



COURTS AND
TRIBUNALS JUDICIARY

A MATTER OF LIFE AND DEATH

Mr. Justice Baker

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INTRODUCTION

The Oxford Shrieval Lecture is a comparatively recent tradition stretching back, I think, for 12 years or so. But High Court Judges have been travelling out to Oxford on circuit for centuries administering justice and hearing the most serious cases. A substantial number of those involved decisions about life and death. Two hundred years ago, dozens of criminal offences were still punishable by death – pickpocketing or poaching, for example. Judges would arrive in the city, attend a church service such as the one taking place later this afternoon, then spend the next week or so conducting a few cursory trials (in which the defendant was not permitted to give evidence) and, if the defendant was convicted, which he usually was, would pass condign punishment - in many cases, the death penalty. Before passing sentence, the judge would put on the top of his bewigged head the fearsome black cap.

The death sentence was suspended in 1965 and subsequently abolished and there is probably no one present here today who has ever seen it being passed. High Court Judges are still issued with the black cap just in case and they sometimes carry it as part of their ceremonial dress, but never take it into court.

For some judges, however, matters of life and death continue to feature in their work, although not with the same regularity. I am referring to those judges like me who sit in the Court of Protection, in cases about incapacitated adults. In those cases, the judge is not concerned with deciding whether death should be inflicted as a punishment, but, rather, whether death is in the best interests of the individual. And unlike the death penalty, which would only be imposed on someone who had carried

out a crime (and latterly really serious crime), the issue of life and death that arises in the Court of Protection can affect anyone.

Let me give three examples. Tony Bland¹ was a seventeen-year-old Liverpool football supporter. On 15 April 1989, he went to Hillsborough football stadium in Sheffield to watch his team play in the FA Cup semi-final. He was at the Leppings Lane end when the disaster occurred, and as a result sustained a severe crushed chest injury which led to hypoxic brain damage. His condition deteriorated and he descended into a state of complete or almost complete unawareness, and was kept alive only by artificial nutrition and hydration (“ANH”). The second example concerns a woman whom I shall call M.² In February 2003, when she was forty-three years old, M and her partner had booked to go on a skiing holiday. When her partner woke up on the morning they were due to leave, he found M in a drowsy and confused condition. She was taken to hospital where she quickly fell into a coma. It was discovered that she had suffered viral encephalitis which left her with extreme and irreparable brain damage. For the next seven years, she was kept alive only by ANH. The third example³ concerned a 68-year-old man called David James who had developed cancer for which he received surgical treatment but subsequently developed an infection which led to pulmonary disease and cardiac arrest, leaving him with profound neurological deficiencies. He, too, was totally dependent on ANH.

The lives of these three ordinary people were devastated by events that could happen to any one of us, although, it has to be said, such events are rare. In each case, the patient was kept alive by ANH. In each case, the patient lacked the capacity to indicate whether or not they wanted to be kept alive in this way. In each case, an issue arose as to whether he or she should be kept alive. The cases were referred to the court, and the first and third cases were the subject of appeals to the highest court in the land. The second case was decided without appeal by the judge at first instance which, as it happens, was me.

These cases raise a number of important issues which I want to discuss today. I am aware that there are other difficult and controversial topics which raise issues which overlap with this subject – for example, the treatment of seriously ill children, assisted suicide, and euthanasia – but those are matters for another lecture. The particular questions I wish to consider are as follows:

- (1) What do we mean by “capacity”?
- (2) What we know about disorders of consciousness?
- (3) How do we decide what should happen in such cases?
- (4) What are the ethical principles underlying the decision?
- (5) Are judges the right people to be making these decisions?

¹ *Airedale NHS Trust v Bland* [1993] AC 789

² *W v M* [2011] EWHC 2443 (Fam)

³ *Aintree University Hospitals NHS Trust v James* [2013] UKSC 67

CAPACITY

As my colleague Peter Jackson J has observed⁴:

“anyone capable of making decisions has an absolute right to accept or refuse medical treatment, regardless of the wisdom or consequences of the decision. The decision does not have to be justified to anyone. In the absence of consent, any invasion of the body will be a criminal assault.”

But not all patients are capable of giving their consent at the time the treatment is proposed. In those circumstances, the decision has to be taken in a different way, either by someone else, or, in some cases, by reference to an earlier statement made by the patient before they lost capacity – a so-called “advance decision”. The first question, therefore, is whether the individual (usually referred to as “P”) has capacity.

The law governing capacity is now set out in the Mental Capacity Act 2005 (“MCA”) and the cases which have been decided under that Act. S.1 sets out five key principles, three of which are relevant to the question of capacity (I shall consider the other two key principles later). The three principles are

- a person must be assumed to have capacity unless it is established that he lacks capacity⁵
- a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success⁶
- a person is not to be treated as unable to make a decision merely because he makes an unwise decision⁷.

