This paper discusses the role of consent in decision making generally and its role in end of life decisions in particular. It outlines a conception of autonomy which explains and justifies the role of consent in decision making and criticised some misapplications of the idea of consent, particular the role of fictitious or “proxy” consents.

Where the inevitable outcome of a decision must be that a human individual will die and where that individual is a person who can consent, then that decision is ethical if and only if the individual consents. In very rare and extreme cases such a decision will be ethical in the absence of consent where it would be massively cruel not to end life in order to prevent suffering which is in no other way preventable.

Where, however, the human individual is not a person, as is the case with abortion, the death of infants like Mary (one of the conjoined twins in a case discussed in the paper), or in the very rare and extreme cases of those who have ceased to be persons like Tony Bland, such decisions are governed by the ethics of ending the lives of non-persons.

The centrality of consent in health care is a function of the importance accorded to autonomy; and autonomy itself is part of our concept of the person because it is autonomy that enables the individual to “make her life her own”. Choices are self defining but also they are self creating. Although the importance of consent derives from our concept of the person, it’s procedural primacy in health care in the United Kingdom and the United States and some other jurisdictions is owed to the common law tradition which protects individuals from assaults—unlawful touchings. It is consent which makes laying your hands on someone else lawful—hence the importance of obtaining valid consents to all medical procedures which involve interventions which compromise the bodily integrity of patients.

Treating someone who has not consented and who is capable of choosing for herself whether or not she wants treatment is a denial of the ethic of respect for persons; why this is so we will examine further in a moment. A decision not to give someone treatment which might sustain their life or postpone death when they desire such life extending treatment is to kill them and in the absence of a justification adequate to the seriousness of the consequences of the decision is as culpable as murder. When considering the ethics of decisions to withhold or withdraw treatment we part company with the common law because the common law tradition, unlike, for example, many continental legal systems (notably that of France) which embody the civil law tradition, do not recognise a binding obligation to rescue or sustain life except where the law has specifically made such provision. I agree with Lord Mustill however, (I discuss this in more detail below) in the Bland Case (or rather he agrees with me) when he says of the difference between so called active and passive courses of action:

However much the terminologies may differ the ethical status of the two courses of action is for all relevant purposes indistinguishable.

“End of life decisions” then are decisions to hasten death by active or passive means (doing or refraining) taken by or on behalf of the subject. The principle of respect for persons is always engaged in such decisions because they will be ethical only in so far as they plausibly demonstrate such respect for the individual whose death is hastened by them.

This principle of respect for persons is a cornerstone of medical ethics and is endorsed by the law in most jurisdictions. Both ethics and prudence therefore combine to support it, so let us begin by considering it further.

I. RESPECT FOR PERSONS

Respect for persons is widely regarded as the fundamental basis of any ethics involving human beings. It is an assumption of our society and indeed most, if not all, others that it is persons that have the highest moral importance or value. There may be differences over how to define a person and difficulties about when persons begin and cease to exist but the ultimate value of those deemed to be persons is largely unchallenged. The philosophical literature shows that this assumption can be explained and defended in a number of ways. Here, we need only note and endorse the wide acceptance of this principle by most religions and cultures. The term “respect for persons” encapsulates this “ultimate” moral importance and attempts to give it content—to explain just what those who accept the moral importance of persons are committed to in concrete terms. Respect for persons understood as a moral principle sets out the ways in which it is appropriate to behave towards those who matter morally.

Respect for persons then not only describes the outcome—treating others in morally appropriate ways—but also points to the origin of this obligation in the ultimate or supreme moral value of individuals of a particular sort.

Respect for persons requires us to acknowledge the dignity and value of other persons and to treat them as ends in themselves and not merely instrumentally as means to ends or objectives chosen by others. Respect for persons has two distinct dimensions:
1. Respect for autonomy.
2. Concern for welfare.

