



JUDGMENT

Aintree University Hospitals NHS Foundation Trust (Respondent) v James (Appellant)

before

Lord Neuberger, President Lady Hale, Deputy President Lord Clarke Lord Carnwath Lord Hughes

JUDGMENT GIVEN ON

30 October 2013

Heard on 24 July 2013

Appellant
Ian Wise QC
Stephen Broach
Sam Jacobs
(Instructed by Jackson and
Canter)

Interveners (The Intensive Care Society; The Faculty of Intensive Care Medicine) Alex Ruck Keene Victoria Butler-Cole (Instructed by Bevan Brittan LLP) Respondent Lord Pannick QC Vikram Sachdeva

(Instructed by Hill Dickinson LLP)

LADY HALE (with whom Lord Neuberger, Lord Clarke, Lord Carnwath and Lord Hughes agree)

1. This is the first case under the Mental Capacity Act 2005 to come before this Court. That Act provides for decisions to be made on behalf of people who are unable to make decisions for themselves. Everyone who makes a decision under the Act must do so in the best interests of the person concerned. The decision in this case could not be more important: the hospital where a gravely ill man was being treated asked for a declaration that it would be in his best interests to withhold certain life-sustaining treatments from him. When can it be in the best interests of a living patient to withhold from him treatment which will keep him alive? On the other hand, when can it be in his best interests to inflict severely invasive treatment upon him which will bring him next to no positive benefit?

The facts

- 2. The patient, David James, was admitted to hospital in May 2012 aged around 68 because of a problem with a stoma he had had fitted in 2001 during successful treatment for cancer of the colon. The problem was soon solved but he acquired an infection which was complicated by the development of chronic obstructive pulmonary disease, an acute kidney injury and persistent low blood pressure. He was admitted to the critical care unit and placed on a ventilator. He remained in the critical care unit and dependent on ventilator support until the hearing before Peter Jackson J on 5 and 6 December 2012: [2012] EWHC 3524 (COP). His condition between May and December fluctuated. There were some severe setbacks, including a stroke, which left him with right-sided weakness and contracture of his legs, and a cardiac arrest which required six minutes of advanced cardio-pulmonary resuscitation (CPR) to save him. He had recurring infections, leading to septic shock and multiple organ failure. In between, there were efforts to liberate him from the ventilator and onto a lesser form of supported breathing (CPAP). A tracheostomy was performed for this purpose. At the time of the hearing, he was not on antibiotics or other medication and able to tolerate at least 12 hours of CPAP a day. He received clinically assisted nutrition and hydration through a nasogastric tube.
- 3. The judge accepted the evidence of Dr Grant, a consultant in critical care medicine, on behalf of the ten consultants and senior nursing staff who had been responsible for Mr James' care, as to the diagnosis and prognosis. The patient suffered from gross muscle wasting, owing to his prolonged period of near immobility, so could not sit or stand for himself. He also suffered from

contractures, similar to very severe cramps, causing grimacing, raised pulse, breathing and blood pressure, indicating distress and pain. He had suffered a stroke, with severe neurological damage. He was completely dependent on artificial ventilation and required regular tube suction. His kidney function was extremely fragile, with a maximum function of 20% or so, although he had not so far required renal therapy. It was almost inevitable that he would face further infections leading to lowered blood pressure and the prospect of further multi-organ failure. Daily care tasks could cause discomfort, pain and suffering. Overall, his prospects of leaving the critical care unit, let alone the hospital, were extremely low.

- 4. The Official Solicitor, acting on Mr James' behalf, had instructed an independent specialist, Dr Danbury, to investigate. His diagnosis and prognosis were consistent with that of the other doctors.
- 5. As to Mr James' mental faculties, he suffered a marked deterioration in his neurological state in July, after which he was considered to lack the capacity to make decisions about his medical treatment. A Wessex Head Injury Matrix assessment in November indicated severe neurological impairment. Nevertheless, the judge recorded the observations in November of Dr Danbury, of Ms Baker, the Official Solicitor's case manager, and of the medical and nursing staff. These indicated, positively, that he recognised and was pleased to see his wife and his son when they visited; kissed his wife when she leaned into him; looked at her when she moved round the bed; mouthed what appeared to be words in answer to his wife, Ms Baker and nursing staff; turned the pages of a newspaper, smiling while he did so, although it was not clear to the doctor whether he was actually reading any of the articles or looking at the pictures; put on and took off his glasses while doing so; and appeared to enjoy watching videos on his son's phone.
- 6. The judge accepted that he qualified for a diagnosis of being in a minimally conscious state. But, as Baker J had pointed out in Wv M [2011] EWHC 2443, [2012] 1 WLR 1653, "there is a spectrum of minimal consciousness extending from patients who are only just above the vegetative state to those who are bordering on full consciousness." Peter Jackson J added that "to that extent the word 'minimal' in the diagnostic label may mislead". Mr James' current level of awareness when not in a medical crisis "might more accurately be described [as] very limited rather than minimal" (para 38).
- 7. Mr James had been a talented professional musician, spending over 50 years in the music business. He was also a devoted family man. He and his wife had celebrated their golden wedding anniversary in September when their daughter said that he had been "very alert". They have three children, three grandchildren and many friends. Family and friends visited him regularly in hospital and his

