice, this means that many patients are maintained for years in vegetative or minimally conscious states in the hope of eventual recovery, and a few of the patients whose families we interviewed had, in fact, recovered full consciousness, albeit with profound multiple neurological (and physical) disabilities which meant that they still lacked capacity to make medical decisions for themselves.<sup>27</sup> However, as we have explored elsewhere, by the time that the patient's diagnosis (for example, as being in a PVS) is finally confirmed, the 'window of opportunity' for a relatively quick death (for example, by removing a ventilator) has usually long passed.<sup>28</sup>

Ongoing medical treatments and procedures provided to these patients can include, in addition to clinically assisted nutrition and hydration, some ongoing

22 See healthtalk.org, 'Reflections on own end of life wishes', available at <http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/reflections-own-end-life-wishes> (accessed 19 December 2014).

23 RCP (n 1) section 1.5.

24 RCP (n 1) section 1.7.

25 RCP (n 1) section 1.7.

26 RCP (n 1) section 1.5: 'Permanent' means, in this context, that recovery 'may be regarded as highly improbable'.

27 See healthtalk.org, 'Recovery', available at <http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/recovery> (accessed 19 December 2014).

28 J. Kitzinger, C. Kitzinger, 'The "window of opportunity" for death after severe brain injury: Family perspectives' (2013) 35 *Sociology of Health and Illness* 1095 (<http://onlinelibrary.wiley.com/doi/10.1111/1467-9566.12020/pdf>).

mechanical ventilation/breathing support (for example, oxygen at night, a tracheotomy, or regular suctioning), a range of medications including antibiotics (especially for pneumonia, which is common in this patient group), and physiotherapy. They may also receive other diagnostic procedures and interventions (such as routine cancer screening and testing for cholesterol, hypertension, or diabetes), plus any relevant treatments for these conditions and immunizations (for example, the ‘flu jab’). For many family members these various treatments became less and less appropriate for their relative over time, as they came to believe that their relative would not want to be kept alive in their current state.

Many families were aware that CPR would not be available to their relative *and accepted this*. The single most common reason was that they came to believe that their relative would not want it. Mikaela’s father had, some years prior to the injury which left him in a vegetative state, survived a stroke which left him impaired but still with a quality of life he considered worthwhile. Mikaela reported having had conversations with him about his wishes because of this earlier injury, ‘I knew how he was. His views on this kind of thing before were so strong after his stroke that he didn’t want to be alive if he couldn’t do things for himself . . . So that [agreeing to no resuscitation] was easy for me’.<sup>29</sup> Mikaela was relieved that she knew her father’s wishes, and it made it ‘easy’ for her to know that (for him) CPR was not an appropriate treatment. Jim, likewise, felt that the burden of deciding about proper treatment for his wife, Amber, was lifted by his knowledge that Amber did not want CPR. Asked how he knew, Jim said:

From our discussion. I knew that Amber, if the only course of action was to resuscitate her, Amber didn’t want it done. And it made – I mean, when the consultant told me, I turned round and said ‘That is Amber’s wishes’. I didn’t have to make the decision.<sup>30</sup>

Another interviewee, Gordon, described how his family arrived at the decision that his wife should be given only limited CPR, and, again, this was based on the family understanding of what the views of the patient would have been:

The three of us discussed it, and we told them what our view was . . . we said they should try and resuscitate her once and if it was a respiratory or if it was a cardiac, they should try and resuscitate her once and if she didn’t respond forget it. And she pulled through. And that happened two – I think two other occasions. (*Interviewer: What did you take into account in trying to make that decision at that time?*) The life that she may have afterwards and also going back to her

29 Watch a video of Mikaela, available at <http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/resuscitation-and-dnr> (accessed 19 December 2014).

30 Watch a video of Jim, available at <http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/resuscitation-and-dnr> (accessed 19 December 2014).

and my discussion, that she didn't want to be a burden on anybody. And if she wasn't going to have a reasonable life after it, if she was going to be more incapacitated than what she was – we didn't want that for her. We didn't want that for her and she wouldn't have wanted it either.