When I suggest that these elements are crucial to any conception of respect for persons I mean simply that no one could claim to respect persons if their attitude to others failed to take account of, and indeed exhibit, these elements. Autonomy, the value expressed as the ability to choose and have the freedom
Consent and end of life decisions

II. PROBLEMATIC CONSENT

End of life decisions, whether they amount to euthanasia as it is usually understood in the United Kingdom—for example, as involving a positive act intended to result in a merciful death or, more simply but no less certainly, involving decisions to withhold or withdraw treatment—are often taken about individuals whose consent is either unavailable or problematic. This is the case with young children, those with dementia, the confused old, mental health patients, and individuals temporarily or permanently unconscious. In such cases their “wishes” may be known but often are not regarded as completely authentic or autonomous. Because of the relative frequency of circumstances in which valid consents are unobtainable, the law has contrived—and I use this term deliberately—various fictional consents to protect well-intentioned practitioners from the guilt of unlawful conduct. And not only practitioners, of course, but all well-intentioned people who touch others where consent cannot be obtained. The moral necessity of obtaining a valid consent where this can be obtained does not require further discussion. To violate the bodily integrity of persons who reject such violation is usually a form of tyranny and should be accepted and treated as such. We must, however, look more closely at those cases where consent or its refusal is problematic, and at the fictionalised consents that are often manufactured in these circumstances.

There are many instances in health care where the patient’s consent is appealed to and used, where her actual consent is unobtainable. These are circumstances in which the patient is either unconscious or unable to process the information required to give a valid consent, or is temporarily or permanently lacking the relevant capacity to consent. Again, children are an obvious case in point. In such cases terms such as “proxy consent”, “substituted judgment”, “presumed consent”, or even “retrospective consent” are used to justify treating a patient. Not only, however, are these all fictions, but they totally fail to be justifications for treating the patient in particular ways.

Either consent matters or it does not. If consent matters because, without consent, a healing “laying on of hands” becomes an assault and a battery which constitutes a violation of the person, then, if violation is to be avoided, real informed consent must be obtained. Where it cannot be obtained there can be no substitute attenuated consent and we have to find quite another justification if we want to treat patients who cannot or do not consent.

I suggest that the reason why it is right to do what presumed consent or substituted judgment seems to suggest in these cases, is simply because treating the patient in the presumed ways is in her best interests and to do otherwise would be deliberately to harm her. It is the principle that we should do no harm that justifies treating the patient in particular ways.

The justification for treatment is not that the patient consented, nor that she would have, nor that it is safe to presume that she would have, nor that she will consent when she regains consciousness or when, on ceasing to be a child she becomes competent, but simply that it is the right thing to do, and it is right precisely because it is in her or his best interests. That it is the “best interests” test that is operative is shown by the fact that we do not presume consent to things that are not in the patient’s best interests, even where it is clear that she would have consented. We do not, for example, usually mutilate patients who have expressed strong desire for mutilating operations. We do not, except where we believe it to be in the patients’ best interests, amputate healthy limbs of patients suffering body dysmorphic disorder. Indeed doctors at Falkirk and District Royal Infirmary were recently much criticised for doing so.

Of course we do not give beneficial treatment to patients who have refused, say by advance directive, because to do so would constitute an assault and a violation of their will. But it is not a violation of someone’s will, nor is it an assault to give a treatment they have not refused, the withholding of which would constitute an injury.

The reason that it is not a violation is not because they have consented in some notional or fictional sense, but because it is the right thing to do. And if we seek the reason why it is the right thing to do, the answer is that to fail or omit to do it would injure the patient. It is the infliction of that injury, by act or omission, that would constitute the violation or assault.

It is widely held that we should not harm people who do not want to be harmed, and that we also should not harm even those who do want to be harmed, and that this is sufficient reason not to withhold treatment, the absence of which would
harm. This raises the question of the right to harm oneself, which raises many fascinating issues, ranging from questions about the legitimacy of unwise lifestyles—rich foods, little exercise—and living in violent and polluted cities, to intermediate cases such as male and female circumcision, body dysmorphic disorder and live organ donation, to cases where people actually give their lives for others, and finally to suicide and euthanasia. These are large problems beyond our present concerns.

However, the fact that they are all to some extent problematic shows how deeply imbedded and how universally important the harm principle is—the principle that we should not harm others. This, I have argued, is the principle that comes into play when consent is not available.

Not only do we not need the concept of implied or assumed or proxy consent, because it literally does not work; we do not need it because it misleads us as to the character and meaning of our actions.