S.2 contains a number of provisions about people who lack capacity in particular subsection (1) , which provides that “a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain⁸. What does the MCA mean by being “unable to make a decision”? The answer is in s.3:

“For the purposes of section 2, a person is unable to make a decision for himself if he is unable—

(a) to understand the information relevant to the decision,

(b) to retain that information,

⁴ *Heart of England NHS Trust v JB* [2014] EWHC 342 at para 2

⁵ MCA s.1(2)

⁶ MCA s.1(3)

⁷ MCA s.1(4)

⁸ MCA s.2(1)

- (c) to use or weigh that information as part of the process of making the decision, or
- (d) to communicate his decision (whether by talking, using sign language or any other means).”⁹

In many cases, it is unclear whether an individual lacks capacity. In those circumstances, the Court of Protection has to order expert medical assessments because unless P lacks capacity the Court has no jurisdiction. Some people have capacity to make some decisions but not others. In the case under consideration here, however, these problems do not arise. Whenever a person has suffered the degree of serious neurological deficit that arises in these cases, there is no doubt that P lacks the capacity “because of an impairment of, or a disturbance in the functioning of, the mind or brain”.

It is important to stress immediately, however, that the fact that someone lacks capacity does not mean that their views wishes and feelings are ignored. On the contrary, as we shall see, these factors play a crucial part in the court’s analysis about what should happen.

DISORDERS OF CONSCIOUSNESS

I turn next to consider the nature of the neurological problem under consideration. Here, of course, I am summarising medical matters. Please bear in mind that I am not a doctor, merely a judge, albeit one who has had some experience of cases involving these disorders and has seen how understanding about them has evolved over the past 20 years.

Most people have heard of the phrase “persistent vegetative state” now usually shortened to “vegetative state” (“VS”). That was the diagnosis given for Tony Bland. Since that case was decided in 1993, understanding about these disorders has developed very significantly. For a full discussion, I refer you to “Prolonged Disorders of Consciousness: National Clinical Guidelines” published by the Royal College of Physicians¹⁰. The guidelines identify three “disorders of consciousness” – coma, VS, and the minimally conscious state (“MCS”). These are defined in the guidelines as follows:

“Coma - absent wakefulness and absent awareness - a state of unrousable unresponsiveness lasted more than six hours in which a person cannot be awakened; fails to respond normally to painful stimuli, light or sound; lacks a normal sleep-wake cycle; *and* does not initiate voluntary actions.

Vegetative state - wakefulness with absent awareness - a state of wakefulness without awareness in which there is preserved capacity for spontaneous or stimulus-induced arousal, evidenced by sleep-wake cycles and a range of

⁹ MCA s.3(1)

¹⁰ RCP 2013

reflexive and spontaneous behaviours. VS is characterised by complete absence of behavioural evidence for self-or environmental awareness.

Minimally conscious state - wakefulness with minimal awareness - a state of severely altered consciousness in which minimal but clearly discernible behavioural evidence of self-or environmental awareness is demonstrated. MCS is characterised by *inconsistent but reproducible* responses above the level of spontaneous or reflexive behaviour which indicates some degree of interaction with their surroundings.¹¹

The existence of the minimally conscious state was not appreciated at the time of the House of Lords' decision in *Bland*. Within MCS, there is a spectrum of consciousness extending from patients who are only just above the VS to those who are bordering on full consciousness¹². Some experts have now suggested that it is no longer appropriate to describe someone as being in a VS. They suggest that there is a spectrum of minimal consciousness including, at one end, those previously diagnosed as being in the VS. As we shall see, such a revised approach would have an impact upon decisions taken about the treatment of such patients.

There are many other points that could be made concerning disorders of consciousness, but I want to make just three this afternoon.

First, the treatment of such patients in this country is of the highest quality. This is a specialist area in which dedicated nurses, care staff and doctors devote their lives to their patients. Not enough recognition is given to their work, and I'm pleased to have this opportunity to salute them today. As a result of the quality of care, many patients in these conditions survive for a number of years.

Secondly, it is important to recognise the anguish and difficulties that these conditions cause to the family and friends of the patient. As all who have had a relative suffering from long-term illness – perhaps dementia or recovering from a stroke – caring for and visiting a relative in these circumstances is challenging and emotionally exhausting. The anguish is perhaps increased by the knowledge that in a few – a very few – cases, patients can emerge from the MCS to full consciousness, albeit usually with profound brain damage.

Thirdly, and most important from the court's perspective, the clinical diagnosis of the level of consciousness is exceedingly difficult. Brainstem activity or inactivity can be demonstrated by neurological tests, but this is not the case with consciousness:

“there is no understanding of how consciousness arises, and there is no equivalent knowledge of the neurophysiological basis for consciousness. Thus, there is no restricted set of functions that can be tested, and it is not possible

¹¹ *Ibid* p.3. NB as the guidance makes clear, all disorders of consciousness are quite distinct from "locked-in syndrome" or "brainstem death".

