The Sanctity Of Life Law Has Gone Too Far

Transcript

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Hello. Let me start by saying that in this lecture I am speaking personally and not as a representative of any of the organisations with which I am associated. I say this because I know that my theme - that sanctity of life law has gone too far- is controversial and that reasonable people, both in this audience and in the organisations with which I am associated, have diametrically opposed opinions about it. Let me also start by thanking our hosts Gresham College for my invitation to speak.

I do not know about you but I am pretty keen on running my own life and I am afraid I do not like other people telling me what is best for me. If I respect them then I am usually ready to listen to their ideas and advice and sometimes I even take such advice! But I do like to make my own decisions about what is best for me. The thought of being classified as legally ‘incapacitated’ to make decisions especially about my care - the thought of becoming legally subservient to other people’s decisions about what is in my ‘best interests’- is to me truly appalling. I know it has to happen for incapacitated people and I know that care staff in nursing homes are often very kind and well meaning, as are very many doctors and nurses and relatives, of whom have to look after their incapacitated elderly clients, patients or relations but the prospect of becoming one of those elderly incapacitated people in their care is, to be honest, quite ghastly.

I am particularly keen, therefore, that if and when I am diagnosed to be afflicted by such incapacity, and that it is very probably irreversible, that my doctors will not prolong it by administering any life pronging treatments- and that includes artificial nutrition and hydration. Let me say at once that I am not advocating suicide or euthanasia or being helped to find some Swiss euthanasia to bump me off when I have lost or am losing my marbles. If I could, I would have voted against changing the law to permit voluntary euthanasia and or physician assisted suicide on the grounds that I think more harm than good would probably come of it. No, I just want nature to be allowed to take its course once those marbles have rolled away in severe dementia or been smashed away by brain trauma of one sort or another. And I would want even more strongly not to have my life prolonged if I was irrecoverably in a vegetative state (alive but having no experiences at all) or else, worse still, in what is now called ‘a minimally conscious state’- having some experiences, some enjoyable some unpleasant but without ability to reason and without ability to respond to questions on the basis of reason.

You might think that no sensible doctor would try to keep me going in those circumstances especially if I had beforehand told people about my views. A few years ago you would probably have been right, but my concern is that the law seems to be moving towards preventing doctors from following their patients’ prior wishes to let nature take its course in this way unless those wishes have been explicitly written into a legally valid and applicable and witnessed document called an Advance Decision to refuse treatment- specifically life prolonging treatment. Those refusals are legally binding under the Mental Capacity Act 2005. But in the absence of such a document, reports of the patient’s prior views- even from family and friends who know the patient well- that an incapacitated patient would not want life prolonging treatment should, according to one judge, be given very little weight when set against the legal principle of the sanctity of life.

Now I am not a lawyer- I am a retired NHS GP and a retired professor of medical ethics- but ethics knows no disciplinary boundaries and in any case medical ethics and medical law have an obviously close inter-relationship; and doctors are inevitably obliged by our professional ethics to do the right thing for our patients; and both these perspectives have long led me to pay attention to relevant legal matters. It was a judgment in 2011 in the Court of Protection concerning an unfortunate woman referred to as M that most acutely prompted my concerns about sanctity of life law. Although aspects of a more recent judgment, to which I will return later in this talk, about a different case- Aintree v James- in our highest court, the Supreme Court, alleviate some of my concerns, the logic of my worries about the M case remains unaddressed, as I hope to demonstrate to you today.

The case of ‘M’

In 2003, as a result of a devastating viral brain infection, 43 year-old Ms M fell into a coma shortly before she was to have gone on a skiing trip. As time went on she was first diagnosed as being in a vegetative state - in which patients are believed to have no experience at all though they appear to be going through episodes of sleep and wakefulness. She was then reassessed and diagnosed to be in a ‘minimally conscious state’- in which the name implies the patient has some degree of experience but at a minimal level. In M’s case she was able to have some pleasurable experience such as apparently enjoying sitting in her wheel chair in the sun; certain music brought tears to her eyes; she seemed to respond with pleasure to certain members of staff at her care home; and she was sometimes able to respond to simple requests such as to press a buzzer, though not in a consistent way and not in a way that made any sort of conversation possible (as, for example, by responding to questions by pressing once for yes and twice for no). She occasionally spoke words and she was able to make ‘unintelligible groans’.
After the change of diagnosis to minimally conscious state in 2007, intensive efforts were made in one of the world’s leading neuro-rehabilitation hospitals in Putney in London to enhance her ability to communicate but without success and she was discharged back to her nursing home in the North of England where she continued to receive excellent care, as all involved agreed. However it was clear – and all involved agreed on this too- that M had no realistic prospects of substantial improvement of her minimally conscious state (let alone ever getting back her capacity to make decisions, including health care decisions, for herself). Her very loving relatives including her mother “W”, her sister “B” to whom she had always been very close, and her loving partner of over twenty years, “S”, decided to apply to the Court of Protection for permission to withdraw her artificial nutrition and hydration- ANH for short- though in the other case that I will talk about it is called clinically assisted nutrition and hydration or CANH for short. Anyway M’s ANH was supplied through a ‘PEG’ (sorry- another acronym - percutaneous endoscopic gastrostomy, widely abbreviated to PEG) - a tube sewn into her stomach- and it was essential to sustain her life - if her ANH was withdrawn as requested M would die. But her family argued that M, who had been a very independent person, would have hated to go on being kept alive in her current and incurable state of total dependence on others, doubly incontinent, unable to do anything for herself, suffering from apparently painful contractures of her arms and legs and manifesting hypersensitivity to being handled during her care. The application was opposed by the Official Solicitor acting as her litigation friend to protect her best interests and by the NHS Trust which was providing her NHS care.