The 19th century philosopher Jeremy Bentham was rightly scathing of fictional consents, when he remarked:

In English law, fiction is a syphilis, which runs in every vein, and carries into every part of the system the principle of rottenness... Fiction of use to justice? Exactly as swindling is to trade. ... It affords presumptive and conclusive evidence of moral turpitude in those by whom it was invented and first employed.6

So where, in medical contexts, we act in the best interests of patients who cannot consent, we do so, I suggest, because we rightly believe we should not harm those in our care and not because some irrelevant person or the law has constructed a consent.

This does not of course help with the vexed problem of who is and who is not competent to consent, but it does explain the justification for intervening in the lives of those we are satisfied are not able to give the consents that would otherwise be required.

One final dangerous fiction in the field of consent remains.

Is it sensible to say that children or the mentally ill are competent to consent to treatment but not competent to refuse treatment?

In the recent and much cited case of Re W it was argued that a child might be competent to consent to treatment but not to refuse it. It is likely that the distinction relied upon in that case was motivated by the same concern for children that that they are the Janus faces of autonomy in all cases including that of life and death. Thus, if someone is competent to choose to live they are competent to choose not to.

Competence as an existential state

One last point requires emphasis. Contrary to widespread belief, competence is not an existential state, a state of being. It is not people who are competent but decisions. So the same person may be competent to make one decision but not another. You may think you are Napoleon and that I am Josephine, and hence face your proposal concerning how we are to spend the next hour or two may not be entirely appropriate let alone competent. But you may still know that you do not want to be punched on the nose (even by Josephine) and hence be competent to refuse that violation of your person.

It comes to this. Either our children or the mentally ill are competent or they are not. If they are then they must decide in particular cases what happens to them. If they are not then no amount of fictional, surrogate or constructed consents will make them so and we must decide, not what they would have wanted, because we cannot know that, but what is in their best interests. Saying that children's wishes must be “taken into consideration” or “listened to” or “heard” or “respected” unless that also means “must be adhered to” may make us feel better about what we propose to do to them, but it in no way respects their autonomy or implies that they have consented to what goes on.

Of course, inviting children to participate in decision making to the extent of hearing what they feel about what it is proposed to do for and to them is part of an educational process for the children, which will help build the capacity for autonomy. But when we listen to children but reserve the right to overrule them, we are not respecting their autonomy nor are we obtaining their consent.

Where we ask for their consent in circumstances in which we would not accept a refusal, we are behaving as good adults should towards incompetent children. We are involving the children in processes which will minimise distress and will enhance the building of their capacity for autonomy. We are not, however, obtaining consent or respecting autonomy. Rather, we are securing acquiescence—quite another thing.

It may be the right thing to do but it is acquiescence and not consent. It is not the acquiescence that licenses the subsequent treatment but the fact that the treatment is required to protect the children from harm or from a greater harm.

III. CONSENT AND EUTHANASIA

Let us now turn to the issue of consent and euthanasia. We saw that in the absence of informed consent, proxy consents have no role to play and we must decide what is in the individual's best interests. We will come in a moment to the question of whether non-voluntary euthanasia, ending the
lives of those who cannot, for whatever reason, consent, is ever in those individuals’ best interests, but let’s start with the issue of fully informed consent to euthanasia.

If, as almost everyone believes, death is a profound misfortune, and premature death a tragedy, then, if we can say what makes this so, we will also be answering a perennial puzzle, namely what it is that makes life valuable. For it is the value that life represents—its sanctity, on some views—that gives content to the wrongness of killing.

I suggest there is only one thing wrong with dying and that is doing it when you don’t want to. (Doing it painfully is a problem about pain not about dying.) There is nothing wrong with doing it when you do want to.

My account of the wrongness of killing and of dying depends upon a theory of personhood, which I do not have time to justify adequately here. But I can just indicate the lines of such a theory.

Most current accounts of the criteria for personhood follow John Locke in identifying self-consciousness, coupled with fairly rudimentary intelligence, as the most important features. My own account uses these, but argues that they are important because they permit the individual to value her own existence. The important feature of this account of what it takes to be a person, namely that a person is a creature capable of valuing its own existence, is that it also makes plausible an explanation of the nature of the wrong done to such a being when it is deprived of existence.

