

## Advance Directives - the Ethical Implications

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About ten years ago I stood in for a hospital chaplain who was on sabbatical, and those months were among the most demanding but also the most rewarding I have ever spent. They provided me with insights which have been continually helpful in my subsequent work as a medical ethics teacher and researcher. At that time, as far as I can recall, the subject of Advance Directives or Living Wills was not raised by any of the patients or professionals I met. But in the meantime it has attracted increasing attention. Many of the medical students and junior hospital doctors I meet nowadays have encountered at least one patient with a living will; and only last week I listened to a case presentation in which the patient's GP as well as solicitor had helped to draw up a very clear and comprehensive advance directive. The final year medical students who presented the case quoted, emphasised and clearly agreed with the statement in the 1995 BMA Code of Practice, that 'An unambiguous and informed advance refusal is as valid as a contemporaneous decision. Health professionals are bound to comply when the refusal specifically addresses the situation which has arisen.' (BMA 1995)

Listening to that presentation, I was impressed by how much these students had taken on board the message of respect for patient autonomy, and how far they were from old-fashioned medical paternalism. In fact when one student, again quoting the BMA Code of Practice, assured us flatly that 'an... advance directive ...made by a competent adult ...does ...have legal force,' I was rather taken aback, and began to wonder if I had missed some radical new legislation on the subject arising from the consultation paper produced by the Lord Chancellor's Department. (LCD 1997) What the student missed out from the quotation, of course, was that it applied not to all advance directives, but to advance *refusals*, which, as the Code of Practice says, 'have legal force... *in certain circumstances*.' This still leaves considerable room for clinicians to determine whether the patient's current circumstances are those that he or she had in mind when drawing up the advance directive, and to decline to carry out anything requested which is either illegal or, in the clinician's view, not in the patient's best interests. Thus neither the law as it stands, nor current proposals for changes in the law, offer much support for a swing away from medical paternalism, not just to respect for autonomy, but beyond that to the kind of consumerism which says that the customer is always right, and that the only responsibility of health professionals is to tell patients the facts,

professionals is to tell patients the facts, let them decide, and do what they want.

A shift to that kind of consumerism is not suggested either by the limited but not, I think, unrepresentative sample of attitudes I meet in ethics sessions with junior hospital doctors. Most practising health professionals seem well aware that more is expected of their relations with patients than 'truth-dumping' and servicing consumer choice. The growing number of medical negligence or malpractice claims, and greater media awareness that clinical judgement is not infallible, do of course increase the pressure on health professionals to pay greater attention to protecting their own as well as their patients' best interests. But if this encourages greater care in risk-assessment, record-keeping and communication with patients it may be no bad thing. (Montgomery 1997)

In theory it could lead to practices that are defensive in the sense of being primarily determined by the professional's as opposed to the patient's interests. But again, it is not my impression that this has happened to any significant extent in the NHS, and I suspect that in both public and professional attitudes in this country, there are fairly ingrained obstacles to us going very much farther down the American road. Moreover even if we did, it is not clear that the safest form of defensive practice from a professional's point of view would be to take an extreme consumerist attitude to advance directives.

That in itself, in certain circumstances, could constitute negligence, or a failure of the duty of care; and even in the more litigious climate of the USA, despite much greater legal recognition of living wills, some of the most debated legal cases have involved hospitals defensively striving to keep alive patients who in this country probably would have been allowed to die in peace.

It is not my intention however to say much more now about the legal implications of advance directives, since what I have been asked to talk about are the ethical implications. Law and ethics differ in a variety of ways, one of the most important being in how they define a person. In law, a person is an individual with those rights and duties that the law recognises, and in the legal context a person can be either an individual or group of individuals forming a corporation. In ethics, the definition of personhood is much more controversial. Some ethical thinkers opt for

criteria based on biological or psychological characteristics, ranging from genetic uniqueness or being an individual member of the human species, to the possession of consciousness or selfconsciousness. But other thinkers hold that personhood is best defined in relational terms, including for example the well-known African saying that 'a person is a person through other persons' Thus while in law a foetus, for example, is not recognised as a person with rights until being born alive, in ethics, depending on how personhood is defined, a foetus may be regarded as a person with full human rights by some ethicists, while others hold that full moral status is not attained until some time after birth.