¹² It has been suggested that MCS should be divided into two subcategories - MCS-plus, in which patients show more complex behaviours such as the ability to follow commands, and MCS-minus, in which patients show only non-reflexive movements such as orientation to noxious stimuli, pursuit eye movements et cetera (Bruno and others - "From unresponsive wakefulness to minimally conscious PLUS and functional locked-in syndrome: recent advances in our understanding of disorders of consciousness" J Neurol 2011, quoted in the RCP Guidelines at page 7)

to develop a set of physiological tests that can prove or disprove that the neurological foundations needed to create and sustain consciousness are intact or otherwise. Instead, we can only infer the presence or absence of conscious experience in another person.”¹³

This involves analysing the behaviour of individuals in a structured assessment. There are a number of such assessments currently available, of which the three recommended in this country are the Coma Recovery Scale – Revised (CRS – R), the Wessex Head Injury Matrix (WHIM), and the Sensory Modality Assessment and Rehabilitation Technique (SMART).

Much has been written about these protocols. The principal potential weakness is that there are no definitive criteria of awareness so that such assessments depend on judgment and interpretation which may be challenging even for the professionals experienced in carrying out the assessments. Furthermore, differences may arise between the observations professionals carrying out assessments and those of family members who, while they may lack the objectivity which the professional possesses, has spent far more time with the patient and have greater experience of interpreting their behaviour. The assessment tools are very important, and the courts invariably require such assessments to be carried out before any application is made to the court, but it is important to recognise that they are not by themselves determinative of the outcome in any case¹⁴.

HOW DO WE DECIDE WHAT SHOULD HAPPEN?

Before turning to the law which is applied by the Court of Protection when deciding applications for the withdrawal of ANH, it is worthwhile looking at other ways in which the decisions can be made about medical treatment for incapacitated adults.

First, there is a statutory power for any adult to set out in written form whether he or she wants to refuse to consent to treatment if he subsequently lose capacity. Such documents, formerly known as “living wills”, are now known as “advance decisions” and are governed by sections 24 to 26 of the MCA. So far as formalities are concerned, a distinction is drawn between those treatments that are life-sustaining and those that are not. In the case of the latter, no formality is required. In the case of life-sustaining treatment, however, s.25(5) and (6) provide that an advance decision is not applicable unless it is verified by a statement to the effect that it is to apply to that treatment even if life is at risk, and further that both the decision and statement must be in writing and signed by P or another person in P’s presence and by P’s direction, in the presence of a witness who also has signed the decision and the statement of verification.

¹³ Wade: “Back to the bedside? Making clinical decisions in patients with prolonged unconsciousness”. J Med Ethics 2016;0:1–7

¹⁴ *Re N* [2015] EWCOP 76 , per Hayden J at para 23.

The statutory requirements for advance decisions about such treatment are thus fairly stringent. If, however, P has made an advance decision which is (a) valid and (b) applicable to a treatment, “the decision has effect as if he had made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued”: s.26(1).

At first sight, this seems a sound and useful the provision. In my experience, however, it is little-known and little used. I will consider below why that may be so.

Secondly, there is also a statutory provision in the MCA¹⁵ that enables a person to appoint someone else to make decisions about his welfare on his behalf in the event that he becomes incapacitated by making a “Lasting Power of Attorney” (“LPA”). This provision, which has replaced the previous so-called “Enduring Power of Attorney”, is, in contrast to the advance decision, both well-known and frequently used. Under s.9(1), the “donor” by executing a LPA, confers on the donee authority to make decisions about his or her personal welfare and/or property and affairs, The MCA contains detailed provisions as to the formalities which must be complied with to create a valid LPA. It is further expressly provided that an authority under a LPA to make decisions concerning P’s personal welfare extends to giving or refusing consent to the carrying out or continuation of health care treatment¹⁶, including the carrying out or continuation of life-sustaining treatment where the LPA contains an express provision to that effect¹⁷.

Importantly, however, some doubt has been expressed as to whether either an advance decision or the power vested in the donee of a LPA extends to decisions concerning a proposal to withhold or withdraw ANH. This is because of the terms of the relevant Practice Direction supplementing the rules governing applications relating to serious medical treatment.¹⁸ It is to say the least unfortunate that there should be such uncertainty and it is to be hoped that the opportunity will arise soon for the courts to resolve this question. So far as I am aware, there is no instance in this country of a case in which ANH has been withheld or withdrawn from a patient in a permanent vegetative or minimally conscious state as defined in the RCP guidelines¹⁹ without reference to the court.