Following a very thorough hearing of evidence on both sides, the judge ruled that it was in M’s ‘best interests’ to continue to be kept alive by feeding her through the ‘PEG’ tube sewn into her stomach. The judge ‘unreservedly’ accepted the testimony of her nearest and dearest who said that she would definitely not have wished to be kept alive any longer in such a state. But he ruled that it would be wrong to give her prior views when she was competent and independent much weight when assessing her best interests now, as the law required him and all who treated her to do. Her reported prior views did not specifically address the situation she was now in, she might in any case by now have changed her mind, and she had not written any sort of valid and applicable advance decision to refuse that life-prolonging treatment of artificial nutrition and hydration. Had there been such a formal valid and applicable advance decision, the judge acknowledged that it would have been previously legally binding under case law and would now be legally binding under statute law provided it had conformed to ‘the stringent safeguards and formalities’ of the Mental Capacity Act 2005. In the absence of a valid and applicable advance decision to refuse artificial nutrition and hydration, although the law required him to consider her previous informally expressed views he did not give them much weight- ‘it would in my judgment be wrong’ - what was to be given substantial weight in assessing M’s best interests, explained the judge, was ‘the sanctity of human life’.

In addition the judge reiterated the requirement, under rule 9E of the Court of Protection, that any proposal to withdraw artificial nutrition and hydration from persons in a vegetative state or in a minimally conscious state must be referred to the Court of Protection. In the meantime such patients must continue to be provided with life sustaining treatment including ANH.

That judgment led me to do two things. I wrote an editorial, published by the British Medical Journal, criticising it; and I began to draft my own formal Advance Decision to refuse any life prolonging treatment whatsoever after I had been legally incapacitated to make decisions about my treatment for longer than three months, and if my chances of recovering such capacity were medically assessed as very unlikely: (and I go into considerable detail about what I mean).

But very few of us will ever go to the trouble of writing such an Advance Decision. If we have not and if we become severely and incurably mentally incapacitated like M, in a minimally conscious state, must doctors be required to keep us alive unless, with very few exceptions, they have obtained the Court of Protection’s permission to withdraw life prolonging treatment? For that is what the judgment states in the M case with its affirmation of the Court of Protection’s rule 9E. And the logic of that judgment is that not only people in minimally conscious state, but all legally incapacitated people should receive life prolonging treatment including ANH if necessary to prolong their lives, again with a few exceptions, until and unless the Court of Protection rules in individual cases that it is not in their best interests to do so. And although last year’s supreme court judgment in the case of Aintree v James, about a patient in minimally conscious state whose relatives made clear that he would have wanted all possible life prolonging treatments, made clear that the court of protection must give weight to the previously expressed views of patients about life prolonging treatment, even if those views have not been written into a legally binding Advance Decision, that Supreme Court judgment did not explicitly address the provision of ANH, nor did it address the issue of which proposals to withhold and or withdraw life prolonging treatment had to be referred to the Court of Protection.

My criticism of the judgment in the case of M

My criticism in the British Medical Journal of the M judgment – on which I am enlarging today - was twofold. First I argued that it failed to give proper weight to the prior views and values of the particular incapacitated patient M. Second I argued that even though the M case formally relates to only one specific individual M, its logic produces two radical and I believe unwelcome general implications. The first is that it will cause a general undervaluing of respect for people’s own informally expressed competent autonomous prior wishes concerning life prolonging
treatment if they become legally incapacitated, in favour of the legal principle of the sanctity of life-and especially of doctors’ legal obligation to prolong life. The second is that the logic of the judgment if pursued will skew medical practice towards having to provide ever more non-beneficial life sustaining treatments, including artificial nutrition and hydration, to all legally incapacitated patients whose lives would be shorter without such treatment. For the logic of the M judgment is that life prolonging treatment must be provided not only to all patients in minimally conscious states but to all legally incapacitated patients whose lives would be shorter without such treatment, with a very few exceptions. The exceptions would be ‘futile’ treatment (with debate about what ‘futile’ means); or that patients are imminently dying; or that such treatment would be intolerable or excessively burdensome to the patient; or that the patient has written a valid and applicable advance decision to refuse it, or that the Court of Protection has ruled - ‘exceptionally’ – that it is in the patient’s best interests to withdraw such treatment.