At the other end of life, the differences between law and ethics, and also among ethicists, are no less evident. The law, as I have said, is reasonably clear, first that in certain circumstances an advance refusal has legal force, and second that an advance statement cannot 'require a doctor to do anything which is not lawful, including taking steps purely to end the patient's life.' (LCD p 25) But in ethics these matters are more contentious. Take the case of a patient with moderate dementia, whose confusion is worsened by a concurrent illness which could be successfully treated with antibiotics, but whose living will specifically mentions antibiotics among the treatments to be refused; and suppose the patient prior to contracting the concurrent illness gave no sign of being unhappy, had not mentioned their living will, offered no objection to the ordinary nursing care and analgesic or other treatments they had been receiving, and now, so far as can be ascertained, was willing to take the antibiotics. In these circumstances, I suspect that the law might allow the doctor to go ahead with the antibiotics in the patient's best interests and on the grounds that the refusal had ceased to be effective because 'the assumption on which it is based is falsified' (HMSO 1995) But would that be ethical? The problem, and the probable dispute between ethicists here, is highlighted by Dworkin's distinction between 'a demented person' and 'a person who has become demented.' (Dworkin 1986) Should the apparent current wishes of 'a demented person' override those clearly stated earlier by the 'person who has become demented'? Or should the wishes of the 'person who has become demented' be respected? The familiar conflict between the principles of beneficence and non-maleficence on the one hand, and of respect for autonomy on the other, is complicated here by the question of their scope, or to whom they apply. (Gillon 1994)

The difference between law and ethics is also illustrated by the second point on which the law

is reasonably clear. In this country and the United States, although not in the Netherlands, advance directives asking doctors 'to take steps purely to end the patient's life' have no legal force. Some ethicists would agree with this, but others would not. Why, they say, is omitting to give life-sustaining treatment morally acceptable, but taking steps to end the patient's life, if that is truly what they want and there is no other way to relieve their suffering, morally unacceptable, especially when 'taking steps' means that the person will have to suffer for a shorter time than if he or she has to wait for the omission to have its effect? Wasn't Bacon right when he wrote that it was 'the office of a physician not only to restore health, but to mitigate pain and dolours; and not only when such mitigation may conduce to recovery, but when it may serve to make a fair and easy passage?' (Vickers 1996)

Ethics then obviously raises a great number of questions about living wills, and certainly more than it can answer. But ethics also occasionally provides a framework within which our thinking about such issues can be organised a little more helpfully. One framework I find helpful in this respect is the traditional distinction between teleological and deontological approaches to thinking about ethical issues. The teleological approach, associated with Aristotle, thinks about these issues in terms of aims or goals in life, a 'good life' and how to achieve it in practice. The deontological approach, associated with Kant, thinks more in terms of norms or rules which all reasonable people ought to agree to obey. If we are to think at all adequately about ethical issues, we need to make use of both of these approaches, as in practice most of us probably do every day. As deontologists we follow the rule of driving on the left, but as teleologists we achieve our aim of continuing to enjoy the good life by breaking the rule and crossing to the other side to avoid a driverless lorry rolling backwards downhill toward us.

The teleological approach is concerned with what is good and bad, the deontological with what is right and wrong. According to the philosopher Paul Ricoeur, (Ricoeur 1995) the teleological concern with what is good and bad is the primary or most basic level of ethical thinking, but to get further with our ethical thinking we need to spell things out in terms of the deontological concern with right and wrong. We also need to think about the norms or rules of right and wrong which all reasonable people ought to agree to obey, because if we thought simply in terms of a good life and how to achieve it in practice, we might be tempted to take unethical short cuts or to make exceptions in our own case.