How then does the court approach this challenging question? I start with the two key principles in s.1 of the MCA which I indicated earlier I would return to. The first is of fundamental importance. It provides that “an act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests”²⁰. The second principle is that “before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as

¹⁵ MCA ss9 - 14

¹⁶ MCA s.11(11)(c)

¹⁷ MCA 2.11(8)

¹⁸ Practice Direction 9E paragraph 5, which provides inter-alia that cases involving decisions about the proposed withholding or withdrawal of ANH from a person in VS or MCS “should be brought to the court”.

¹⁹ In the original draft of this lecture, I mistakenly said that “there is no instance in this country of a case in which ANH has been withheld or withdrawn from a patient suffering from a disorder of consciousness without reference to the court”. I am grateful to Professor Lynne Turner-Stokes for pointing out that this was too broad a statement.

²⁰ MCA s.1(5)

effectively achieved in a way that is less restrictive of the person's rights and freedom of action"²¹. This is of less direct importance in the context of the type of case under consideration at present, but it does have some relevance when we are seeking to identify the underlying ethical principles, which I shall consider shortly.

What does the MCA mean by "best interests"? It is necessary to set out the principal provisions of section 4 which contained the definition of this concept:

- (1) In determining for the purposes of this Act what is in a person's best interests, the person making the determination must not make it merely on the basis of (a) the person's age or appearance or (b) a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about what might be in his best interests.
- (2) The person making the determination 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 the 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 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 (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind; (b) anyone engaged in caring for the person or interested in his welfare; (c) any donee of a lasting power of attorney granted by the person, and (d) any deputy appointed by the court."

These factors are taken into account in all decisions about incapacitated adults – where they should live, what care they should receive, what contact they should have other people, as well as decisions about medical treatment. Again, there is much that could be said about these provisions. I confine myself to three points at this stage.

²¹ MCA s.1(6)

First, although the MCA identifies factors to be taken into account in the best interests analysis, it says nothing about the weight to be attached to each factor. That will plainly vary from case to case. In evaluating the arguments for and against a particular course, the court will often adopt a balance-sheet approach²². In doing so, however, the court must be wary not to be misled simply by the number of factors on one side of the scales. It is the weight to be attached to each factor that is important rather than the number of factors on each side of the argument²³.

Secondly, as section 4 makes clear, although a best interests analysis involves considering the wishes and feelings of the individual concerned, the Act does not stipulate that these factors should necessarily be decisive. In this respect, the approach under the MCA is different from that adopted in some other jurisdictions (notably a number of states in the USA) which requires the court to identify and adopt what P would have wanted, a process known as “substituted judgment”.

Thirdly, all these provisions, including the MCA itself, have to be read in the context of the Human Rights Act 1998, which incorporated into our law the European Convention on the Protection of Human Rights and Fundamental Freedoms. Of particular relevance here are article 2 (the right to life), article 3 (the right not to be subjected to torture or inhumane or degrading treatment or punishment) and article 8 (the right to respect for private and family life). These provisions do not invalidate a best interests approach. On the contrary, as I observed in *W v M*²⁴:

“a best interests assessment, properly conducted under English law in accordance with established principles, is fully compliant with ECHR....”

But they obviously as a matter of law affect the weight to be attached to various factors when assessing best interests.

For some years before the MCA was introduced, courts had been asked to determine issues concerning incapacitated adults including, in particular, issues around serious medical treatment, and had applied a best interests approach in doing so²⁵. So this approach was well established by the time of the decision of the House of Lords in *Bland* although it was not as fully developed or expressed as now set out in the MCA.

The leading judgment in *Bland* was given by Lord Goff of Chieveley. Time does not permit me to quote from the judgment in a detail, and any summary cannot hope to do justice to the erudition, wisdom and humanity displayed by that great judge, who sadly died a few weeks ago. With that caveat, I cite the following passages from his judgment.

“[T]he fundamental principle is the principle of the sanctity of human life - a principle long recognised not only in our own society but also in most, if not all, civilised societies throughout the modern world, as is indeed evidenced by

²² *Re (Male Sterilisation)* [2000] 1 FLR 549 per Thorpe LJ at page 560

²³ *Re F (A Child) (International Relocation Cases)* [2015] EWCA Civ 882

²⁴ *Supra*, at para 96

²⁵ See, for example, *Re F (Mental Patient)(Sterilisation)* [1990] 2 AC 1

its recognition ... in article 2 of the European Convention But this principle, fundamental though it is, is not absolute [T]here is no absolute rule that the patient's life must be prolonged by such treatment or care, if available, regardless of the circumstances [I]t is established that the principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so To this extent, the principle of the sanctity of human life must yield to the principle of self-determination”²⁶

Lord Goff acknowledged the difficulties that arose where the patient was incapable of indicating his consent, but observed that it was now accepted that a doctor could lawfully treat such a patient where it was established that such treatment was in his best interests, and that it followed that it must follow that such treatment should be discontinued where it was no longer in the patient’s best interests to provide it.²⁷ He then set out his rationale for his conclusion that in the case before him, involving a patient in a VS, the treatment could be lawfully discontinued:

“a distinction may be drawn between (1) cases in which, having regard to all the circumstances (including, for example, the intrusive nature of the treatment, the hazards involved in it, and the very poor quality of the life which may be prolonged for the patient if the treatment is successful), it may be judged not to be in the best interests of the patient to initiate or continue life-prolonging treatment, and (2) cases such as the present in which, so far as the living patient is concerned, the treatment is of no benefit to him because he is totally unconscious and there is no prospect of any improvement in his condition. In both classes of case, the decision whether or not to withhold treatment must be made in the best interests of the patient. In the first class, however, the decision has to be made by weighing the relevant considerations By contrast, in the latter class of case, of which the present case provides an example, there is in reality no weighing operation to be performed. Here the condition of the patient, who is totally unconscious and in whose condition there is no prospect of any improvement, is such that life-prolonging treatment is properly regarded as being, in medical terms, useless[F]or my part 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. It is reasonable also that account should be taken of the invasiveness of the treatment and of the indignity to which, as the present case shows, a person has to be subjected if his life is prolonged by artificial means, which must cause considerable distress to his family - a distress which reflects not only their own feelings but

²⁶ {1993} AC 789 at page 863

²⁷ Ibid at pages 866-7

their perception of the situation of their relative who is being kept alive. But in the end, in a case such as the present, it is the futility of the treatment which justifies its termination”.²⁸

In the years after *Bland*, this approach was adopted consistently in cases involving patients in what was described as the VS. As a result, the outcome of such cases was usually, if not invariably, the same. Once the court was satisfied that the patient was in a VS, with no prospect of recovery, treatment was regarded as “futile” and it followed that no process of weighing best interests was necessary or appropriate.

In recent years, however, developments in law and medicine have led lawyers, doctors, academics and others to challenge this approach. The passing of the MCA, and the identification of best interests as the key principle, expanded by the detailed provisions of section 4, led some to question whether a process that, in effect, short-circuited any such analysis by labelling the patient’s condition as “futile” was appropriate. This was reinforced by the greater recognition given to the rights and interests of people under disability.²⁹ Alongside this came the developments in medical understanding to which I have already referred – first, the identification of MCS as a distinct form of disorder of consciousness and, subsequently, the recognition that disorders of consciousness represent a spectrum, leading some to challenge the idea that VS exists as a separate distinct condition at all.

The case of M,³⁰ which was decided after the MCA came into force, was the first case involving an application for a declaration that a doctor may lawfully withdraw or withhold ANH from a patient in a MCS. I rejected a submission that I should adopt the approach advocated for VS patients in *Bland*, holding that, in cases involving patients in a MCS, the law required the court to identify those factors which are relevant to the person’s best interests and carry out a balancing exercise. But I followed the principle identified by Lord Goff, and reiterated by all judges in the intervening cases, that “the fundamental principle” was “the sanctity of life”. Although there was evidence that M had made some informal comments in earlier years before her illness about not wanting to be kept alive like Tony Bland, I concluded on the facts of the case that such declarations should not carry decisive weight and, having weighed up all the various factors, I decided not to make the declaration authorising withdrawal of ANH.

Although the case attracted much publicity and was the subject of extensive academic argument and criticism, there was no appeal against the decision. Three years later, however, in the case of *Aintree v James*³¹, the Supreme Court delivered a judgment which although it did not actually involve a patient suffering from either VS or MCS, represented a small but important change in the law.

²⁸ Ibid pages 868-9

²⁹ See for example *W v M*, supra, at para 235 and *Kent CC v A Mother and others* [2011] EWHC 407 (Fam) at para 132

³⁰ *W v M*, supra

³¹ [2013] UKSC 67

First, the Supreme Court (in the judgment of Baroness Hale, with whom the other judges agreed) confirmed that the best interests approach should be adopted. Although the starting point was the “strong presumption” that it is in a patient's best interests to stay alive, this is not an absolute rule and there are cases where it is not in a patient’s best interest to receive life-sustaining treatment.³² Every case is different and each case must be decided on its own facts.³³ The court accepted that there were cases, such as *Bland*, where there was no balancing exercise to be conducted, but rejected the approach favoured in the Court of Appeal in *Aintree v James* which had sought to extend the concept of a “futile” treatment to all cases where there was no real prospect of curing or palliating the life-threatening condition. Beyond that, and given the infinite range of cases that might come before the court, Baroness Hale observed as follows:

“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.”³⁴

Later, Baroness Hale added:

“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... But in so far 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.”³⁵

The impact of the decision in the *Aintree v James* is still being assessed, but it seems to me that, in the context of the other developments in law and medicine to which I have referred, the following consequences can be discerned.

³² Ibid para 35

³³ Ibid para 36

³⁴ Ibid para 39

³⁵ Ibid para 45

First, the best interests approach, based on the factors identified in s.4 of the MCA, should be applied in every case.