daughter felt that he got a lot of enjoyment from seeing them. She herself visited for four hours every day.

The proceedings

- 8. In September 2012, the hospital trust issued proceedings in the Court of Protection, seeking declarations (1) that Mr James lacked capacity to consent to or refuse treatment of any kind (this was uncontentious); and (2) that it would be in his best interests for four specified treatments to be withheld "in the event of a clinical deterioration". Originally, those four treatments included "intravenous antibiotics for further infectious complications" but the trust did not pursue that. Nor was there any suggestion that the current treatment, ventilation and clinically assisted nutrition and hydration, should be withheld. The three treatments in question, as described by the judge (para 8), were as follows:
- (1) Invasive support for circulatory problems. This meant the administration of strong inotropic or vasopressor drugs in order to correct episodes of dangerously low blood pressure. The process is painful, involving needles and usually the insertion of a central line. The drugs have significant side effects and can cause a heart attack. They had previously been used to treat Mr James.
- (2) Renal replacement therapy. This meant haemofiltration, filtering the blood through a machine to make up for the lack of kidney function. It too requires a large line to be inserted and an anti-coagulant drug which brings the risk of bleeding or a stroke. It can be very unpleasant for the patient and may cause intense feelings of cold. Mr James had not so far required this treatment.
- (3) Cardiopulmonary resuscitation (CPR). This aims to make a heart which has stopped beating start beating again. So the decision has to be taken at once. It can take various forms, including the administration of drugs, electric shock therapy and physical compression of the chest and inflation of the lungs. To be effective, it is "deeply physical" and can involve significant rib fractures. CPR had successfully been given to Mr James when his heart had stopped beating in August.
- 9. The unanimous view of the clinical team was that it would not be in Mr James' best interests to receive these treatments, should his condition deteriorate to the extent that he needed them (that was what was meant by a "clinical deterioration"). The judge commented that these views were the result of careful thought and bound to carry considerable weight. Dr Danbury took the same view. But the judge did not attach additional weight to his assessment, because in his

first report he had said that it was not appropriate to continue even with the current treatment, because there was no prospect of Mr James being able to function again as a musician. He later withdrew this, but the judge did not feel able to rely upon his later assessment, given what the judge regarded as this "false start".

- 10. The family took a different view from the clinicians. They felt that every time Mr James had had an infection he had pulled through. The gaps between episodes of infection had become wider. While he would never recover his previous quality of life, he got a lot of enjoyment from seeing his family and close friends. He had been determined to beat his cancer and the family believed that he would feel the same about his current predicament.
- 11. Counsel agreed the following list of considerations both for and against treatment in the event of a deterioration (para 79). In favour were:
 - Life itself is of value and treatment may lengthen Mr James' life.
 - He currently has a measurable quality of life from which he gains pleasure.
 Although his condition fluctuates, there have been improvements as well as deteriorations.
 - It is likely that Mr James would want treatment up to the point where it became hopeless.
 - His family strongly believes that this point has not been reached.
 - It would not be right for him to die against a background of bitterness and grievance.

Against treatment were:

- The unchallenged diagnosis is that Mr James has sustained severe physical and neurological damage and the prognosis is gloomy, to the extent that it is regarded as highly unlikely that he will achieve independence again; his current treatment is invasive and every setback places him at a further disadvantage.
- The treatment may not work.