Persons who want to live are wronged by being killed because they are thereby deprived of something they value. Persons who do not want to live are not on this account harmed by having their wish to die granted, for example, through voluntary euthanasia. Non-persons or potential persons cannot be wronged in this way because death does not deprive them of anything they can value. If they cannot wish to live, they cannot have that wish frustrated by being killed. Creatures other than persons can, of course, be harmed in other ways, by being caused gratuitous suffering, for example, but not by being painlessly killed.

The life cycle of a given individual passes through a number of stages of different moral significance. Once a new human individual comes into existence she will gradually move from being a potential or a preperson into an actual person when she becomes capable of valuing her own existence. And it is very difficult to say precisely when this is. And if, eventually, she permanently loses this capacity, she will have ceased to be a person.

The morality of killing persons
The harm you do in taking a life is the harm of depriving someone of something that they can value. But you may also wrong those who care about them and those who value life intrinsically or for what Ronald Dworkin, for example, has termed its “investment” value. The crucial issues are autonomy and integrity and we will be returning to these in a moment.

The distinction between persons and other sorts of creatures explains, for example, the distinction many people draw between abortion, infanticide, and murder; and allows us to account for how we might have benefited persons by having saved the lives of the human potential persons they once were. At the same time it shows why we do not wrong the person who might otherwise have existed by ending that life, whether it be the life of an unfertilised egg or a newborn infant. I do not expect that my account will be universally acceptable. I deploy it now because it gives one answer to the dilemma that concerns us here. But also to draw attention to the inescapable fact that, if not my account, then some account must be given which enables us to distinguish between the various sorts of human individuals who inevitably become subjects of end of life decisions. We could not justify discarding preimplantation embryos, termination of pregnancy, or end of life decisions like that of the Bland case, or cases of choosing between lives as in Re A (The Manchester conjoined twins case)—more of both in a moment, or indeed so many resource allocation decisions which involve choosing who will get life saving treatment, unless we had some theory about the value of life.

My account, very starkly presented, yields a difference in the morality of ending the lives of persons and that of ending the lives of all other creatures including human non-persons.

If the harm of ending a life is principally a harm to the individual whose life it is and if this harm must in turn be understood principally as the harm of depriving that individual of something that they value and want, then voluntary euthanasia will not be wrong on this account.

Persistent vegetative state
To see what this means in practice we can consider the case of persistent vegetative state (PVS) and the landmark House of Lords judgment in the case of Tony Bland.

Tony Bland’s parents, who accepted that their son had ceased to exist in any real, biographical sense although his body remained alive, were prevented from obtaining the solace of grief. In desperation they asked the English courts to declare that it would be lawful for medical staff to withdraw feeding and other life sustaining measures so that their son would die. It is not clear why there was any necessity to take the Bland case to the courts because it was already well established that there was no obligation to sustain a baby by feeding.

Eventually the House of Lords ruled unanimously that such a course of action would be lawful. The problem was of course that although Tony Bland had permanently ceased to have “a life” in any meaningful sense of that term, he was not dead and would not die unless the courts permitted doctors to take steps to that end. A more recent case was concluded in the Court of Appeal in January 1994. The Master of the Rolls Sir Thomas Bingham held, in a judgment with which the other two lord justices of appeal concurred, that it was permissible for doctors to end the life of a patient by refusing life prolonging treatment when the consultant and “a number of other doctors” agreed that such a course was in the patient’s best interests and “no medical opinion contradicted”.

Tony Bland’s condition resembles those with brain death in that he had irrevocably lost the capacity for consciousness. The difference is that those in PVS still have electrical activity in the brain and through the brain stem. Does this difference amount to a morally relevant difference between those in PVS and those who are brain dead? Although the House of Lords was reluctant to change the definition of death, or even address that issue, it is clear from its decision that the House of Lords thought Tony Bland’s life did not retain the sort of value that required it to be sustained, and did not do so because he had lost all capacity for consciousness.

In the words of Lord Keith of Kinkel in his judgment in that case: “It is, however, perhaps permissible to say that to an individual with no cognitive capacity whatever, and no prospect of ever recovering any such capacity in this world, it must be a matter of complete indifference whether he lives or dies.”