Now, of course, the judge in the M case did not say that medical treatment should be skewed in this way. He was concerned only with the particular patient M and whether the particular treatment of artificial nutrition and hydration was in her particular best interests. But by confirming the Court of Protection’s rule 9E which requires proposed decisions to withhold or withdraw life prolonging treatments from minimally conscious patients to be referred to that Court, the M judgment’s logic simply and relentlessly leads to my conclusions. For if people in a minimally conscious state must be protected from possible mistaken decisions by doctors by having to be given life prolonging treatment including ANH until and unless the Court of Protection rules, ‘exceptionally’, in individual cases that it is not in their best interests to receive such treatment then ‘a fortiori’ as philosophers say – ie with still stronger reason - must incapacitated people who have higher than minimal consciousness be similarly protected. So, if the logic of the M judgment is followed, then pending a possible Court of Protection decision to the contrary, life prolonging treatment including ANH by tube feeding, must be provided, with the few exceptions just mentioned, to all legally incapacitated people who cannot (or will not) eat and drink normally, and whose lives would be shorter without such life prolonging treatment. Such patients would include all legally incapacitated people suffering from dementia, from severe and incurable brain damage of any other sort, from disseminated and incurable cancer, and indeed from any other sort of disease or damage that renders them legally incapacitated to consent to or reject life prolonging treatment including artificial nutrition and hydration.

Respect for prior autonomy?

When the Mental Capacity Act 2005 was introduced it looked to some of us as though it was a major move towards respecting people’s prior autonomy after they became mentally incapacitated. Its requirements (in section 4) that in assessing a person’s ‘best interests’ efforts should be made to ascertain the person’s ‘past and present wishes and feelings’, ‘the beliefs and values that would be likely to influence his decision if he had capacity’, and ‘the other factors that he would be likely to consider if he were able to do so’ seem to manifest an indisputable concern in the Act to ensure respect for the incapacitated person’s prior autonomy or self determination. However judicial interpretation of the Act in the case of M belies that understanding so far as prolongation of life is concerned.

In particular, the judge in the M case made clear, as I have said, that while he accepted ‘without qualification’ that M had had the beliefs and values that the family reported her as having, he gave little weight to M’s prior views because to do so ‘would be wrong’. Thus the judge accepted, for example, that M had told her partner ‘don’t ever put me in a place like this’ meaning a long term nursing home such as both her grandmother and her father had been in; that she would want ‘to be off quick’ and not dependent on others; that she had told her sister that she would prefer to live ten fewer years than have to be looked after by others; that in discussion of the Tony Bland case she said that it would be better to allow him to die. The judge accepted all the evidence of her family including that of her long term partner S who stated that M would be ‘horrified’ at being kept alive in her present state; the judge accepted the evidence of her sister who said her sister’s life in her minimally conscious state was ‘not a life, it’s an existence and I know she would not want it’. Nonetheless the judge gave these views little weight. What did carry decisive weight, in the judge’s opinion, was the sanctity of life: ‘Given the importance of the sanctity of life, and the fatal consequences of withdrawing treatment, and the absence of an advance decision that complied with the requirements previously specified by the common law and now under statute, it would in my judgment be wrong to attach significant weight to those statements made prior to her collapse’. Quoting another judge he said: ‘there is a very strong presumption in favour of taking all steps which will prolong life and, save in exceptional circumstances, or where the person is dying, the best interests of the patient will normally require such steps to be taken’; and he concluded that ‘In my judgment, the importance of preserving life is the decisive factor in this case’.

My own admittedly very succinct summary of this judgment is; sanctity of life law trumps prior autonomy unless there is a valid and applicable advance decision to the contrary. And my own contrary view, again in very succinct summary, is that prior autonomy even if not expressed in a legally valid and applicable Advance Decision to refuse life prolonging treatment should trump sanctity of life law.

Seven counterarguments to my own position

So what about the counterarguments to my own position? These can be summarised as follows.
1) A fundamentalist objection is that human life is sacred - hence the origin of the phrase 'the sanctity of life' - and must never be taken and where possible must be prolonged. I do not propose to argue with this view though I have elsewhere pointed out (a) its implausibility and (b) the awful effects on our society and on our health services if prolongation of human life became an absolute obligation. Our law does not adopt this position and very few people do.

2) Nonetheless helping people to survive who would otherwise die is a widely acknowledged moral value and some would argue that it is both the main moral value in general and the main moral purpose of medicine in particular. Correspondingly not being killed and being helped to stay alive comprise together a fundamental human right - the right to life - which is enshrined in international declarations of human rights and in national laws including UK laws.

3) A counterargument linked to the previous one is that 'so called allowing people to die' by deliberately not giving them life prolonging treatment and especially by withholding food and water is actually killing them. Withholding and withdrawing of ‘so called artificial nutrition and hydration’ is in reality starving and droughting people to death (droughting someone is my neologism for deliberately depriving that person of water - just as starving someone is deliberately depriving that person of food and suffocating someone is deliberately depriving that person of air). Such deliberate starving and droughting people to death are particularly heinous, heartless and callous ways of killing people and should be unthinkable for all but especially for doctors.