- The treatment would be extremely burdensome to endure.
- It is not in his interests to face a prolonged, excruciating and undignified death.
- 12. Despite the unanimous medical views, backed by the Official Solicitor, the judge concluded that it would not be appropriate to make the declarations sought (para 84). He was not persuaded that treatment would be futile or overly burdensome or that there was no prospect of recovery (it will be necessary later to consider the meaning he gave to these terms). The arguments in favour undervalued the non-medical aspects of Mr James' situation: his family life was "of the closest and most meaningful kind". Care had to be taken when making declarations in circumstances which were not fully predictable or fluctuating. He recognised that leaving things as they were, for discussion and decision should the need arise, "did not sit easily with an emergency decision about CPR, and for what it is worth I think it unlikely that further CPR would be in Mr James' best interests". But the case for making that an absolute decision at that time did not exist (para 86).
- 13. The trust appealed and the hearing took place only 15 days later, on 21 December. The trust were given permission to put in further evidence, in the shape of a letter dated 19 December from Dr Cope on behalf of the clinical team. This showed that Mr James had suffered a significant deterioration on 5 December and since 14 December had been completely dependent on mechanical ventilation. On 18 December he suffered a "further dramatic deterioration" such that it was difficult to achieve adequate mechanical ventilation. This was accompanied by a fall in blood pressure which required intravenous vasopressors. His renal function had deteriorated further. In this setting of progressive deterioration, attempting CPR was highly unlikely to be successful, and in that unlikely event it was likely to leave him with greater brain damage in addition to other organ damage. He was comatose, or semi-comatose, but efforts to support his breathing and blood pressure on 18 December had clearly caused him great distress and discomfort. He was extremely weak and unable to move. The clinical team remained convinced that it would not be in his interests to provide the listed treatments and would cause him greater suffering whilst conveying extremely limited benefit.
- 14. The Court of Appeal allowed the appeal and made a declaration in similar terms to that sought by the trust. In the early hours of 31 December 2012, Mr James suffered a cardiac arrest and he died.
- 15. The Court of Appeal handed down their written reasons on 1 March 2013: [2013] EWCA Civ 65, [2013] Med LR 110. Although Mr James has died, this

Court gave his widow permission to appeal, in view of the importance of the issues and the different approaches taken by the trial judge and the Court of Appeal to the assessment of the patient's best interests in these sensitive and difficult cases.

The law

- 16. This application was made for a declaration under section 15 of the 2005 Act. Section 15(1) provides that the court may make declarations as to whether a person has or lacks capacity, either in relation to a specified decision or in relation specified matters, and as to the "lawfulness or otherwise of any act done, or yet to be done, in relation to that person". Section 15(2) expressly provides that "act" includes an omission and a course of conduct. The application was for a declaration that it would be lawful to withhold the three specified treatments should Mr James' condition deteriorate to the extent that he needed them.
- 17. It is tempting therefore to approach the case as if the question is whether it would be in Mr James' best interests to withhold those treatments should they become necessary in order to sustain his life. But is that in fact the right question? Whatever may be the position in relation to declarations about matters other than medical treatment, there are some basic principles relating to medical treatment which may help us to identify how these cases ought to be approached.
- 18. The judge began in the right place. He was careful to stress that the case was not about a general power to order how the doctors should treat their patient. This Act is concerned with enabling the court to do for the patient what he could do for himself if of full capacity, but it goes no further. On an application under this Act, therefore, the court has no greater powers than the patient would have if he were of full capacity. The judge said: "A patient cannot order a doctor to give a particular form of treatment, although he may refuse it. The court's position is no different" (para 14). In Re J (A Minor) (Child in Care: Medical Treatment) [1991] Fam 33, at 48, Lord Donaldson MR held that the court could not "require the [health] authority to follow a particular course of treatment. What the court can do is to withhold consent to treatment of which it disapproves and it can express its approval of other treatment proposed by the authority and its doctors." He repeated that view in Re J (A Minor)(Child in Care: Medical Treatment) [1993] Fam 15, at 26-27, when it was clearly the ratio decidendi of the case. To similar effect is R v Cambridge District Health Authority, ex p B [1995] 1 WLR 898, where the court would not interfere with the health authority's decision to refuse to fund further treatment of a child with leukaemia. More recently, in R (Burke) v General Medical Council [2005] EWCA Civ 1003, [2006] QB 273, Lord Phillips MR accepted the proposition of the General Medical Council that if a doctor concludes that the treatment which a patient wants is "not clinically indicated he is not required (ie he is under no legal obligation) to provide it" (para 50), and

"Ultimately, however, a patient cannot demand that a doctor administer a treatment which the doctor considers is adverse to the patient's clinical needs" (para 55). Of course, there are circumstances in which a doctor's common law duty of care towards his patient requires him to administer a particular treatment, but it is not the role of the Court of Protection to decide that. Nor is that Court concerned with the legality of NHS policy or guidelines for the provision of particular treatments. Its role is to decide whether a particular treatment is in the best interests of a patient who is incapable of making the decision for himself.