On the other hand, several families successfully challenged 'do not resuscitate' notices. For them, CPR *was* appropriate medical treatment because they did not want to 'give up on' the patient. They believed the patient 'deserved a chance', and would have wanted to take that chance themselves.<sup>31</sup> Fern, talking about her partner, said that she at first believed: 'He's got to have a fighter's chance, how dare you give him a DNR [Do Not Resuscitate order].' Shortly after the DNR had been removed, Fern's partner had a second cardiac arrest and was resuscitated. Reflecting on this some years later Fern commented:

the brain damage he sustained the second time has been catastrophic. Absolutely catastrophic. . . . And I do regret that, you know, well no I don't, I don't regret it. At the time I made a choice for him that I felt was right at that time. But I now know I could never put another one on him and should I be in a situation with anybody else I care about, I probably wouldn't do it . . . I just couldn't do it to another human being what I feel like we've done to him . . . But having seen the damage of . . . removing the DNR . . . I think they were right to put it on him. I can't regret it. What can I do now – we did it. But I definitely – should I repeat this over again in some weird parallel universe I would not remove it. I would let him die on that second cardiac arrest.<sup>32</sup>

Like Fern, Daisy and the rest of her family also, at first, insisted that their relative should be resuscitated if necessary and receive all other possible treatments. However, the whole family subsequently came to believe that he would rather be dead than continue in his MCS. Looking back, Daisy (like Fern) still sees decisions made to demand treatments considered inappropriate by the medical professionals as right *at the time*. The decisions were right because they would have been what her brother would have wanted them to do, even though, like the rest of the family, he would later have changed his mind about wanting to be kept alive and might have made different decisions had he had more information:

At the time we didn't know anything at all [about serious brain injury and its implications], and Nathan wouldn't have known anything at all. If Nathan

31 See *Aintree* (n 14), where there was a long disagreement between a family and a hospital as to whether particular medical treatments were appropriate. The patient, David James, died of a cardiac arrest after the Court of Appeal declared that it was lawful to withhold CPR, a decision subsequently upheld by the Supreme Court.

32 Watch a video of Fern, available at <http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/resuscitation-and-dnr> (accessed 19 December 2014).

had *me* in that situation, he would have fought for *me* to have everything possible . . . Because of what we've experienced we now know the consequences of everything. But not having known what the consequences were, we definitely, definitely, wanted to fight [for treatment] . . . I mean if all of us had been experts at the time in brain injury and Nathan had as well, then we would have all said, 'Oh no, don't worry about treatment. I know that he would prefer to die.' But the whole point is we *didn't*.

The importance placed on what the patient would have wanted extends, in some of these accounts, then, to recognising that the patient (like the family) would at first, albeit out of ignorance, have wanted all possible life-prolonging treatments and would (like the family) have only gradually come to realise that they were only extending a life which would never again be (for them) a life worth living.

Some family members reflected guiltily that the treatments they wanted for their relative, and were fighting for, might be ethically unjustifiable. The mother (Ann) and sister (Bea) of a long-term PVS patient (interviewed together) commented:

*Bea:* The other thing that . . . I had trouble with, was fighting for Fiona's care at the [financial] cost that we know it is and fighting for that above the care for possibly a cancer patient who's a parent of young children or something. And we find – I find that very difficult to deal with, to think about. I just try not to think about it.

*Ann:* Yeah, it gives you very much a guilt complex when you think how much money is involved and how that money could be used. Yes. But, you know, when it's your own, you have to fight for them. There's nothing else you can do. But, you know, common sense tells you that it could be used a lot better.