Secondly, all arguments based on the “futility” of treatment are confined to cases of VS and, in so far as medical science is moving to the view that disorders of consciousness should be seen as a spectrum and the concept of VS outmoded, it may be that it is no longer appropriate to decide any cases on that basis.

Thirdly, if it is right that “the purpose of the best interests test is to consider matters from the patient’s point of view”, it seems likely that the courts will now focus much more intensely on identifying the patient’s wishes, feelings, values and beliefs looking carefully at all statements, formal and informal, made by the patient at an earlier stage to a greater extent than hitherto. As a result, although there will undoubtedly continue to be a strong presumption that it is in a person’s interests to stay alive, it may be somewhat easier for that presumption to be rebutted.³⁶

WHAT ARE THE ETHICAL PRINCIPLES UNDERLYING THE DECISION?

Medical ethics and bioethics play a crucial role in a wide range of decisions involving health care, both at a macro level – decisions about the allocation of resources and public health policy – and at a micro level – decisions about the care of individual patients. Concepts like beneficence, non-malificence, and utilitarianism feature prominently in such decision-making. It is therefore perhaps surprising that ethical arguments feature relatively rarely in court proceedings. As one commentator has observed³⁷:

“It is a great pity that the close but estranged cousins, medical law and ethics, talk so little to each other. The estrangement is dangerous for both of them.”

Bear in mind that, just as I am not a doctor, neither am I a philosopher or ethicist. I therefore approach this subject with a degree of trepidation, conscious that this university is privileged to have a number of experts in the field. The writings of, for example, Prof Jonathan Herring and Charles Foster, amongst others, contain fascinating and sophisticated analyses of the many ethical issues that arise in these cases. What follows is inevitably a brief and imperfect summary of some of the ethical approaches to these difficult questions.

Why is it necessary to consider this aspect? The reason was summarised by Hoffman LJ in the Court of Appeal in the *Bland* case:

“this is not an area in which any difference can be allowed to exist between what is legal and what is morally right. The decision of the court should be

³⁶ See for example the decision of Pauffley J in *United Lincolnshire Hospitals NHS Trust v N* [2014] EWCOP 16

³⁷ Charles Foster "Choosing Life, Choosing Death: the Tyranny of Autonomy in Medical Ethics and Law" (Hart Publishing, 2009)

able to carry conviction with the ordinary person as being based not merely on legal precedent but also upon acceptable ethical values.”

The problem is that there is not agreement or even consensus about what those values should be. This is an area of the law about which many people have strong contrasting views which are often based on an ethical position, although it may not always be recognised or described as such. Time does not permit me to consider all ethical principles underpinning these cases. I will therefore focus on just a few.

For some people, the overriding principle is the importance of preserving life at all costs. This view can be detected in the use of phrases such as “the sanctity of life” and is often, but not always, linked to religious convictions – that life is given by God and it is not for man to take it away. This belief in something as self-evidently good or right, regardless of the consequences, is sometimes referred to as “deontological reasoning”.

A second principle is personal autonomy – which centres on the individual’s freedom to choose. Under this principle, it is the patient who decides what treatments to receive. Personal autonomy has acquired an importance in modern ethics during the last 50 years. The prevalence of personal autonomy does not extend to a right to insist on being given a certain treatment but it is seen in the absolute right to refuse treatment, as reflected in the quotation from Peter Jackson J above³⁸.

Although there are some who propound purist versions of these ethical approaches, many writers specialising in the field acknowledge that both have a role to play in decision-making. This is reflected in the case law, notably in the *Aintree* decision. The Supreme Court acknowledged the principle that it is in a patient’s interest to be kept alive, and described this as amounting to a “strong presumption” but added that it was not an absolute. Baroness Hale’s subsequent assertion that “the purpose of the best interests test is to consider matters from the patient’s point of view” might, on one view be seen as a strong endorsement of the pre-eminence of the autonomy principle, although she was quick to add that this did not mean that the patient’s wishes would always prevail.

Most ethicists would accept that personal autonomy has acquired pre-eminence as the most important ethical principle in medicine in recent years. The Law Commission has now indicated that it will shortly be proposing an amendment to s.4 of the MCA aimed at giving great priority to the person’s wishes and feelings³⁹. It seems to me, however, that there is a danger in an approach that focuses exclusively on identifying the patient’s wishes and feelings. First, there is the very great difficulty in identifying what those wishes and feelings really are. When a person has gone to the trouble of writing down precisely what he wishes, and getting the document witnessed by someone else, it may be straightforward. But if they have not done so, one is dependent on hearsay evidence, and the testimony of witnesses with inevitably

³⁸ See note 4

³⁹ Law Commission “Mental capacity and deprivation of liberty – interim statement” (May 2016) para 1.41

imperfect recollections of what was said, and very probably their own views and opinions which may, consciously or unconsciously, influence their account of what was said. And how can we be satisfied that what the patient is alleged to have said represents their true wishes unaffected by outside influence? Furthermore, how much thought has the person given before expressing their views? Not everyone is of a reflective disposition. Are all expressions of wish to be treated equally, irrespective of the degree of thought that preceded them? As Charles Foster has observed⁴⁰:

“when, if ever, will a patient be in a sufficiently receptive state of mind for perfectly autonomous decision-making?”