4) A further though linked counterargument to my position is that (a) it is morally repugnant to ration any sort of life prolonging treatments and (b) even if scarcity of resources for health care does require that some perhaps very expensive life prolonging treatments must be rationed, artificial nutrition and hydration must never be withheld on grounds of scarce resources; there is something morally special about providing life-sustaining food and water that makes the idea of withholding and or withdrawing artificial nutrition and hydration from minimally conscious patients on the grounds of ‘opportunity cost’ to others- utterly morally repugnant (as one blogger responded to my BMJ editorial- though in rather more abusive terms than those that I have just uttered on his behalf!).

5) Another justice counterargument claims that allowing severely disabled people such as M to die when people with normal abilities would be kept alive is a pernicious form of unjust discrimination against disabled people. For others to assess that the pleasure or other benefits derived by people like M from their admittedly limitedly sensate lives are not sufficient to justify keeping them alive ‘represents grave discrimination against disabled persons’ as Chand and Tiptoe put it in response to Wilkinson and Savulescu’s contribution in the Journal of Medical Ethics extensive symposium on the M case in its September 2013 edition.

6) A philosophical counterargument is that the person in minimally conscious state is no longer the same person as the competent autonomous person he or she previously was and so the views of the previous competent person are of no relevance to the treatment of the current incapacitated person.

7) Finally, as the judge in the M case argued, the person in minimally conscious state may have changed her or his mind.

Well in this talk I can only give you summary responses to these counterarguments while of course each issue has had - in the words of the judge in the M case – ‘much ink spilt ’ on it.

I have already summarised my response to the first, vitalist, counterargument - that human life is of absolute value and prolonging people’s lives so far as is possible is an absolute moral obligation. Fortunately this implausibly absolutist view is not widely held and is certainly not a part of UK law, despite the misleading use in English law of the term ‘sanctity of human life’.

The right to life and medical ethics oblige doctors to provide life prolonging treatments?

The second non-absolutist counterargument does seem so obviously right does it not, based as it is on everyone’s right to life and on doctors’ ethical obligation to preserve life? But the argument needs careful analysis. Of course trying to keep people alive is usually an integral and literally vital moral objective of medicine and of course the ‘right to life’ is a hugely important moral and legal right and of course doctors start from a presumption in favour of prolonging life as the General Medical Council puts it. But medicine’s astonishing recent developments have increasingly facilitated doctors’ ability to keep people alive in a state that those people themselves do not – or would not when they were able to make such assessments - consider worth living. Incurable vegetative state - what used to be called permanent or persistent vegetative state or PVS - in which a patient has no experience at all but goes through apparent sleep wake cycles – is widely agreed to be a state of living that very few people would wish to have prolonged. Nonetheless there are some who vigorously assert that they would wish to have their lives prolonged even if they were reliably diagnosed to be in incurable vegetative state. Since the Bland case that I mentioned - of a young man who was crushed during the Hillsborough stadium disaster and went into PVS - English law permits the withdrawing of life sustaining treatments including artificial nutrition and hydration from patients in PVS if a court decides that such treatment is not in the patient’s best interests. The main justification for such withdrawal is that such treatment can provide...
It becomes clear that the patient’s brain damage is irremediable and life prolonging measures including fluids, maximal life prolonging measures as they attempt to diagnose and then remedy the brain damage. Sometimes it patients who have sustained massive and catastrophic head injuries. The doctors and nurses will have instituted palliative care, that the objective of prolonging people’s lives even if it can be achieved at least for a while by life prolonging treatments, may sometimes cause too much of a burden either for the patient or for others who would be deprived of the scarce resources required.

Let me give you a different example. Neurosurgical intensive care wards regularly look after unconscious patients who have sustained massive and catastrophic head injuries. The doctors and nurses will have instituted for example incurable severe dementia and incurable and disabling disseminated cancer - there is a growing need for non-doctors to be aware that sometimes prolongation of life does not actually benefit patients and allowing to die it does not follow that there necessarily are never moral distinctions to be made between killing and letting die. To adapt an ancient ‘philosopher’s thought experiment’ originally offered by Phillippa Foot; if I omit to send money to Oxfam and as a result someone in the third world dies of starvation who would have been saved had I sent that money, that may or may not be morally culpable - it depends whether you think I am morally obliged to send money to Oxfam; but it is clearly morally different from and less morally culpable - if it is morally culpable at all - from my deliberately sending poisoned food parcels to that part of the world (perhaps to demonstrate a philosophical point). In medicine it is widely acknowledged, most obviously in the speciality of palliative care, that the objective of prolonging people’s lives even if it can be achieved at least for a while by life prolonging treatments, may sometimes cause too much of a burden either for the patient or for others who would be deprived of the scarce resources required.