No question was made in Bland’s case of competing claims on the resources required to sustain him, so that the decision to permit a course of action designed to achieve the death his parents sought, was a deliberate, conscious decision to end his life. A hotly debated question is whether such a decision constitutes a form of euthanasia.

Although the House of Lords strongly denied this is what it was doing, its decision in the Bland case is thought by many (myself included) to legalise, for the first time in the United Kingdom, a form (albeit very restricted) of euthanasia. This makes the United Kingdom the second country in Europe to
have recognised judicially the necessity of bringing the lives of at least some innocent individuals who have not requested death, to an end. The Netherlands legalised euthanasia under certain conditions in a High Court case decided in 1984 and have since formally enshrined euthanasia in their legal system.

It is important to emphasise the proviso “who have not requested death” for other instances of courts defending the right to die have turned on precisely this issue.

The landmark United States case concerning PVS, that of Nancy Cruzan, turned crucially on whether or not Ms Cruzan had expressed a wish to die prior to falling into PVS, indeed, it is often described as a case establishing the right to die.

That the case of Tony Bland establishes a precedent for legally sanctioned euthanasia or, if you like, for physician assisted suicide, in the United Kingdom is confirmed by the words of Lord Mustill in his judgment in that case:

The conclusion ... depends crucially on a distinction drawn by the criminal Law between acts and omissions, and carries with it inescapably a distinction between, on the one hand what is often called “mercy killing”, where active steps are taken in a medical context to terminate the life of a suffering patient, and a situation such as the present where the proposed conduct has the aim for equally humane reasons of terminating the life of Anthony Bland by withholding from him the basic necessities of life. The acute unease which I feel about adopting this way through the legal and ethical maze is I believe due in an important part to the sensation that however much the terminologies may differ the ethical status of the two courses of action is for all relevant purposes indistinguishable.

The key features of Lord Mustill’s judgment are: firstly, the acknowledgement that the course of action requested of, and approved by, the courts “has the aim, of terminating the life of Anthony Bland”; and secondly, that the supposed difference between acts and omissions relied on by the common law tradition to make moral and legal distinctions, characterises two courses of action that are ethically “for all relevant purposes indistinguishable”.

Aiming at terminating the life of a moral person when they cannot request it is always problematic. To aim, for example, at the death of Lord Mustill would be to violate the value that the life of a person represents. Consider now another recent English case, that of Re A.17

Rina and Michaelangelo Attard, the parents of the twins, came to Manchester from the Maltese Island of Gozo to give their twins the best possible chance of survival. The twins were born on the 8th of August 2000, their bodies fused from the umbilicus to the sacrum, and the lower ends of their spines and spinal cords also fused. The medical facts related here were agreed upon by several teams of doctors, including specialists from other hospitals called in as experts by the Court of Appeal. It was believed and accepted by all that if the twins were not separated either Jodie’s heart and lungs would slowly become affected by the strain of providing a blood supply for two bodies, and the twins would die of congestive heart failure (within a time span estimated to be between six months and two years) or Mary would die, possibly from thrombosis of major vessels, and it would be necessary to perform an emergency separation procedure in order to save Jodie.

The decision in essence was as to whether an operation to separate the twins and save Jodie’s life by killing Mary was both lawful and morally preferable to leaving them conjoined with the almost certain result that both twins would die within six months to two years.

On 22nd September, the Court of Appeal ruled that the operation to separate the twins was lawful and must take place. On 6th November, the elective separation operation was performed. Mary died in the operating room; Jodie is expected to enjoy a relatively good quality of life with her family.26

The case of the Manchester conjoined twins is interesting in the context of a discussion of consent and euthanasia because it involved the Court of Appeal effectively ordering the death of Mary so that Jodie could survive. This may sound a tendentious way of expressing the verdict but I do not believe any other conclusion can be reached. There was no way Mary could survive the operation to separate her from Jodie, to order the operation was to order Mary’s death because without it she would have survived for months, possibly years. If we compare Jodie and Mary with two adults in the same situation we find immediately a dissonance.