Once families accept a permanent diagnosis, they oppose many more treatments. When death is seen as what the patient would prefer, many treatments designed to keep the patient alive are seen as inappropriate. As Fern says, it is not a life her partner would want:

You get to a point when there's no improvement and you stop being able to convince yourself there is. When they are constantly hooked up to IVs and having painful UTI infection . . . When they spend their entire life in a state of pain and discomfort . . . this isn't a life worth sustaining. It's not a life they would want and it's not a life I want for him. And no matter how much I would like to believe he would have a miracle and we would see him recover and how much joy that hope would give me, if you can't see that anymore and you realise that death would be better now, I think that's when the acceptance comes . . . There's better ways to show I love him than to prove I'm sustaining him. You know, he knows I loved him. I've done it. I've got my medals. I was there [laughs]. I supported him. I fought for him . . . Don't need to prove it to

anyone, because I proved it to myself and I proved it to him. He knows it. He knows that I did everything I could.<sup>33</sup>

Phil was more ambivalent about whether antibiotics were appropriate treatment for his (minimally conscious) partner, setting his partner's previous views (that 'no one would ever want to be like this') against what he felt facing that situation, and holding open the 'horrible' possibility of non-treatment. Again, the touchstone for deciding on appropriate treatment was what the patient himself would have wanted and/or what he might plausibly want now:

But I think if he did get really ill then I probably would look to see if he could just go quietly. And I talked to his – luckily he and I and his mum were always on the same page about no one would ever want to be like this. They say that if you *are* like this then your perspective changes, so you can't guarantee that he wouldn't want to have an existence where he could have pleasure from my daily visits, daily visits from other people and the dog and all those things. But if something serious happened to him health-wise again we might look to see if he would be able to go quietly instead of fighting so hard to help him live, and that's horrible.<sup>34</sup>

Withholding or withdrawing treatment is often described by families (and clinicians) as 'leaving nature to take its course' or 'letting fate decide', or even allowing the patient – or the patient's body – to decide. Ann and Bea, mother and sister of the patient, agreed with the hospital early on that mechanical ventilation was an inappropriate treatment for her pneumonia:

*Ann:* Yeah, but there was a question of her going back on a ventilator.

*Bea:* They suggested that we probably didn't want to do that.

*Ann:* And *we* decided we didn't want to do that because-

*Bea:* But it's interesting that they did suggest it.

*Ann:* Yes, because they said, 'Well, you know, she might get over it this time, but maybe two months down the line it'll happen again', and so on. And so we decided, no, we don't want to just see her weakened, weakened and weakened and, you know, go that way. So we decided that we'd leave it to fate at that point, you know.

Untreated illness without proper palliative care leads patients to behave in ways that family members interpret as evidence of pain; for example, the ragged

33 Watch a video of Fern, available at <http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/aggressive-treatment-infections#ixzz3KZize9Zt> (accessed 19 December 2014).

34 Watch a video of Phil, available at <http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/aggressive-treatment-infections#ixzz3KZhTB9KA> (accessed 19 December 2014).

breathing, choking, coughing, and gurgling phlegm of untreated pneumonia. When families experienced the patient as suffering they saw treatment such as ventilators and antibiotics as appropriate, even if they had previously believed that these treatments should be withheld to allow the patient to die. When life-prolonging treatments could also relieve suffering, they were actively requested for that reason. Ann and Bea (quoted above) subsequently reversed their agreement to non-treatment for their relative, with Bea actively involved in providing chest physiotherapy on one occasion when her sister became very unwell with pneumonia because she felt her sister was suffering. The wife of another patient similarly could not sustain her position that no treatment should be provided for her husband's chest infections. She said that, 'He had a lot of phlegm and was choking – and that's horrific, watching someone who's going through like that. And again you think, "Can I really be that cruel?" You can't'. (Shula)

Thus, distress about patient suffering during the dying process led families to request life-prolonging treatments, even when they considered them otherwise inappropriate and believed the patient would rather be dead.

When family members viewed treatment as possibly illegitimate they compared it to criminal acts like torture, Kathy said, 'I feel like I've sat watching her being tortured at times and I've tried to comfort her while that's happening to her. And that's a very morally ambiguous position'. Similarly, '[c]ontinuation of this painful, frustrating non-existence and not being able to do anything he was before is not in his best interests. Prolonging it is akin to torture' (Daisy). And Dee said:

They kept saying, she'll still be PVS in a year. So just wait a year and then you go to court. And we were going, 'But she's suffering now. Why make her suffer 365 days before she can be put out of her suffering? And they just said, well, that's the law, you have to wait 365 days.' So as far as we saw it, she was being tortured for 365 days and then we would get a court to agree that she could be allowed to die.

