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Advance Directives

by James Paul

Many people are worried that serious illness may leave them 'kept alive' by medical technology. They fear that in such a state they would be unable to express their wishes about which treatments they do or do not want. Making an advance directive is one proposed solution. While these may be useful they are not without problems. It's important that everyone weighs up the strengths and limitations of such directives, as well as understands their legal status.

You are suffering from dementia and are in a nursing home. Unable to recognise your family, speak or swallow, you are fed through a tube down your nose. You have repeated chest infections and doctors keep giving you antibiotics. You would not have wanted to live like this, but the staff seem unwilling to 'let you go'.

This scenario highlights a situation that many people fear and has fuelled the debate about advance directives. Afraid of being trapped between life and death, people have sought ways of telling doctors that if they can no longer express their wishes, they would rather be allowed to die than be kept alive by extraordinary or disproportionate means. Some have chosen to record this decision in a written document termed an advance directive, or 'living will'.

In broad outline, advance directives fit in with the British Medical Association's views, which say that while 'life should be cherished despite disability and handicaps', it should not be 'indefinitely sustained in all circumstances, for example, when its prolongation by artificial means would be regarded as inhumane and the treatment itself burdensome'.[1]

While at first sight, advance directives seem to raise few ethical problems, closer examination shows they need to be treated with caution. There has also been considerable confusion about their legal status.

Background influences

Advance directives have appeared because of three key issues and influences within society.

Call for autonomy

One powerful drive is the demand for people to make their own decisions. This call for autonomy says that, while a doctor may have a better understanding of the patient's medical needs and the likelihood of success of any particular treatment, individuals have primary responsibility for their health and must live with the consequences of any decisions. The previous paternalistic mentality of 'the doctor knows best', has been replaced with the notion of 'informed consent' - the idea that clinicians give information so that patients can make sound choices.

In reality autonomy is not that simple. In any democratic society every person has the right to personal autonomy, but other people's rights to personal autonomy necessarily restrict this. We do not tolerate a burglar's autonomous desire to rob someone else's house. Problems start when autonomy is given the status of an unbreakable principle or law.

With an advance directive, one person's desire for a particular style of treatment demands that others provide it. This may conflict with the provider's personal and professional views of what is the best course of action. A person's refusal of treatment can also conflict with their family's desire to do everything to avoid losing a much-loved relative.

Loss of trust

The dawn of the twenty-first century has seen a loss of trust. Many institutions and professions are under suspicion. These include the church, police, monarchy and doctors. The abuse of power shown by mass-murderer Harold Shipman, or negligence in the case of Alder Hey Hospital's unauthorised retention of organs after post-mortems, have fuelled the mistrust.

This loss of trust is not one-sided. Doctors are increasingly fearful that they will be sued if their patients don't

like the outcome of any intervention; they are losing trust in their patients.

Medical progress

Both of these are set against ever-increasing medical capability. Seldom a week goes by without some new treatment being announced. However, while these advances often sustain life, many people find that they are left with a quality of life they feel unable to bear.

There is no denying that many who would formerly have died of cardiac arrest, pneumonia or kidney failure have been given a new lease of life. On the other hand, many are left half-cured – alive but with distinct disability and declining health.

Medical progress has gone a long way to remove suffering, but now some people are pointing out that our society has lost any sense of the value that can come from adversity.

At the same time, medical progress has caused a further problem. While it has enabled more people to live to old-age, many of these have conditions like Alzheimer's disease. Consequently some people now fear degradation and indignity from degenerative diseases far more than death itself.

Arguments for...

There is a clear call to help people express their autonomy, protect themselves from what some see as a self-serving medical profession, and avoid any potentially damaging effects of medical technology.

People argue that advance directives can help them to:

- avoid degrading and drawn-out treatment for a terminal illness
- achieve a death with dignity, or a 'good death' (although this is often not defined very well)
- avoid the expense of medical costs during a prolonged final illness
- avoid breaching a patient's personal or religious beliefs

In addition, some doctors believe that advance directives will give them some protection in the event of a patient's death or disability. In effect, they hope that the directive removes some of their responsibility.

Arguments against...

There is, however, a number of reasons why the situation is not that straight-forward.

Uncertain outcome

Advance directives often state that 'in the event of 'x' medical condition occurring with no chance of recovery, I would want 'y' to be done'. In order for a doctor to carry out this directive he has to be certain of several things. First that he is certain in his diagnosis that the patient has medical condition 'x'. Secondly that there is no chance of recovery if given suitable treatment.