Thinking in terms of right and wrong however, can and sometimes does lead us into moral dilemmas or impasses, when our choice is between two rights or between two wrongs for example; and when that happens, Ricoeur says, we need to go back to teleological thinking and overall goals in order to consider what is the best way forward. To do this, he argues, is 'practical wisdom'; and using the word 'solicitude' to mean 'feelings that are revealed in the self by the other's suffering,' he sums up what ideally should happen when we return from a deontological dilemma to teleological thinking, in the following way. 'Practical wisdom consists in inventing conduct that will best satisfy the exception required by solicitude, by betraying the rule to the smallest extent possible.' (Ricoeur p 269) Ricoeur's philosophy is highly sophisticated (his work in religious studies (Ricoeur 1995) and biblical interpretation (Lacocque 1998) is rather more accessible) and the short summary I have just given grossly oversimplifies it. But let me try now to use his general approach to say something about the ethical aims and difficulties of advance directives. Let me just repeat the main points. Thinking ethically, we begin with good and bad, the idea of a good life and how to achieve it in practice; we then spell out the implications with reference to the rules of right and wrong which all reasonable people ought to agree to obey; and when that lands us in a moral dilemma or impasse, we go back to teleological thinking and the 'practical wisdom' (which) consists in inventing conduct that will best satisfy the exception required by solicitude, by betraying the rule to the smallest extent possible.'

Beginning with good, bad and a good life then, what in these terms do people who write living wills have in mind? In one particular living will I read recently, a sentence in bold print which particularly struck me was 'I wish it to be understood that I fear degradation and indignity far more than death.' That sentence reinforced my impression that although people who wrote living wills in the past may have done so because they were worried about

terminal pain, that is no longer the main concern. In this respect the hospice movement has been very successful, not only in relieving terminal pain, but in persuading the public that it can be controlled in most cases. What people who write living wills nowadays are most concerned about then, I think, is the possibility not of cancer (unless it affects the brain), but conditions such as stroke, dementia and degenerative diseases.

Many people are concerned about this because, as the living will I have just quoted puts it, they 'fear degradation and indignity far more than death.' The primary ethical consideration here, I think, is the idea that 'a good life' is one in

which you retain independence and control, physically and mentally, and thus have 'a good death' also. So what is bad about that? One possible answer to that question might be framed in terms of the final entry in the diary of the religious philosopher Kierkegaard, which begins with the words

Our destiny in this life is to be brought to the highest pitch of world-weariness. He who when brought to that point can insist that it is God who has brought him there, out of love, has passed life's examination and is ripe for eternity.' (Kierkegaard 1996)

The implication of that for the present purpose, might be that wanting to retain independence and control to the last moment is not being willing to sit 'life's examination' (whose final question or test may be a period of dependency or even 'degradation and indignity') through to the end. But is that a valid objection? In terms of a religious ideal that has sustained countless people through their living and dying, what Kierkegaard describes is accurate, or at least almost accurate. (I say 'almost' because Kierkegaard's own other writings would paradoxically add joy or happiness to 'worldweariness.' (Kellenberger 1997) But Kierkegaard would be the first to point out that this ideal is worth nothing, unless it is freely chosen by the individual; and one has to add that when a week later, Kierkegaard collapsed in the street in Copenhagen and was taken at his own request to hospital, he spent his remaining six weeks of life there deteriorating steadily physically but remaining mentally lucid, and so in that sense retained independence and control to the end of his examination. A very different fate awaited another great existential thinker of the nineteenth century, who opposed Christianity as fiercely as Kierkegaard defended it. Thirty two years later Nietzsche too, collapsed in the street, in Turin, but then became insane and survived in that state for a further eleven years. Had he been living today, I imagine Nietzsche would have been one of the first to sign a living will, and to say that morally, as opposed to psychologically, he feared 'degradation and indignity far more than death.'

In terms of teleological concerns with a good life and a good death then, it is difficult to see what ethical objection can be raised to advance refusals.

Even in terms of moral theology they amount to no more than requesting that the person concerned should not be kept alive by extraordinary or disproportionate means. Indeed from a teleological point of view, it seems to me that ad-

vance refusals which discourage clinicians from using modern medical technology to prolong terminal suffering, are ethically uncontentious. That does not resolve the problem, of course, of whether the apparent wishes of 'a demented person' or the clear wishes of 'a person who has become demented' should have priority. But I do not think there is any way of resolving that difficulty, which does not require clinicians to make a judgement about whether the circumstances of the 'demented person' are those envisaged by the 'person who has become demented.' In this sense therefore, while advance directives may be ethically uncontentious, they also are limited in their sphere of application. Thus it is difficult to see how they can ever provide an unqualified guarantee, to those who 'fear degradation and indignity far more than death,' that their wishes when making an advance directive will be respected.