Furthermore, the conduct of medicine/practitioners/medical institutions was sometimes presented as illogical, improper, and an abuse of power akin to hijacking and kidnapping:

Just because you're in a uniform and you work for a big corporation, it does not give you the right to kidnap someone and force them. But evidently it does in the world we live in. Evidently, they can hide behind that . . . You love them. They don't . . . And if you don't have the right, which you don't, you know, and that goes all the way from the beginning all the way through. It's, well, disgusting. Disgraceful isn't the word for it. Again, it is just so wrong. They're hijacked and kidnapped throughout, yeah, because the kidnapping started for Bill there, and continued. (Rose)

In sum, families' beliefs as to what constitutes proper medical treatment for patients in long-term disorders of consciousness is a complex phenomenon

generally rooted in their belief about what their relative would have wanted, with an understanding that this would have changed over time (as the outcome for the relative became clearer). Views are also informed by the desire to release the patient from a life not worth living, balanced by the desire to avoid the patient suffering repeated near-death experiences.

### **The special case of artificial nutrition and hydration**

Severely brain-injured patients cannot swallow and can only be provided with the nutrition and hydration essential to sustain life by tube feeding. Usually, artificial nutrition and hydration (ANH) is delivered via a nasal-gastric tube within the first few days after injury, followed a few weeks or months later by surgery to insert a tube directly into the stomach (for example, percutaneous endoscopic gastrostomy (PEG) or other surgically inserted gastrostomy tube). Both inserting feeding tubes and delivering substances through them are legally defined as ‘medical treatment’,<sup>35</sup> and can be done without the patient’s consent if (in the absence of a valid and applicable advance decision to refuse them) they are considered to be in the patient’s best interests. What makes ANH a special case, and unlike all other medical treatments provided to patients in disorders of consciousness (and indeed, unlike all treatments for patients with any other diagnosis), is that, in England and Wales, it *cannot* be withheld or withdrawn without a declaration from the courts of the lawfulness of so doing.<sup>36</sup>

Inserting a feeding tube is an invasive procedure, and its use is associated with risks (for example bleeding, displacement, and infection) and burdens (discomfort caused by pulmonary edema and gastrointestinal disturbance). Feeding tubes can also become blocked, worn out, or require repositioning due to infection, all of which require further invasive procedures. It is widely recognised that ANH may not always be in a patient’s best interests, especially near the end of life, and treatment is commonly withheld or withdrawn in these circumstances.<sup>37</sup> When a patient is not imminently dying, the General Medical Council’s guidance requires that a second clinical opinion is sought before withholding or withdrawing ANH.<sup>38</sup> However, for PVS and MCS patients, and *only* for this group of patients, withdrawal of ANH requires legal review. An application *must* be made to the Court of Protection for a declaration that it would be lawful to withdraw ANH.<sup>39</sup> This requirement is a legacy of the *Bland* case, in which the House of Lords recommended that a court declaration should be required in such cases ‘at least for the time being and until a body of experience and practice has been built up which might obviate the

35 *Airedale NHS Trust v Bland* [1993] AC 789, HL.

36 Court of Protection Practice Direction 9E, Applications relating to serious medical treatment, para. 5.

37 L. Ganzini, ‘Artificial nutrition and hydration at the end of life: Ethics and evidence’ (2006) 4 *Palliative & Supportive Care* 135.

38 General Medical Council (GMC), *Treatment and Care Towards the End of Life: Good Practice in Decision Making* (GMC, 2010) para. 106. Also, paras. 121–122.