This is seldom easy to do and people are known to make remarkable and unexpected recoveries. It can be particularly difficult to predict the outcome of emergency treatment.

Predicting an outcome presupposes that you have correctly diagnosed the illness or disease. If you don't know what is wrong, it is going to be very difficult to come up with any meaningful predictions of outcome. One study showed that about half of the cases of Persistent Vegetative State are incorrectly diagnosed.[2] Requiring two or more doctors to agree on a prognosis simply reduces the error, but does little to eliminate the problem.

New attitudes

Trying to imagine what it would be like to be terminally ill is one thing. Being terminally ill is quite another and people's attitudes and wishes frequently change with the onset of serious illness. It appears that life often seems more precious when it is more precarious, and most patients when confronted with a choice between death and seriously disabled life, choose life.

A study of 21 people who were paralysed from the neck down and needed ventilators to help them breathe, found that only one person wished that she had been allowed to die. Two were undecided, but the remaining 18 were pleased to be alive.[3] It is reasonable to believe that while healthy, they would have said they would rather die than live in this highly-dependent state.

New treatments

When writing an advance directive, a person will make assumptions based on current abilities of technology to control pain or other symptoms. Developments in medical practice are increasing our ability to make life comfortable, and the advance directive may not be able to take these changes into account.

New circumstances

Many events in life can influence one's attitude to disability. For example, the arrival of a grandchild can give an elderly person a new reason for wanting to continue living, and changes in religious conviction can revolutionise a person's attitudes to life, death and disability. Even without religious convictions, many people come to see real meaning and purpose in their suffering.

Doctors need to do everything possible to check that a patient hasn't changed his or her mind, rather than simply relying on an advance directive. A study of 150 competent people with advance directives concluded that 61% thought there could be times when their best interests would be served if clinicians ignored their directive.[4] Anyone who does make an advance directive needs to be encouraged to keep it up to date

Two different opinions

Having considered the options, Christians may come to different conclusions. Two Christian doctors explain their choices:

In favour...

I do not think doctors should oppose advance directives because to do so would be perceived as paternalistic and a denial of patient autonomy. There is nothing to fear, provided the door is kept firmly closed against the legalisation of euthanasia. We should take comfort from the fact that, although advance directives may, in principle, be legally enforcible, they are rarely so in practice, because the precise state of the patient at the time when a decision regarding management has to be made has not been envisaged in their directive.

There is no doubt that misguided and uncompassionate medical care of patients with incurable and painful diseases has done much to fuel the demand for euthanasia. Many patients now survive in a wretched state who would have died with far less suffering if they had been born a century earlier. This must be changed.

I do not want my life maintained artificially in an unconscious or vegetative state, tying up valuable resources because, like the apostle Paul, I want to depart and be with Christ, which is far better.[5] I have prepared an advance directive to make this clear, and I have nominated my wife and family members as proxy decision makers.

Emeritus clinical professor of medicine, David Short

Against...

Some Christians carry cards asking people to call a priest or member of their Church if they are seriously ill, so that prayers may be offered for healing and forgiveness. It may seem strange therefore that many Christian doctors oppose legally binding advance directives.

Advance directives, however, can prohibit care. They may say, 'Treat me only with medication to relieve pain if I am unconscious or have severe dementia'. This could prevent a stroke patient receiving antibiotics, which could treat a kidney infection and remove suffering. They could cause neglect or prevent rehabilitation, so that rather than dying, the person risks permanent disability.

Another concern is that healthy people choose differently to people who are sick, and we can rarely predict future illness. Even in childbirth, which is much more predictable than most medical conditions, birth plans are routinely discarded as circumstances change. Legally binding advance directives are therefore dangerous and best avoided. If implemented they may enforce neglect and bad care, and as a result, promote calls for euthanasia.

Consultant psychogeriatrician, Adrian Treloar

with their current wishes.

People also argue that advance directives are virtually useless in practice. This is because the exact situations described in an advance directive hardly ever arise. The effect is that clinicians still have to decide what is in the patient's best interests.

Finance and fraud

There is also the concern that people will be coerced into signing a directive, and that unscrupulous carers or potential beneficiaries may exploit the feeling of 'I don't want to be a burden to my carers'.