Even where one can be satisfied that P has indeed written or said what he is alleged to have written or said, and that the utterance represents his true wishes and feelings, the most that can be said is that it represents his wishes and feelings at that point. To what extent can it safely be assumed that this remains his wishes and feelings? I suspect that this doubt lies behind the widespread reluctance to execute advance decisions. We may now think we would never want to be in a MCS, but we don't truly know how we will feel when the moment arrives. We are concerned that, if we change our minds at a later date, it may be too late and our apparently clear expressions when we had capacity will prevail.

Secondly, because “no man is an island”, it must be wrong to give unqualified pre-eminence to the individual. What happens to an individual, whether he lives or dies, has a significance beyond the individual and extends to his family, friends, carers and the wider society. To some extent, section 4 of the MCA reflects this by requiring a court to take into account the views of others, including “anyone engaged in caring for the person or interested in his welfare”. It is also true that decisions that we make about our own lives may well have an impact on future decisions about other people. We must remember that our concept of personal autonomy is rooted in Western philosophy and its pre-eminence a relatively recent phenomenon. It does not always carry the same importance in other cultures.

Thirdly, there is a danger that too great an emphasis on an individual's wishes and feelings overlooks the importance of other aspects of the individual. There is after all more to being human than simply the freedom to express wishes and feelings. When discussing the ethical principles involved in these decisions, some judges and academics have used the word “dignity” – an old-fashioned concept but one which encapsulates an important aspect of the human condition. Hoffman LJ in the Court of Appeal in *Bland* ⁴¹described respect for the dignity of the individual human being: as equating to

⁴⁰ Charles Foster: "Choosing Life, Choosing Death: the Tyranny of Autonomy in Medical Ethics and Law", page

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⁴¹ [1993] AC 789 at p826

“our belief that, quite irrespective of what the person concerned may think about it, it is wrong for someone to be humiliated or treated without respect for his value as a person”

Subsequently, Sir James Munby, now of course the President of the Family Division and the Court of Protection, has emphasised the role that respect for dignity plays in decision-making in cases of serious medical treatment⁴². As he has pointed out, the right to dignity is, like the right to autonomy, an integral aspect of the article 8 right to respect for private life, and also protected by the article 3 prohibition of degrading treatment⁴³. Although unlike some other international instruments, ECHR does not mention it, the European Court of Human Rights observed in *Pretty v United Kingdom*⁴⁴ (a case on assisted suicide)

“The very essence of the Convention is respect for human dignity and human freedom.”

In an earlier case⁴⁵ Munby J (as he then was) observed:

“the recognition and protection of human dignity is one of the core values – in truth *the* core value – of our society”.

A further example is found in article 1 of the UN Convention of the Rights of Persons under Disabilities 2006, which describes the purpose of the Convention:

“to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”

There have been much academic discussion of what is meant by dignity as an ethical concept. It has been suggested that at its heart is the notion that every human has an intrinsic worth which should be recognised and respected by others.⁴⁶ Charles Foster, who as an academic and practising lawyer straddles both sides of the fence, has written extensively and perhaps provocatively of what he calls the “tyranny of autonomy”⁴⁷, and identified dignity as the “bioethical Theory of Everything”⁴⁸, *the* fundamental ethical principle which embraces all others, so that autonomy should be seen as but one manifestation of dignity, albeit an important one. We recognise that dying with dignity is an important aspect of human life, But “dignity” in this context means more than appearing dignified. There are indignities in being totally dependent on others for personal care. There are also potential indignities in the withdrawal of ANH. But beyond dignity as a qualitative description, there is a broader concept of dignity which Foster defines as “objective human flourishing”.

⁴² See in particular *R (Burke) v GMC* [2005] EWHC 1879 (Admin)

⁴³ *Ibid* paras 59 - 64

⁴⁴ (2002) 35 EHRR 1 at para 65

⁴⁵ *R *A, B, X and Y v E. Sussex CC and Another* [2003] EWHC 167 (Admin) at para 86

⁴⁶ McCrudden "Human Dignity and Judicial Interpretation of Human Rights"

⁴⁷ Charles Foster: "Choosing Life, Choosing Death: the Tyranny of Autonomy in Medical Ethics and Law" (Hart Publishing, 2009)

⁴⁸ Charles Foster: "Human Dignity in Bioethics and Law" (Hart Publishing, 2011)

It might be thought that taking human dignity into account when making these decisions will always lead to ANH being withdrawn. But it does not follow that a patient in a disorder of consciousness has no intrinsic worth. For family, friends and carers, and, I would suggest, society as a whole, such a patient may retain their essential human qualities even if they cannot be described as flourishing. This is a sensitive matter which requires careful analysis.