- 19. However, any treatment which the doctors do decide to give must be lawful. As Lord Browne-Wilkinson put it in Airedale NHS Trust v Bland [1993] AC 789, which concerned the withdrawal of artificial hydration and nutrition from a man in a persistent vegetative state, ". . . the correct answer to the present case depends upon the extent of the right to continue lawfully to invade the bodily integrity of Anthony Bland without his consent. If in the circumstances they have no right to continue artificial feeding, they cannot be in breach of any duty by ceasing to provide such feeding" (p 883). Generally it is the patient's consent which makes invasive medical treatment lawful. It is not lawful to treat a patient who has capacity and refuses that treatment. Nor is it lawful to treat a patient who lacks capacity if he has made a valid and applicable advance decision to refuse it: see 2005 Act, sections 24 to 26. Nor is it lawful to treat such a patient if he has granted a lasting power of attorney (under section 10) or the court has appointed a deputy (under section 16) with the power to give or withhold consent to that treatment and that consent is withheld; but an attorney only has power to give or withhold consent to the carrying out or continuation of life-sustaining treatment if the instrument expressly so provides (section 11(8)) and a deputy cannot refuse consent to such treatment (section 20(5)).
- 20. Those cases aside, it was recognised by the House of Lords in *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1 that where a patient is unable to consent to treatment it is lawful to give her treatment which is necessary in her best interests. Section 5 of the Mental Capacity Act 2005 now provides a general defence for acts done in connection with the care or treatment of a person, provided that the actor has first taken reasonable steps to establish whether the person concerned lacks capacity in relation to the matter in question and reasonably believes both that the person lacks capacity and that it will be in his best interests for the act to be done. However, section 5 does not expressly refer both to acts and to omissions, the giving or withholding of treatment. The reason for this, in my view, is that the fundamental question is whether it is lawful to give the treatment, not whether it is lawful to withhold it.
- 21. In *Bland*, Lord Goff (with whose judgment Lord Keith and Lord Lowry expressly agreed) pointed out that "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 treatment" (p 868). To the same effect was Lord Browne-Wilkinson, at p 884:

- "... the critical decision to be made is whether it is in the best interests of Anthony Bland to continue the invasive medical care involved in artificial feeding. That question is not the same as, 'Is it in Anthony Bland's best interests that he should die?' The latter question assumes that it is lawful to perpetuate life: but such perpetuation of life can only be achieved if it is lawful to continue to invade the bodily integrity of the patient by invasive medical care."
- 22. Hence the focus is on whether it is in the patient's best interests to give the treatment, rather than on whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course that they have acted reasonably and without negligence) the clinical team will not be in breach of any duty towards the patient if they withhold or withdraw it.

Deciding upon best interests

- 23. A person who has the capacity to decide for himself can of course make decisions which are not in his own best interests and no doubt frequently does so. Indeed, the Act provides that a person is not to be treated as unable to make a decision simply because he makes an unwise one: section 1(4). But both at common law and under the Act, those who act or make decisions on behalf of a person who lacks capacity must do so in his best interests: section 1(5). How then is it to be determined whether a particular treatment is in the best interests of the patient? The Act gives some limited guidance. Section 4 relevantly provides:
 - "(2) The person making the determination [for the purposes of this Act what is in a person's best interests] must consider all the relevant circumstances and, in particular, take the following steps.
 - (3) He must consider—(a) whether it is likely that the person will at some time have capacity in relation to the matter in question, and (b) if it appears likely that he will, when that is likely to be.

- (4) He must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.
- (5) Where the determination relates to life-sustaining treatment he 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.
- (6) He must consider, so far as is reasonably ascertainable—(a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity), (b) the beliefs and values that would be likely to influence his decision if he had capacity, and (c) the other factors that he would be likely to consider if he were able to do so.
- (7) He must take into account, if it is practicable and appropriate to consult them, the views of— . . . (b) anyone engaged in caring for the person or interested in his welfare, . . .

as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).