Moving on from teleological concern with good and bad to deontological concern with right and wrong, it seems clear what is the main ethical obstacle to recognition of an advance directive which requests a doctor 'to take steps purely to end the patient's life' in circumstances when doing so might shorten the length of terminal pain, suffering, degradation or indignity. It is the rule that active killing of a human being by any other human being, except perhaps in self-defence, is always wrong. For many people this rule is so fundamental that it needs no supporting argument. But one argument which can be advanced in its support, is that if any exception will make it that much more difficult to resist further exceptions being made, for which the reasons are weaker, and may reflect the wish to individuals or groups to make exceptions in their own (but not necessarily others') self-interest. From what is known about human behaviour both historically and psychologically, this 'slippery slope' argument is difficult and in principle probably impossible to refute; and when combined with the deep moral institution that killing another human being is always wrong, it is difficult to see (Ricoeur 1992 p 269) how making a rule of any exception to this rule can ever be justified.

The difficulty here however, is that in certain cases, maintaining this exceptionless rule is an offence to 'solicitude' - to feelings that are revealed in the self by the other's suffering.' The strength of these feelings is revealed, I think, by the lengths to which many staunch upholders of the rule against killing are prepared to go to expand the scope of the principle of double effect, by allowing that a patient" suffering as well as pain may be relieved by appropriate measures, even if these may shorten the patient's life - but at the same time claiming that this does not

constitute euthanasia. (Oxenham and Boyd 1997) Those who take this approach, it could be argued, are doing what Ricoeur suggests should be done when the attempt to follow conflicting deontological rules leads to a moral dilemma or impasse. They are going back to teleological thinking and to the practical wisdom which 'consists in inventing conduct that will best satisfy the exception required by solicitude, by betraying the rule to the smallest extent possible.'

But does this inventive use of double effect in fact 'satisfy the exception required by solicitude?' That depends on how far it goes to relieve 'other's suffering'; and this involves practical as well as ethical considerations. For while double effect could be used to justify relief of suffering and symptoms in advanced cancer and perhaps severe obstructive airway disease for example, it would be much more difficult to justify its use in the case of someone, with no concurrent life threatening condition, who had Alzheimer's, or who was paralysed and aphasic following a stroke. Yet these are precisely the kinds of condition which many people who have living wills may 'fear far more than death'; and so it could reasonably be asked whether postponing any use of double effect until some further life-threatening event occurs (which might mean waiting for some time), really does 'satisfy the exception required by solicitude.'

In certain circumstances, it could be argued, nothing short of 'taking steps to end the patient's life' might be sufficient to satisfy this requirement. But in that case, what kind of conduct could be invented that achieved this end without betraying the rule against killing, not 'to the smallest extent possible' but much more substantially, and thus making it that much more difficult to resist further and much less justifiable exceptions being made to the rule?

In some circumstances therefore, there does seem to be an impasse. On the one hand, the only way to 'satisfy the exception required by solicitude' in relation to what many people who make living wills 'fear far more than death,' is by permitting voluntary euthanasia, or medically assisted suicide. On the other hand, it is questionable whether either 'voluntary,' or 'suicide' would be an appropriate way of describing killing, once the people concerned had actually reached the state that they 'feared far more than death'; and so this would give even more substance to the fear that any relaxation of the rule would lead to further exceptions. Underlying this impasse are two hard facts, with which I conclude. One is that a 'good death' as part of a 'good life' is an ideal that can be aimed at but

never guaranteed. The other is that while a living will may make it less likely that someone's terminal suffering is prolonged by modern medical technology, it can never replace the current role of the scientific and humane clinical judgement of the doctors and nurses into whose care the patient is delivered. Thus whether as many people as possible will have as good a death as possible, depends less on whether they have living wills, or on whether euthanasia is allowed or not, than on the solicitude of their carers. Just as a person is a person through other persons, so it is through other persons that our personal end is shaped. Ultimately, for better or for worse, it is the human factor that counts.

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