So to my response to the third counter argument - that ‘allowing people to die’ is morally and often legally the same as killing them. Again, there is a huge literature on this issue but my summary response is that sometimes it is and sometimes it is not! Philosophers such as James Rachels and John Harris have established conclusively that there is no necessary moral difference between killing and letting die - and the law makes it just as clear that in some circumstances ‘allowing to die’ can be homicide. Let me offer an obvious if unrealistic example - well I hope it is unrealistic: if a doctor deliberately omits to treat his diabetic patient with the insulin needed to prevent him dying in a diabetic coma - and to make the point very obvious let us say the doctor does this because he is having an affair with the patient’s wife and sees a wonderful opportunity to get rid of her husband - then that doctor is as morally culpable as if he had deliberately killed the patient by injecting poison, and probably also legally culpable - and he will not get out of a ‘guilty’ verdict, either morally or legally, by pleading that he was only ‘allowing the patient to die’. But just because there is no necessary moral distinction to be made between killing and allowing to die it does not follow that there necessarily are never moral distinctions to be made between killing and letting die. To adapt an ancient ‘philosopher’s thought experiment’ originally offered by Phillippa Foot; if I omit to send money to Oxfam and as a result someone in the third world dies of starvation who would have been saved had I sent that money, that may or may not be morally culpable - it depends whether you think I am morally obliged to send money to Oxfam; but it is clearly morally different from and less morally culpable - if it is morally culpable at all - from my deliberately sending poisoned food parcels to that part of the world (perhaps to demonstrate a philosophical point). In medicine it is widely acknowledged, most obviously in the speciality of palliative care, that the objective of prolonging people’s lives even if it can be achieved at least for a while by life prolonging treatments, may sometimes cause too much of a burden either for the patient or for others who would be deprived of the scarce resources required.

**Allowing to die is killing?**

So to my response to the third counter argument - that ‘allowing people to die’ is morally and often legally the same as killing them. Again, there is a huge literature on this issue but my summary response is that sometimes it is and sometimes it is not! Philosophers such as James Rachels and John Harris have established conclusively that there is no necessary moral difference between killing and letting die - and the law makes it just as clear that in some circumstances ‘allowing to die’ can be homicide. Let me offer an obvious if unrealistic example - well I hope it is unrealistic: if a doctor deliberately omits to treat his diabetic patient with the insulin needed to prevent him dying in a diabetic coma - and to make the point very obvious let us say the doctor does this because he is having an affair with the patient’s wife and sees a wonderful opportunity to get rid of her husband - then that doctor is as morally culpable as if he had deliberately killed the patient by injecting poison, and probably also legally culpable - and he will not get out of a ‘guilty’ verdict, either morally or legally, by pleading that he was only ‘allowing the patient to die’. But just because there is no necessary moral distinction to be made between killing and allowing to die it does not follow that there necessarily are never moral distinctions to be made between killing and letting die. To adapt an ancient ‘philosopher’s thought experiment’ originally offered by Phillippa Foot; if I omit to send money to Oxfam and as a result someone in the third world dies of starvation who would have been saved had I sent that money, that may or may not be morally culpable - it depends whether you think I am morally obliged to send money to Oxfam; but it is clearly morally different from and less morally culpable - if it is morally culpable at all - from my deliberately sending poisoned food parcels to that part of the world (perhaps to demonstrate a philosophical point). In medicine it is widely acknowledged, most obviously in the speciality of palliative care, that the objective of prolonging people’s lives even if it can be achieved at least for a while by life prolonging treatments, may sometimes cause too much of a burden either for the patient or for others who would be deprived of the scarce resources required.

Let me give you a different example. Neurosurgical intensive care wards regularly look after unconscious patients who have sustained massive and catastrophic head injuries. The doctors and nurses will have instituted maximal life prolonging measures as they attempt to diagnose and then remedy the brain damage. Sometimes it becomes clear that the patient’s brain damage is irremediable and life prolonging measures including fluids,
nutrition and mechanical ventilation, are withdrawn even though the patient would have gone on living longer had these life prolonging treatments been continued. This is not widely regarded either ethically or legally as killing the patient; as starving or droughting or suffocating the patient to death; it is regarded – in my view correctly regarded - as allowing the patient to die – and the morally and legally relevant cause of the patient’s death is the massive brain damage he or she has sustained, not the doctors’ withdrawal of life-prolonging treatments. So no, allowing to die is not necessarily morally or legally the same as killing, and it certainly is not when doctors allow patients to die because they cannot benefit those patients by prolonging their lives.

And so to the two justice objections; rationing of scarce life prolonging resources and especially of rationing artificial nutrition and hydration; and discrimination against disabled people.

**Discrimination against disabled people?**

Let me invert the order and deal first with the discrimination counterargument. It asserts that withholding life prolonging treatments from patients in minimally conscious states when one would not withhold it in patients with normally conscious states manifests immoral discrimination against disabled people. I respond by going back to the earlier issue of benefit and asserting that the basic moral purpose of any medical intervention is the ancient Hippocratic medical commitment to aim to provide net health related benefit with minimal harm; in modern times this ‘Hippocratic commitment’ is supplemented by the additional moral qualifications of doing so in ways that respect the autonomy of, and are just and fair to, all those potentially affected. By definition, all legally incapacitated patients are not in a state in which they then have sufficient, if any, autonomy; but as I have just argued their prior autonomy prima facie ought to be respected, even if it has not been expressed in a legally valid and applicable document. So the first issue to be addressed is would the ANH/CANH provide net health benefit with minimal harm? With non-disabled patients we would ask the patient. One way of reducing discrimination against inadequately autonomous or non-autonomous disabled people is to respect their prior autonomous views if these are discoverable even if these views have not been expressed in valid and applicable advance decisions; and conversely failing to respect their previously expressed competent views does discriminate against them.