It would not be permissible in English Law; neither would it be ethical to kill a competent adult to save another. If Mary had been a competent adult it is surely inconceivable that the Court of Appeal would have come to the same conclusion.21 Could we imagine a court ordering the operation if it had heard Mary plead for her own life in open court, could we imagine her “being dragged kicking and screaming” into the operating theatre and to her inevitable death—I don’t think so. I have examined the legal reasoning in this case in detail elsewhere and there wasn’t a respectable moral, let alone legal, argument to be found among all the adjudicating judges. That is not of course to say they did the wrong thing, although I think they did; rather it is to say that they did not find a plausible legal or moral justification for their judgment. Can such a justification be found? I believe so and I believe it is to be found in the concept of personhood and in the respect for autonomy that personhood encapsulates.

If the courts and indeed most people feel differently about the cases of Mary and that of Tony Bland, for example, it is surely because they place such individuals in a moral category different from that of themselves. If that difference is not the difference between humans who are “persons” and those that are not, then there is both a puzzle as to what it might be, and a bigger puzzle as to how legal abotions and the judgments in Bland and in Re A are to be justified. It certainly looks as though the judges tacitly assumed that Mary and Jodie were more like fetuses or individuals in permanent vegetative state than legal persons.

The fact that neither Mary nor Jodie were persons at the time of the operation separating them and killing Mary explains the moral difference between such a case and that of two competent adults in the same situation as Jodie and Mary, and also explains why the decision to operate knowing that Mary must die was not unethical. It also shows, however, that had the wishes of the parents been followed and both Mary and Jodie had been allowed to die, equally this would not have involved the premature death of any persons. So that although reflections on personhood can perhaps alone provide the ethical justification for the decision in Re A, such reflection would also underpin an alternative decision. This would have been for the Court of Appeal to declare the operation to be lawful but not mandatory and that following the wishes of the parents would also have been lawful.

IV. EUTHANASIA

We can now return to a question we posed at the start of this discussion. Are there cases where a human individual who is also a person might ethically and justifiably be the subject of euthanasia without giving informed consent?

The policeman’s dilemma

Consider the policeman’s dilemma. A lorry driver is trapped in the blazing cab of his vehicle following an accident. A policeman is on the scene and sees that the driver cannot
extracted before the flames get to him and he is burned alive. The policeman can let him be burned alive or can give him a quick and relatively painless end by shooting him in the head. The driver says “please shoot me, don’t let me be burned alive!” Those opposed to euthanasia in all circumstances must give one answer to the policeman’s dilemma; those in favour will give the alternative. Most people will feel the policeman to have been justified in such a case.

Now consider a modified policeman’s dilemma. Suppose the policeman can see what’s happening but cannot communicate with the driver. He sees that the driver must be burned alive but cannot ask what he wants or hear his requests. Would the policeman still be justified in sparing the driver terrible suffering by killing him? I believe so and hope you do too because the alternative is to take responsibility for the death by torture of the driver.

Where the inevitable outcome of a decision must be that a human individual will die, and where that individual is a person who can consent then that decision is ethical if and only if the individual consents. In very rare and extreme cases, such a decision will be ethical in the absence of consent where, in cases such as the modified policeman’s dilemma, it would be massively cruel not to end life in order to prevent suffering which is in no other way preventable. Where, however, the human individual is not a person, as is the case with abortion, the death of infants like Mary or those who have ceased to be persons like Tony Bland, such decisions are governed by the ethics of ending the lives of non-persons.

REFERENCES AND NOTES

5 I argued against the relevance of the moral distinction between acts and omissions in my Violence and responsibility. London: Routledge and Kegan Paul, 1980. This irrelevance has recently and belatedly been recognised by the highest court in the United Kingdom. See Lord Mustill’s judgment in Airedale NHS Trust v Bland [1993] 1 All England Rep 821 HL.
7 Re W [1992] 4 All ER 627.
12 My account of this case follows that given in my euthanasia and the value of life: see reference 1.
14 Airedale NHS Trust v Bland [1993] 1 All England Rep 821 HL.
19 See also Re A (children) (conjoined twins: surgical separation) 2000. 4 All ER 972, per WARD LJ.
22 Adapted from Herbert Hart’s famous (true?) example in his intention and punishment in his Punishment and responsibility. Oxford: Oxford University Press, 1968.