39 Practice Direction (n 36).

need for application in every case'.<sup>40</sup> The requirement remains, despite the view of the British Medical Association and expressed more than a decade after the decision in *Bland*, that PVS cases should no longer inevitably require court review where consensus exists, as long as such withdrawal is in accordance with agreed guidelines.<sup>41</sup>

Following the decision of the Supreme Court in *Aintree University Hospitals NHS Foundation Trust v James*, the focus of the court is not supposed to be on whether it is in the patient's best interests to withhold treatment (of any kind) but on whether it is in their best interests to give or to continue treatment.<sup>42</sup> But the requirement to seek declaratory relief *specifically* in relation to withholding or withdrawing ANH from patients in a PVS or a MCS, and not for providing or continuing to provide this medical treatment, appears contradictory. It also places ANH in an anomalous position in relation to the concept of the medical exception. A procedure considered a tortious or criminal offence if it is not performed in the best interests of the patient is singled out for special scrutiny by the courts. But this special scrutiny is designed in order to establish the lawfulness of *non-treatment* rather than of treatment, and only for this particular group of patients. Following the decision in *Bland*, courts must be approached for declarations that it is lawful to *withdraw* feeding tubes from patients in a PVS, but not for permission to (re)insert them or to continue administration of nutrition and hydration through them after a PVS diagnosis is confirmed. Two recent Court of Protection cases addressed treatment provision for patients in a PVS for whom ANH had been provided for four years<sup>43</sup> and nine years,<sup>44</sup> respectively. Withdrawal was declared to be lawful in both cases, but neither judge conveyed any concern about the improper medical treatment meted out to these patients over such long periods of time. It is this focus on the lawfulness of *non-treatment* rather than of *treatment* that makes ANH a special case for patients with disorders of consciousness and for their families.

Every court case in England and Wales concerning the administration of ANH to a patient with a confirmed PVS diagnosis has resulted in the treatment being withdrawn or withheld. In the over 100 cases since *Bland*, ANH has never been found to be in the best interests of a patient in a PVS. There is, then, no legal justification for making a medical exception of ANH for PVS patients. However, ANH for PVS patients is routine practice, supported by families, treating clinicians, Clinical Commissioning Groups (CCG), insurance companies, and NHS continuing healthcare funding. Doctors do not seem to fear prosecution for offences against the person of the PVS patients to whom they *deliver* ANH, and the law seems tacitly to condone the widespread administration of ANH to PVS patients.

40 *Bland* (n 35) 859, *per* Lord Keith.

41 British Medical Association, *Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for Decision Making* (3rd edn, Blackwell Publishing, 2007) 61.

42 *Aintree* (n 14).

43 *NHS Trust v AW* [2013] EWHC 78 (COP).

44 *Gloucestershire Clinical Commissioning Group v AB* [2014] EWCOP 49.



For example, there has been no litigation against medical professionals who have authorised, permitted, or performed ANH-related treatments on their PVS patients, and public funds are used to support the practice.<sup>45</sup> Perhaps, then, we overstate the importance of the medical exception as providing protection for doctors who might otherwise face tortious or criminal charges, since it seems that a medical treatment that cannot claim this status is, nonetheless, widely practiced, commonly accepted, has never been prosecuted, and does not, even when treatment cessation is declared lawful, attract the censure of the courts.

One contributory factor that may help to account for this apparently contradictory situation is a widespread perception that ANH differs from other medical treatments in being an ordinary (as opposed to an extraordinary) part of basic care, and, perhaps, from some perspectives, not a medical treatment at all. Providing food and water has a powerful symbolic value, and the alternative is often described as starving someone to death. The legal requirement to apply for declaratory relief for withdrawing ANH, but not other treatments (such as antibiotics or mechanical ventilation), supports that perception. Most of the families we interviewed, even those who approved or initiated court applications for withdrawal of ANH, believed that ANH was, in fact, appropriate or proper treatment for their relative.<sup>46</sup> Those who accepted or advocated its withdrawal did so only because it was the ‘least worst’ option in a desperate situation; that, it was the only (lawful) way of bringing about the patient’s death. For example, Jane responded angrily to a care home manager’s advice about the possibility of ANH being withdrawn from her father, and expressed her baffled outrage to the interviewer:

Have you heard of that? That’s crazy to me. Because they can’t tell you if they can feel anything, but they will let them die if they stop his feed. So you have to watch your family member starve to death. It’s just – what – who would do – why? Why? Why would you want-? Why? That’s the bit – *why*? It just doesn’t make sense.