But, of course, people’s views about life prolonging treatment in incurable minimally conscious state will depend to a large extent on whether they believe that prolongation of life is a benefit in itself or is instead a means to an end – that end being a life that the person concerned would consider worth prolonging. My own view as I have indicated is that prolongation of life is not a good in itself though usually but not always it is a means to achieving such a good. That, of course, is in no way to deny the obvious fact that life - being alive - is a necessary condition of having a life that the person living that life does or would consider worth living and prolonging. But though being alive is a necessary condition for having a life that one considers worth living it is not a sufficient condition. For many of us a life in permanently vegetative state is not a life worth living and so too for many of us a life in minimally conscious state would be even worse. Emily Jackson, a professor of medical law, movingly interprets, in her September 2013 Journal of Medical Ethics paper, M’s plight along these lines, in stark contrast to the judge’s optimistic interpretation of her state. But of course some people do believe that having their lives prolonged for as long as possible, no matter what the quality of their lives might be, is a benefit and they would want life prolonging treatment to be provided for as long as possible. The Aintree v James case, which I will discuss briefly in a few minutes, is a very recent Supreme Court case about just such a patient. That judgment offers some welcome clarification of the Mental Capacity Act and to some extent potentially allays (if lawyers and judges interpret the case similarly!) some though not all of the worries I have been discussing. But the judgment does reiterate and make clear that under the MCA it is unlawful to discriminate against patients on the basis of any disability; the Act requires that the treatment of all incapacitated patients must be based on their best interests. However it is, of course, true that all legally incapacitated people are at a disadvantage compared with those who have capacity because if you have legal capacity you have the legal right to make decisions for yourself. And it is surely true that those who make decisions on behalf of incapacitated people at least may make the wrong decisions: those of us who oppose the decision in the M case believe that the judge made the wrong decision (and of course vice versa). But whichever way the case had been decided it would not have been because of a problem of discrimination against disabled people - instead we need to understand that the need to make such decisions on behalf of legally incapacitated people arises because their disability whatever it might be renders them inadequately autonomous to make their own decisions.

‘Rationing’ life sustaining treatments is morally repugnant and ANH must never be rationed?

So what about the fourth counterargument – rationing of scarce life prolonging treatments is morally repugnant; but even if scarcity of resources makes rationing of life-prolonging treatments, sometimes unavoidable, rationing of artificial nutrition and hydration on the grounds of scarce resources and opportunity cost to others is always morally unacceptable: provision of ANH is morally obligatory basic care and must be provided whenever possible if necessary to preserve life.

My response to the first part of this counterargument is that, of course, rationing of scarce health care resources is necessary and if life-prolonging treatments are to be immune from such rationing the inevitable result must be that fewer resources will be available for health care that improves but does not sustain or prolong life. It seems clear that medicine’s ability to produce beneficial treatments of one sort or another grows...
year on year (as well, alas, as its ability to produce some treatments of doubtful benefit). It seems equally clear that the capacity and/or willingness of societies to pay more and more for health care does not grow at the same rate. So rationing is and will continue to be necessary - QED for that part of the argument! Amongst the rationing decisions needed – or allocation decisions as some prefer to call them – are choices between allocating resources to life prolonging treatments or to non-life prolonging treatments. If new life prolonging therapies are developed and to be immune from rationing and if existing life-prolonging therapies including ANH are to be used in all cases where they can prolong life then clearly use of health care resources will be skewed towards life prolongation and away from therapies that are not life-prolonging. QED for that part of the argument! Perhaps the most widely discussed examples of new life prolonging treatments are those for advanced cancer; and they already compete for NHS resources with, for example mental health treatments and joint replacements to treat pain and mobility problems. There are huge debates, of course, about the best ways of making such allocation decisions, and especially about the use of measures that try to combine length and quality of life such as cost per QALY or per DALY (ie cost per quality adjusted life year or per disability adjusted life year gained by a treatment). But so long as there are insufficient resources to pay for all available beneficial health care treatments - and it seems safe to assume that this will always be the case - then painful and unwelcome rationing or allocation decisions will be necessary, and at the very least it seems highly implausible to exclude from such rationing or allocation decisions any therapy that prolongs life, regardless of such factors as their cost, the extent of the increased life span that they produce and the quality of that increased life span as experienced by the patient.

As I have said my first worry about the M judgment was that it ignored incapacitated people’s prior autonomy while my second worry was that its emphasis on the sanctity of life would skew the allocation of health care resources towards prolongation of life and away from health care that improves but does not prolong life. In this regard I was greatly encouraged by the Supreme Court’s judgment in the case of Aintree v James. That judgment state, amongst much else, that neither patients nor the Court of Protection acting on their behalf could instruct doctors on what treatments they had to provide.