Legal position

A key principle of UK law is that every mentally competent adult has the right to refuse any treatment offered, even if that treatment may save their life. This was demonstrated in the 2002 case of Miss B, where the courts ruled that artificial ventilation should be discontinued in accordance with her wishes, even though this action would probably lead to her death.

Furthermore, case law has established that if a patient is no longer competent to make a decision a clinician must not provide treatment that they know a patient would have refused if that patient were competent to state his or her opinion. This was clearly shown in a case where a doctor was convicted of assault after transfusing blood into a Jehovah's witness. The problem was that the doctor knew that the patient would have refused the transfusion had he been competent.[6]

Patients, however, have no legal right to demand treatments that are not in their best interests.

This means that if in an advance directive a patient refuses a treatment, and the exact situation arises in which the advance refusal is applicable, then a doctor has a legal duty to respect that refusal. However, even if the advance directive requests specific treatments, a clinician is not obliged to provide them if in his or her judgement it would be clinically unnecessary or inappropriate.

Finally, a person can not demand the termination of life, because according to the Murder Act 1965, the intentional killing of a human being by any other human being is illegal.

Christian position

Any assessment of advance directives from a Christian viewpoint will start by acknowledging that each human being is made 'in the image of God',[7] and as such every person has built-in value. This is regardless of any physical or intellectual capacity or any other characteristic. Christians need to resist any measures that may devalue human life, especially that of the most vulnerable people in society for whom God has special respect.[8]

This high regard for all human life makes many Christians wary of the contemporary devaluing of people who are old or have handicaps. Decisions about treatments should focus on a consideration of the benefits and burdens of any medical intervention, rather than viewing some

states of existence as being excessively burdensome in themselves.

In making such decisions, Christians should take the patient's point of view seriously. If advance directives encourage patient involvement in decision making they will have a positive influence.

At the same time, we need to recognise that no one has an absolute right to autonomy. The case of Diane Pretty saw an outworking of this principle. Pretty had motor neurone disease and sought permission for her husband to assist her to end her life. The court refused, reasserting the principle that there are legally accepted and moral limits to personal autonomy. Pretty was claiming her right to self-determination under Article 8 of the European Union Human Rights Act. The judge, however, ruled that this right to autonomy could not override the protection afforded to a large class of vulnerable individuals by section 2(1) of the Suicide Act 1961.

Advance directives are seen as a way of letting a person assert their 'rights'. But a Christian emphasis of moral decision-making should encourage people to look at their responsibilities towards others.

Advance directives may help people feel in control of their future. But Christians place their confidence in God rather than written documents. For them God is Lord of their lives, including the points of entry and exit.[9] He is personally with us in our suffering, providing his strength and comfort. He can empathise with us fully, as God himself has experienced death when he was nailed to the cross.[10] But more than this, he can also bring good out of even the worst situations, just as he did when Jesus' death brought new life to all those who follow him.

God calls us to trust him. Ultimately, Christians have a true hope that this life is not all there is and that the best is yet to come.[11]

Why not euthanasia?

There are those who argue, 'why bother about advance directives, why not simply legalise euthanasia?' Then the person or his or her proxy could say, 'let's call it a day'.

First, on top of the acceptance that killing people is wrong, there are grave reservations about deliberately shortening a person's life (see CMF File 7). And secondly, what if a patient is not competent and there is no proxy? Ending a person's life in this situation would no longer be voluntary euthanasia – it could be the start of a 'slippery slope' to widespread euthanasia. Financial pressures not to 'waste' family or state resources would be immense, and could soon be applied to people with conditions like Alzheimer's disease.

It's all about trust

It would be better if advance directives were superfluous and people trusted doctors to act wisely and humanely: fighting for life when there was a chance of success, and using palliative care when cure was no longer possible. Christian doctors should take a lead in working to establish a relationship of trust that uses their medical expertise, while recognising the personal expertise represented by each patient.

Advance directives are already part of the legal structure, and if they foster trust and communication between patients, doctors, family and friends, advance directives could be helpful. They will work best if all involved recognise their strengths and limitations. Legal documents will, however, always be poor substitutes for good doctor-patient relationships.

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8. *Exodus 22:22-23*
9. *Ecclesiastes 3:1-2, Job 14:5; Psalm 139:16*
10. *John 19*
11. *Revelation 21:1-5*

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