- (8) The duties imposed by subsections (1) to (7) also apply in relation to the exercise of any powers which—. . . (b) are exercisable by a person under this Act where he reasonably believes that another person lacks capacity.
- (9) In the case of an act done, or a decision made, by a person other than the court, there is sufficient compliance with this section if (having complied with the requirements of subsections (1) to (7)) he reasonably believes that what he does or decides is in the best interests of the person concerned.
- (10) "Life-sustaining treatment" means treatment which in the view of a person providing health care for the person concerned is necessary to sustain life.

- (11) "Relevant circumstances" are those—(a) of which the person making the determination is aware, and (b) which it would be reasonable to regard as relevant."
- 24. This approach follows very closely the recommendations of the Law Commission in their Report on Mental Incapacity (1995, Law Com No 231) on which the 2005 Act is based. It had been suggested in Re F that it might be enough if the doctor had acted in accordance with an accepted body of medical opinion (the Bolam test for medical negligence). However, as the Court of Appeal later recognised in Re S (Adult Patient: Sterilisation) [2001] Fam 15, there can only logically be one best option. The advantage of a best interests test was that it focused upon the patient as an individual, rather than the conduct of the doctor, and took all the circumstances, both medical and non-medical, into account (paras 3.26, 3.27). But the best interests test should also contain "a strong element of 'substituted judgment'" (para 3.25), taking into account both the past and present wishes and feelings of patient as an individual, and also the factors which he would consider if able to do so (para 3.28). This might include "altruistic sentiments and concern for others" (para 3.31). The Act has helpfully added a reference to the beliefs and values which would be likely to influence his decision if he had capacity. Both provide for consultation with carers and others interested in the patient's welfare as to what would be in his best interests and in particular what his own views would have been. This is, as the Explanatory Notes to the Bill made clear, still a "best interests" rather than a "substituted judgment" test, but one which accepts that the preferences of the person concerned are an important component in deciding where his best interests lie. To take a simple example, it cannot be in the best interests to give the patient food which he does not like when other equally nutritious food is available.
- 25. Section 4(5) and (10) was an addition while the Bill was passing through Parliament: in considering whether treatment which is necessary to sustain life is in the patient's best interests, the decision-maker must not be motivated by a desire to bring about the patient's death. Like much else in the Act, this reflects the existing law.
- 26. Beyond this emphasis on the need to see the patient as an individual, with his own values, likes and dislikes, and to consider his best interests in a holistic way, the Act gives no further guidance. But section 42 requires the Lord Chancellor to prepare a code or codes of practice for those making decisions under the Act. Any person acting in a professional capacity or for remuneration is obliged to have regard to the code (section 42(4)) and a court must take account of any provision in or failure to comply with the code which is relevant to a question arising in any civil or criminal proceedings (section 42(5)).

- 27. The Mental Capacity Act *Code of Practice* was published in 2007. Lord Pannick QC, on behalf of the trust, accepts that if there is any conflict between what it says and what is said in the guidance given by the General Medical Council under section 35 of the Medical Act 1983 (*Treatment and care towards the end of life: good practice in decision-making*, 2010) or by the British Medical Association (*Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for decision-making*, 3rd edition 2007), then the Mental Capacity Act Code must prevail.
- 28. The Mental Capacity Act Code deals with decisions about life-sustaining treatment in this way:
 - "5.31 All reasonable steps which are in the person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the person's death. The decision-maker must make a decision based on the best interests of the person who lacks capacity. They must not be motivated by a desire to bring about the person's death for whatever reason, even if this is from a sense of compassion. Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment.
 - 5.32 As with all decisions, before deciding to withdraw or withhold life-sustaining treatment, the decision-maker must consider the range of treatment options available to work out what would be in the person's best interests. All the factors in the best interests checklist should be considered, and in particular, the decision-maker should consider any statements that the person has previously made about their wishes and feelings about life-sustaining treatment.
 - 5.33 Importantly, section 4(5) cannot be interpreted to mean that doctors are under an obligation to provide, or to continue to provide, life-sustaining treatment where that treatment is not in the best interests of the person, even where the person's death is foreseen. Doctors must apply the best interests' checklist and use their professional skills to decide whether life-sustaining treatment is in the person's best interests. If the doctor's assessment is disputed, and there is no other way of resolving the dispute, ultimately the Court of

Protection may be asked to decide what is in the person's best interests." (Emphasis supplied.)