‘This Act [the Mental Capacity 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 [first] 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”’. And the judgement reiterated a previous judgment that stated “Ultimately, however, a patient cannot demand that a doctor administer a treatment which the doctor considers is adverse to the patient’s clinical needs”. 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.’

So plainly the Supreme Court is stating that it is not the role of the Court of Protection to tell doctors what treatments they must give nor to tell health authorities how to prioritise their resources - eg in favour of life-prolonging treatments. In the context of my argument, I find that reassuring. But what the Supreme Court judgment does not address is the contrary ‘a fortiori’ logic of the Court of Protection’s Rule 9E, which I outlined earlier in this talk. To remind you of my simple argument: if the ‘serious treatment’ - as 9E calls any proposed withholding or withdrawing of life prolonging treatment including artificial nutrition and or hydration - for legally incapacitated patients in minimally conscious state must be referred to the Court of Protection, then ‘a fortiori’ the same degree of protection should be accorded to legally incapacitated patients who have greater than minimal consciousness. The rules of the Court of Protection are (it seems clear to this non lawyer) are general rules and rule 9E is a general rule that includes general instructions about types of cases of serious treatment that must be referred to the Court. And while it is true that the judgments of the Court of Protection are about individual patients, the rationale used by judges in those individual judgments is bound to be generalised in practice and acted on by doctors and health authorities. So it is not clear to me that the Supreme Court in Aintree v James has relieved my worries that the logic of the M judgment including its endorsement of Rule 9E implies that ANH must be provided to all legally incapacitated patients whose lives would be prolonged (with the few types of exception I have mentioned) until and unless the Court of Protection rules otherwise in particular cases and that as a result allocation of health care resources will in practice be skewed towards life prolongation thus reducing resources available for treatments that are not life-prolonging.

Is artificial or clinically assisted nutrition and hydration a special case that must always be provided?

The second part of this counterargument is that even if rationing of life prolonging treatments is sometimes necessary provision of food and water including food and water delivered by tube feeding of various sorts is morally special and must never be deliberately withheld or withdrawn if needed to prolong life? Unlike his predecessor Pope Pius XII, Pope John Paul II certainly stated that this was the case. In an address to a congress organized jointly by the Pontifical Academy for Life and the International Federation of Catholic Medical Associations, he called the withdrawing of ANH from patients in vegetative state ‘euthanasia by omission’ and ‘a serious violation of the law of God. And of course if it is euthanasia and contrary to God’s law for PVS patients
then it is euthanasia and contrary to the law of God for patients in minimally conscious states.

I am not a Roman Catholic (let me declare my own background in this context - I am an atheist Jew, offspring of a mixed marriage, and educated at an ancient and excellent Church of England boarding school, Christ's Hospital) but I found that John Paul II's papal statement inconsistent with Pope Pius XII's famous doctrine of Ordinary and Extraordinary Means, which interestingly was also delivered to doctors, back in 1957 in relation to the use of then newly developed artificial respirators. Years ago, I praised that doctrine of Ordinary and Extraordinary Means as a statement of common sense morality relevant to us all regardless of our religion or lack of it. To this self-acknowledged outsider Pope John Paul's assertion that ANH was always morally obligatory actually ignored the advice of his predecessor; furthermore everything that John Paul said in justification of his view that ANH was always morally obligatory, because food and water were basic and essential to life was equally true of air which is also basic and essential to life. His predecessor Pope Pius XII made it clear, in relation to respirators, that they were not always morally obligatory; that whether a life-prolonging medical intervention was 'ordinary' and therefore morally obligatory or 'extraordinary' and therefore morally optional all depended on the burdens and benefits 'to self or others'. Careful assessment along these lines enabled doctors and others to decide whether in a particular case the medical provision of air by means of a ventilator (what I have called 'artificial aeration') to make the similarity clear was an 'ordinary means' and thus morally obligatory, or whether it was an 'extraordinary means' and therefore permissible to be withheld or withdrawn.

Well I do not expect to convince Roman Catholic listeners about my interpretation of papal statements! The important practical point is that in the UK – not a Roman Catholic country for a few hundred years now - biological nutrition and hydration are regarded as medical interventions that in some circumstances are not legally or medically obligatory even when death will result if they are not provided. This was legally established by the House of Lords when they permitted withdrawal of ANH in their judgment in the case of Tony Bland, the patient who had been badly crushed in the Hillsborough stadium disaster and had survived in a permanent vegetative state- the patient whom M had said ought to be allowed to die. The law lords agreed that it was not in Bland's best interests to continue to be provided with ANH. But recognising that withdrawing or withholding ANH was a contentious issue about which there were strongly opposed religious and cultural views (religious opposition was and is by no means restricted to Roman Catholics, who were themselves divided about the issue) the law lords advised in their ruling that it would be good practice for any withholding and withdrawing of ANH from patients in PVS to be referred to the courts. And as already noted, more recently Rule 9E of the Court of Protection requires such referral to the Court of Protection not only if the patient is in vegetative state but also if he or she is in a minimally conscious state.