Thus when judges come to apply Baroness Hale's dictum that "the purpose of the best interests test is to consider matters from the patient's point of view", they should be careful not to confine themselves exclusively to striving to identify the patient's wishes and feelings, important though they undoubtedly are. The patient's point of view includes an objective analysis of what is in his or her best interests, as well as subjective expressions of wishes and feelings. S.4 requires the decision-maker to have regard to all the circumstances. I suggest that this requires an assessment of all aspects of the individual.

ARE JUDGES THE RIGHT PEOPLE TO BE MAKING THESE DECISIONS?

Some people may be wondering why it is that these issues had to be brought before a court at all. In most other areas of medicine, decisions about treatment are taken without resort to litigation. Serious decisions about the treatment of children, for example, are taken by the parents on advice from doctors and only brought to court where there is a dispute. At present, however, all cases involving a proposal to withdraw ANH from a patient in a VS or MCS have to be brought to court, even when all interested parties are unanimous that the proposed withdrawal is in the individual's best interests.

In *Bland*, the House of Lords upheld the view expressed by the Court of Appeal that applications should be brought to court in all cases "at least for the time being and until a body of experience and practice has been built up which might obviate the need for application in every case"⁴⁹. In a subsequent case⁵⁰ the Court of Appeal stated that

"good practice may require medical practitioners to seek such a declaration where the legality of proposed treatment is in doubt. This is not something they are required to do as a matter of law"

Subsequently, however, the provisions of the Court of Protection Rules and the associated Practice Direction have made it clear that at present all proposals for the withdrawal of ANH must be brought to court⁵¹.

⁴⁹ *Bland*, supra, per Lord Keith of Kinkel.

⁵⁰ *R (Burke) v GMC* [2005] EWCA Civ 1003 at para 80

⁵¹ In particular, Practice Direction 9E para 5(a)

It has been strongly argued in a number of quarters⁵² that court proceedings should no longer be required in such cases as a matter of course. It is pointed out that many medical decisions leading to the death of the patient are taken without reference to a court. Furthermore, the history of such court proceedings has regrettably demonstrated the chronic problems of all litigation – delay and cost. These problems greatly exacerbate the strain and distress experienced by family members and carers⁵³. It has therefore been suggested that applications to the court should be confined to those cases where there is a dispute as to whether withdrawal of ANH would be in the patient’s best interests.

I have considerable sympathy for these arguments. I acknowledge that in many cases hitherto proceedings have been unnecessarily drawn out and delayed, and with others I am in the process of attempting to streamline and simplify the court process. In particular, the adoption of a pre-proceedings protocol which spelt out the obligations on the parties to ensure that all necessary steps were undertaken before the start of the case, including independent testing of the level of consciousness, could lead to a significant reduction in delays. When all parties are agreed as to the outcome, and all the necessary evidence is available, there is no reason why the court’s decision should not be made in weeks rather than months or years as has happened hitherto.

I certainly would not wish to retain the obligation to apply to court indefinitely. The time may come when applications to the court are unnecessary save where there is a dispute. But for my part, I do not believe that we have yet got to that point. When the House of Lords in *Bland* predicted that the time would come when applications would no longer be required as a matter of routine, their Lordships anticipated that a body of experience and practice would be built up. But as I have, I hope, demonstrated above, both medical science and the law are still evolving. Until such time as we have greater clarity and understanding about the disorders of consciousness, and about the legal and ethical principles to be applied, there remains a need for independent oversight.

At present that oversight is provided by the twenty High Court Judges of the Family Division who sit in the Court of Protection. The task could, I suppose, be passed on to some other body, perhaps a panel of specialists who might include doctors, ethicists, lay people as well as lawyers. I doubt, however, whether there is much appetite for a reform of that nature. I stress that I see the urgent need for a more streamlined procedure which avoids undue cost and delay. In my opinion, however, applications to the court should continue to be obligatory in all cases where the withdrawal of

⁵² See e.g. Derick Wade "Back to the bedside? Making clinical decisions in patients with prolonged unconsciousness" J Med Ethics 2016, and Kitinger and Kitinger "Causes and Consequences of Delays in Treatment – Withdrawal from PVS Patients" J Med Ethics 2016

⁵³ See for example *Re S* [2016] EWCOP 32, in particular the comments of Hayden J at para 13, and the detailed analysis of the causes of delays in these cases by Kitinger and Kitinger in "Causes and Consequences of Delays in Treatment – Withdrawal from PVS Patients", supra.

ANH is proposed, at least for the time being. Whoever makes the decision will never find it easy. On the contrary, all these cases are challenging and the responsibility grave. But that is only to be expected when the issue is a matter of life and death.