29. It is important to read these paragraphs as a whole. As paragraph 5.33 makes clear, doctors have to decide whether the life-sustaining treatment is in the best interests of the patient. Section 4(5) does not mean that they have to provide treatment which is not in the patient's best interests. Paragraph 5.31 gives useful guidance, derived from previous case law, as to when life-sustaining treatment may not be in the patient's best interests. Both the judge and the Court of Appeal accepted them as an accurate statement of the law and so would I. However, they differed as to the meaning of the words in italics. The Code is not a statute and should not be construed as one but it is necessary for us to consider which of them was closer to the correct approach.

How the judge and the Court of Appeal interpreted the patient's best interests

- 30. In concluding that he was not persuaded that treatment would be futile or overly burdensome or that there was no prospect of recovery, Peter Jackson J said this:
 - "(a) In Mr James' case, the treatments in question cannot be said to be futile, based on the evidence of their effect so far.
 - (b) Nor can they be said to be futile in the sense that they could only return Mr James to a quality of life which is not worth living.
 - (c) Although the burdens of treatment are very great indeed, they have to be weighed against the benefits of a continued existence.
 - (d) Nor can it be said that there is no prospect of recovery: recovery does not mean a return to full health, but the resumption of a quality of life that Mr James would regard as worthwhile. The references, noted above, to a cure or a return to the former pleasures of life set the standard unduly high".
- 31. In the Court of Appeal, Sir Alan Ward regarded the "real question" as whether the judge correctly applied the guidance and in particular whether he was right to find that the treatments could not be said to be futile. He considered that futility had to be judged against the goal which was sought to be achieved. He listed six possible goals, ending with this:

"The goal may be to secure therapeutic benefit for the patient, that is to say the treatment must, standing alone or with other medical care, have the real prospect of curing or at least palliating the life-threatening disease or illness from which the patient is suffering." (para 35)

In his view, this was the goal against which futility should be judged (para 37). The judge had adopted too narrow a view of the futility of treatment. He should have had regard, not just to its effectiveness in coping with the current crisis, but to the improvement or lack of improvement which the treatment would bring to the general health of the patient (para 38).

- 32. He also took the view that the judge was wrong to conclude that the three treatments in question were not overly burdensome (para 40). Moreover, the judge had applied the wrong test of a "recovery". In his view, the focus was on the medical interests of the patient. In a case where "life was ebbing away", "no prospect of recovery means no prospect of recovering such a state of good health as will avert the looming prospect of death if the life-sustaining treatment is given" (para 44).
- 33. Having held that the judge had applied the wrong test, the Court of Appeal went on to reach its own decision. Sir Alan accepted that his conclusion that the treatment would be futile, overly burdensome and that there was no prospect of recovery was only one pointer. The term "best interests" encompassed more than merely medical issues. It included the patient's welfare in the widest sense as well as his wishes and feelings. But his wishes, if they were to be the product of fully informed thought, would have to recognise the futility of treatment, its burdensome nature and the fact that he would never go home. In the overall assessment, therefore, his wishes must give way to what is best in his medical interests (para 47). Laws LJ agreed with Sir Alan Ward.
- 34. Arden LJ reached the same result but by a different route. She thought that the starting point was the patient's wishes. But if the court had any doubt as to an individual's wishes or as to whether treatment should be given, it should proceed on the basis that the individual would act as a reasonable person would act (para 50). Agreeing with Sir Alan Ward that the treatment would be unduly burdensome, she considered that a reasonable individual would reject it. Hence it was not in his best interests.