Similarly, Morag was completely opposed to withdrawing ANH from anyone, however badly brain-injured:

We could have applied for a court order to remove his feeding, his tube feeding, but you wouldn’t starve an animal to death, so you certainly wouldn’t

45 See P. Lewis, ‘The medical exception’ (2012) 65 *Current Legal Problems* 355, for a cogent and incisive analysis of the ineffectiveness of the medical exception as a selection tool for new and controversial medical procedures.

46 Extending the torture analogy, a small number of interviewees described ANH as ‘force-feeding’ and drew comparisons with the force-feeding of political prisoners on hunger strike at Guantanamo Bay Detention Camp, or the force-feeding of imprisoned suffragettes in the early twentieth century. This view may be particularly likely for families whose relative is in a MCS rather than a PVS, and where the feeding tube is dislodged or pulled out by the patient. See *United Lincolnshire Hospitals NHS Trust v N* [2014] EWCOP 16 for one such case.

starve your loved one to death because people can live for such a long time without food and just getting weaker and in more pain. And there was no way – you know, you wouldn't starve an animal to death, so there's no way that, you know – for me, that's not an option, you know. I just don't see how that could ever be an option.<sup>47</sup>

Families said they had come to see ANH as an *option* at the point at which they believed that the patient's suffering could no longer be justified and there seemed no other way out. For example, Helen initially believed that 'there's no way I would even consider that', but later changed her mind, and supported an application for ANH to be withdrawn so that her son could die:

[A]bout twelve months later I'd seen him through several nightmare urinary tract infections. I'd watched him lose weight. I'd watched his skin start to break down. I'd seen him in pain. I'd seen the splints that he'd got on his hands start to cut into his wrists. And just the general wear and tear of intensive and invasive nursing practice began to tell on his overall physical health. And it was at that point I started to reassess.<sup>48</sup>

Another interviewee, Gunars, said that he had first realised that his sister was probably in a PVS after reading a newspaper story about the death of Helen's son from ANH-withdrawal. The family had never been given a diagnosis, but the journalist's description of PVS 'ticked every box'. His family then initiated the process whereby the CCG applied for a declaration from the courts that withdrawing the feeding tube from his sister would be lawful, and his sister died ten days after this declaration had been granted. Despite actively participating in this process, Gunars was, nonetheless, clear that the provision of nutrition and hydration to a PVS patient *is* appropriate treatment, and that withdrawing it in order to allow death is neither compassionate nor dignified:

What we look for as human beings is to be treated compassionately and with dignity, and in many ways a prisoner on death row in America gets treated better because at the end of the day he will eventually find out that the day of reckoning's come and it's a simple injection. But what we discovered in the process we entered into was my sister was effectively going to be denied hydration and nutrition which basically means that you're starving somebody to death. Is that a humane way to treat a human being? My response to that is not . . . And fundamentally in this country we treat our pets, our farm

47 Watch a video of Morag, available at <http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/artificial-nutrition-and-hydration#ixzz3Kae439jJ> (accessed 19 December 2014).

48 Watch a video of Helen, available at <http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/artificial-nutrition-and-hydration#ixzz3Kae450Lm> (accessed 19 December 2014).

animals, our equine friends, more sympathetically and with greater compassion and dignity than we do human beings.<sup>49</sup>

Gunars' partner, Margaret, pointed out that:

[I]f we wished to bring this to a conclusion because we considered that it was in her best interests, then that was the only route that was available to us . . . We don't think it is the best option. We think there should be other options. But within the law at the moment it would appear that is the only option.<sup>50</sup>