In its advice on end of life care the General Medical Council advises doctors of these legal obligations. Otherwise its advice in general concerning all legally incapacitated patients who cannot eat and drink normally and who are not imminently dying (ie their death is not expected within hours or days) is nuanced but heavily weighted towards an assessment of overall benefit in the light of patients' own preferences: 'you must provide clinically assisted nutrition or hydration if it would be of overall benefit to them, taking into account the patient’s beliefs and values, any previous request for nutrition or hydration by tube or drip and any other views they previously expressed about their care. The patient’s request must be given weight and, when the benefits, burdens and risks are finely balanced, will usually be the deciding factor’ (my emphasis). Even when patients are imminently dying, if they have previously requested, or those close to them are sure they would have wanted, ANH until they actually died, then 'the patient’s wishes must be given weight and, when the benefits, burdens and risks are finely balanced, will usually be the deciding factor’. In cases where doctors judge that providing or continuing to provide clinically assisted nutrition and hydration would not be of ‘overall benefit’ to the incapacitated patient, having assessed the patient’s nutrition and hydration needs separately, they should explain this to the patient ‘if appropriate’ and to ‘those close to them and respond to any questions or concerns they express’; in addition they should ‘take all reasonable steps to get a second opinion from a senior clinician (who might be from another discipline'- eg a senior nurse).

My own interpretation of this advice is that the GMC recognises as do the UK Courts that while CANH is a type of medical treatment, any proposed withholding or withdrawing of food and/or water even when this is delivered by medical means such as PEG tubes or intravenous catheters (tubes inserted into blood vessels), is a highly sensitive and emotive issue in which the patient’s own views and the views of those close to the patient must be given very great weight. From the point of view of assessing an individual's best interests this seems entirely sensible and morally defensible advice. What is not sensible in my view and difficult to defend morally is the assumption that provision of CANH is always beneficial - always of 'overall benefit’. But if a person has a strong belief - as of course religious beliefs often are- that he ought to be given artificial hydration and/or nutrition in all circumstances in which these are needed to keep him alive, and that such provision ought to continue until either he dies or recovers sufficiently no longer to need it, then that individual person’s best interests are likely to be honoured by following his wishes. However it is important for doctors to advise the patient and or his family and supporters about the actual likely clinical benefits or lack of benefits and of the risks of harm that may result in that particular patient’s case.

Not the same person and if the same person may have changed his/her mind?

I propose to deal very briefly with the last two counter arguments - not the same person, and if the same person may have changed his or her mind. While the philosophical issue of personal identity is highly complex
and contended, clearly the law does consider that the legally incapacitated person is the same person as he or
she was when capacitous - for the Mental Capacity Act requires the valid and applicable advance decision to
refuse life prolonging treatment to be honoured. Similarly the ‘might have changed his or her mind’
counterargument applies equally to valid and applicable advance decisions - yet these must, by law, be
honoured. In the case of best interests assessments I am not claiming that prior autonomous or competent
views must be honoured as Advance Decisions must be honoured – I am claiming that a person’s informally
expressed prior autonomous views - such as M’s views - should be given significant weight when assessing his
or her best interests. If there is evidence that the person has changed his or her mind (which there was not in
M’s case) then that evidence should be considered in the balancing exercise of factors favouring and
disfavouring treatment of a legally incapacitous person.

To conclude:

To conclude my lecture, I hope I have convinced at least some of you that the judgment in the M case combined
with its endorsement of Rule 9E of the Court of Protection does threaten to skew provision of medical treatment
towards provision of life prolonging treatment, especially in the context of provision of clinically assisted nutrition
and hydration. That, according to the logic of the M judgment should be provided, with the very few exceptions I
have mentioned, to all legally incapacitated patients whose lives would be prolonged and who have not refused
such treatment in a written valid and applicable Advance Decision, until and unless the Court of Protection rules
otherwise in particular cases. And I hope I have convinced you that the M judgment gave excessive weight to
sanctity of life law and far too little weight to the previously expressed autonomous views of legally incapacitated
patients. My hope is that the Supreme Court’s judgment in Aintree v James will alleviate both these problems by
its reiteration that according to the Mental Capacity Act’s criteria for assessment of best interests a person’s
prior informally expressed views and values even about life sustaining treatment must be taken seriously; and by
its reiteration that the Court of Protection cannot order doctors to provide treatments that they do not believe to
be appropriate, any more than individual patients can do so, nor can it tell health authorities how to allocate their
resources. But given my arguments about the logical implications of Rule 9E and its requirement that proposals
to withhold or withdraw life prolonging treatment from patients in minimally conscious states must be referred to
the Court of Protection before they are implemented I can only hope that I will be proved wrong about my
assertion that Sanctity of Life Law has gone too far. Meanwhile it might be sensible for any of you who share my
worries to write an Advance Decision.

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