Discussion

- 35. The authorities are all agreed that the starting point is a strong presumption that it is in a person's best interests to stay alive. As Sir Thomas Bingham MR said in the Court of Appeal in *Bland*, at p 808, "A profound respect for the sanctity of human life is embedded in our law and our moral philosophy". Nevertheless, they are also all agreed that this is not an absolute. There are cases where it will not be in a patient's best interests to receive life-sustaining treatment.
- 36. The courts have been most reluctant to lay down general principles which might guide the decision. Every patient, and every case, is different and must be decided on its own facts. As Hedley J wisely put it at first instance in *Portsmouth Hospitals NHS Trust v Wyatt* [2005] 1 FLR 21, "The infinite variety of the human condition never ceases to surprise and it is that fact that defeats any attempt to be more precise in a definition of best interests" (para 23). There are cases, such as *Bland*, where there is no balancing exercise to be conducted. There are cases, where death is in any event imminent, where the factors weighing in the balance will be different from those where life may continue for some time.
- 37. Nevertheless, there has been some support for a "touchstone of intolerability" in those cases where a balancing exercise is to be carried out. In Re B (A Minor) (Wardship: Medical Treatment) [1981] 1 WLR 1421, authorising an operation which was necessary to save the life of a baby with Down's syndrome, Templeman LJ said that the question was whether "the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die", and Dunn LJ said that there was "no evidence that this child's short life is likely to be an intolerable one". Taylor LJ, in Re J (Wardship: Medical Treatment) [1991] Fam 33, also adopted a test of whether life would be intolerable to the child. However, Lord Donaldson and Balcombe LJ did not see "demonstrably so awful" or "intolerable" as laying down a quasi-statutory test which would apply in all circumstances. And in Portsmouth Hospitals NHS Trust v Wyatt [2005] EWCA Civ 1181, [2005] 1 WLR 3995, the Court of Appeal considered that observations on "intolerability" in W Healthcare NHS Trust v H [2005] 1 WLR 834 were obiter, given that the judge had correctly "decided the case by a careful balance of all the factors in the welfare equation" (para 84).
- 38. In *Re J*, Lord Donaldson stated that account had to be taken of the pain and suffering and quality of life which the child would experience if life were prolonged and also of the pain and suffering involved in the proposed treatment. Here we can see a possible genesis for the references in the Code of Practice to the "prospect of recovery" and the "overly burdensome" nature of the treatment. Similarly in *Bland*, Lord Goff referred to the class of case where "having regard to all the circumstances (including the intrusive nature of the treatment, the hazards involved in it, and the very poor quality of life which may be prolonged) it may be judged not in the best interests of the patient to initiate or continue life-prolonging treatment" (p 868). But he expressed no view as to the precise principles

applicable to such cases, because Anthony Bland's case was in a different category, where the treatment was of no benefit to him at all. Here there was no weighing operation to be performed because treatment was useless: "I cannot see that medical treatment is appropriate or requisite simply to prolong a patient's life when such treatment has no therapeutic purpose of any kind, as where it is futile because the patient is unconscious and there is no prospect of any improvement in his condition (p 869)". Here we can see a possible genesis of the word "futile" in the Code of Practice and in that case it referred to treatment which was of no benefit at all to the patient.

- 39. The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.
- 40. In my view, therefore, Peter Jackson J was correct in his approach. Given the genesis of the concepts used in the Code of Practice, he was correct to consider whether the proposed treatments would be futile in the sense of being ineffective or being of no benefit to the patient. Two of the treatments had been tried before and had worked. He was also correct to say that "recovery does not mean a return to full health, but the resumption of a quality of life which Mr James would regard as worthwhile". He clearly did consider that the treatments in question were very burdensome. But he considered that those burdens had to be weighed against the benefits of a continued existence. He was also correct to see the assessment of the medical effects of the treatment as only part of the equation. Regard had to be had to the patient's welfare in the widest sense, and great weight to be given to Mr James' family life which was "of the closest and most meaningful kind".
- 41. Perhaps above all, he was right to be cautious about making declarations in circumstances which were not fully predictable or fluctuating. The judge was invited to address the question whether it would be lawful to withhold any or all of these treatments. But if he had been asked the right question, whether it would be in the patient's best interests to give any or all of them should the occasion arise, his answer would clearly have been to the same effect. He would have said, as he was entitled to say that, on the evidence before him, it was too soon to say that it was not. That conclusion is quite consistent with his statement that "for what it is worth" he thought it unlikely that further CPR would be in the patient's best interests.