There is a real disjuncture here between legal and family perspectives relating to ANH cessation. From the legal perspective, at least in theory (though as we have outlined above, the situation is more complicated in practice), ANH *is* medical treatment, and has never been considered appropriate for patients in a PVS. In addition, a person making a best interests decision regarding life-sustaining treatment 'must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death'.<sup>51</sup> From the family perspective, ANH is very often considered to be basic care, and, as such, *is* appropriate for PVS patients. They are often horrified and dismayed at the idea of ANH being withheld or withdrawn. The only reason family members are willing to support cessation of nutrition and hydration is because they believe their relative would rather be dead, and they understand that this is the only lawful method whereby this objective can be definitely accomplished,<sup>52</sup> most especially if, as most have, they have repeatedly witnessed the failure of other lawful methods of allowing death, for example, untreated pneumonia.

## **Conclusion**

In this chapter we have explored family perspectives on proper treatment in relation to their vegetative and minimally conscious relatives. What is distinctive here, as compared to other treatments considered in this collection, is that the majority of the treatments provided to such patients are now commonplace and well-established treatments for patients generally, for example ventilators and feeding tubes, rather than being particularly new or controversial per se. Our analysis has shown that families' views about proper medical treatment for severely

49 Watch a video of Gunars, available at <http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/artificial-nutrition-and-hydration#ixzz3Kaf84oi3> (accessed 19 December 2014).

50 Watch a video of Margaret, available at <http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/artificial-nutrition-and-hydration#ixzz3Kfv1jcO1> (accessed 19 December 2014).

51 MCA 2005, s. 4(5).

52 Kitinger and Kitinger (n 18).

brain-injured patients generally include full emergency treatments and all possible life-prolonging measures in the acute period in order to stabilize the patient and buy time to consider diagnosis and prognosis. However, treatments seen as appropriate in the first year or so may be viewed as no longer appropriate two or three years later because if the patient remains in a vegetative or minimally conscious state, then the rationale for such interventions is no longer justified. The possibility that the suffering and indignity the patient is enduring might open the door to a future life that the patient would find worthwhile has receded. At this point families may agree with clinicians that certain treatments should not be given, in the full expectation that the patient may soon die (after all, the patient's life seemed to 'hang on a thread' in the emergency period). However, unlike patients with terminal cancer, or the very frail and elderly, these patients (often young and physically healthy) may continue to live for years or decades as long as ANH continues to be provided, despite decisions such as 'no aggressive treatment' of infections. This leaves some families retrospectively to view initial treatment decisions as misguided, questioning treatments that resulted in their relative being kept alive. On the other hand, some people retain a belief that decisions to deliver life-sustaining treatments early on were proper *at the time*, based on their own or their relative's ignorance, the clinician's lack of certainty of the outcome, and the need to give their relative the chance of a meaningful recovery (even if, as it turns out, that chance has not 'paid off').

The special place of ANH as a treatment that cannot be withdrawn without resort to the courts is highly significant in shaping family views of proper medical treatment. By requiring declarative relief for withdrawal of this particular treatment (and no other) from this patient group uniquely (while ANH can be withdrawn from all other patients without legal review), the law acts to deter ANH withdrawal from PVS and MCS patients, adding to the already hugely symbolic freight of ANH withdrawal the additional, often intimidating, obstacle of courtrooms with lawyers, expert witnesses, judges, and, potentially, the media. It leads to life-prolonging treatment by default, without reference to the best interests of the person who (in the opinion of many families) is 'trapped' in a 'fate worse than death'. Keith Andrews, a leading neuro-rehabilitation specialist, commented on the reasoning in *Bland* that 'the only reason that tube feeding has been identified as "treatment" has been so that it can be withdrawn'.<sup>53</sup> It is ironic, then, that two decades later, routine medical practice is to *deliver* ANH to PVS and MCS patients *as if* it were a proper and legitimate treatment, and that the law (in particular, Practice Direction 9E)<sup>54</sup> constitutes a barrier to any systematic consideration of whether or not continued delivery of this medical treatment is covered by the medical exception as being in the patient's best interests.

53 K. Andrews, 'Letter – Tortuous arguments evade the issue' (1995) 311 *British Medical Journal* 1347, 1347.

54 Practice Direction (n 36).