- 42. That is not to say that I would have reached the same conclusion as the judge in relation to each of these treatments. There was no question of withdrawing clinically supported nutrition and hydration or ventilation or other supported breathing or, by the time of the hearing, intravenous antibiotics. The treatments in question were all highly invasive. I might have drawn a distinction between them. Invasive support for circulatory problems had been used successfully in the past and the patient had rallied. Renal replacement therapy had not so far been needed and so it might be difficult to predict both its effectiveness and its impact upon the patient's overall wellbeing. Cardiopulmonary resuscitation, on the other hand, although it had been used successfully in the past, is designed to restart a heart which has stopped beating or lungs which have stopped breathing, in effect to bring the patient back to life. I can understand why the judge thought it premature to say that it should not be attempted. But given the particular nature of this treatment, given its prospects of success, and particularly given the risk that, if revived, the patient would be even more seriously disabled than before, I would probably have declared that it would not be in the patient's best interests to attempt it. But if the judge has correctly directed himself as to the law, as in my view this judge did, an appellate court can only interfere with his decision if satisfied that it was wrong: Re B (A Child) (Care Proceedings: Appeal) [2013] UKSC 33, [2013] 1 WLR 1911. In a case as sensitive and difficult as this, whichever way the judge's decision goes, an appellate court should be very slow to conclude that he was wrong.
- 43. It follows that I respectfully disagree with the statements of principle in the Court of Appeal where they differ from those of the judge. Thus it is setting the goal too high to say that treatment is futile unless it has "a real prospect of curing or at least palliating the life-threatening disease or illness from which the patient is suffering". This phrase may be a partial quotation from Grubb, Laing and McHale, Principles of Medical Law (3rd edition 2010), para 10.214, where the authors suggest that "Treatment can properly be categorised as futile if it cannot cure or palliate the disease or illness from which the patient is suffering and thus serves no therapeutic purpose of any kind". Earlier, they had used the words "useless" or "pointless". Given its genesis in *Bland*, this seems the more likely meaning to be attributed to the word as used in the Code of Practice. A treatment may bring some benefit to the patient even though it has no effect upon the underlying disease or disability. The Intensive Care Society and the Faculty of Intensive Medicine, who have helpfully intervened in this appeal, supported the test proposed by Sir Alan Ward. But this was because they believed that it reflected clinical practice in which "futility' would normally be understood as meaning that the patient cannot benefit from a medical intervention because he or she will not survive with treatment". That is much closer to the definition adopted by the judge than by Sir Alan.
- 44. I also respectfully disagree with the statement that "no prospect of recovery" means "no prospect of recovering such a state of good health as will

avert the looming prospect of death if the life-sustaining treatment is given". At least on the evidence before the judge, this was not, as Sir Alan Ward put it, a situation in which the patient was "actively dying". It was accepted in Burke (as it had been earlier) that where the patient is close to death, the object may properly be to make his dying as comfortable and as dignified as possible, rather than to take invasive steps to prolong his life for a short while (see paras 62-63). But where a patient is suffering from an incurable illness, disease or disability, it is not very helpful to talk of recovering a state of "good health". The patient's life may still be very well worth living. Resuming a quality of life which the patient would regard as worthwhile is more readily applicable, particularly in the case of a patient with permanent disabilities. As was emphasised in Re J (1991), it is not for others to say that a life which the patient would regard as worthwhile is not worth living.

- 45. Finally, insofar as Sir Alan Ward and Arden LJ were suggesting that the test of the patient's wishes and feelings was an objective one, what the reasonable patient would think, again I respectfully disagree. The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament. In this case, the highest it could be put was, as counsel had agreed, that "It was likely that Mr James would want treatment up to the point where it became hopeless". But insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.
- 46. However, in my view, on the basis of the fresh evidence which was before them, the Court of Appeal were correct to allow the appeal and make the declarations they did (which were in the present tense). There had been such a significant deterioration in Mr James' condition that the prospect of his regaining even his previous quality of life appeared very slim. The risk that cardiovascular resuscitation would make matters even worse appeared great. The time had indeed come when it was no longer premature to say that it would not be in his best interests to attempt to restart his heart should it stop beating. Indeed, had the judge been asked to reach a decision on the basis of the evidence then available, it seems clear on the basis of his reasoning that he would have done the same.

Conclusions

- 47. There are some additional comments to be made. First, the interveners have argued that to allow this appeal would be to change the law as previously understood. As I have endeavoured to show, upholding the judge's view of the law does not in any way change the law as previously understood. If anything, it was the Court of Appeal which did that. Second, there is nothing in this judgment which is inconsistent with the sensible advice given by the General Medical Council in their guidance on Treatment and care towards the end of life: good practice in decision making. Third, if the clinical team are unable to reach agreement with the family or others about whether particular treatments will be in the best interests of the patient, they may of course bring the question to court in advance of those treatments being needed. But they may find that, as here, the court is unable to say that when they are needed, they will not be in the patient's best interests. Fourth, it is important to be precise in framing the terms of the declarations sought. In this case, "in the event of a clinical deterioration" in fact meant "should his condition deteriorate to the extent that they become necessary" and it would have been helpful to say so.
- 48. It follows that I would dismiss this appeal on the ground that the Court of Appeal reached the right result but for the wrong reasons, while the trial judge had reached a result which was open to him having correctly directed himself as to the law.