



CHURCH of IRELAND GENERAL SYNOD
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Advance Directives

In this short response it is assumed that in considering Advance Directives that it is treatment that the person involved would not wish to be given, in certain circumstances, and not instructions for treatment that they wished to have whatever. But where is the demand coming from for these directives? Is it a failure of communication between the public and the medical profession? Is it a non-event? Is it an item of the chattering classes? Much of the written material seems to come from those who are deliberately muddying the waters by using this approach to lead to the legalisation of patient-assisted suicide and euthanasia. There have been changes in names to much more euphemistic sounding titles such as “Dignity in Dying” the new title for the Voluntary Euthanasia Society, and Doctors for Assisted Dying. In a letter published in the British Medical Journal one of its main arguments for advance directives is that the cost of terminal cases was only one third for those making Advance Directives compared to patients who did not have a directive. Entering “death with dignity” onto Google produced over 25 million hits.

If you ask people about the concept of Advance Directives or Living Wills generally the response is favourable. And it seems not to be to put off death, though there is a contradiction in that people do seem to feel that death is a failure of the medical profession, with a subsequent pressure on medical attendants to do more than they might wish, so as not to be challenged, but rather it is to avoid the perceived indignity, degradation and loss of autonomy in certain terminal conditions. But when you start teasing out the issues then it becomes much more complex.

Within the Church of Ireland we would argue that there is not a need for Advance Directives, as a legally binding contract, but if they aid communication between patients, their families and the caring professions then they could be of value. But if they are available then they should be indicative, helpful in decision making for the health professionals and the family and friends, and ease the pain of the family and friends at a difficult time, to know that the wishes of a loved one were being followed.

But if they are to become a reality then who should be able to, what conditions should it include, should it be written and should it be legally enforceable?

It is generally accepted that only adults can sign Advance Directives, but what about teenagers who can give their own informed consent to medical treatment, before they

are legally adults, though they must be competent to make those decisions. Should it only include those conditions that are causing most lay concern, that is severe degenerative brain disease e.g. Alzheimer's, severe brain damage, e.g. injury, stroke, severely incapacitating nerve or muscle disease, or should it include any severe injury such as quadriplegia and should any patient of any age be able to make their list? Who should they discuss the details with? If it is someone already in the system with a disease should it be with a medical expert who is not their medical carer, who has access to their medical information? Should it be with a lawyer, as it should be written? Or should it be written with both a lawyer and a doctor present or at least discussing the document, so that the person was clear as to what they had signed up to? It certainly should be time limited, as both medicine advances and people change in their thinking. "I wouldn't want to live past 85, said aged 60, but now I am 84½. Ah!"

The biggest argument resides around the nature of this document. Should it be very tightly worded and very specific or should it be more indicative in its phraseology, perhaps with the inclusion of a proxy. The tighter it is worded the less opportunity there is for difficulty in interpretation, but that may cause problems that treatment is withheld when it is not desired. What about the situation of a patient who in liver failure stated in the past that he would not wish to have surgery, until he is informed that he has reached a stage that without a liver transplant he will rapidly die? There is a complete change of instruction. Or the younger person who if asked what they would wish to happen if they, through disease or injury, were quadriplegic, on a respirator and being dialysed. There is little doubt as to the answer, but ask the patient who is alive following that acute situation, but still quadriplegic, and there is frequently a different answer.

So often in medicine there is a problem of obtaining fully informed consent for a treatment or a surgical procedure to be carried out in the here and now, with all the arguments expressed. How then can people consent to things that are abstract and in the future? We would argue that rather than being legally binding, with all its attendant difficulties, Advance Directives should be regarded as having a presumption of being followed, in the spirit of indicativeness expressed, but that there must be opportunity for all concerned to discuss any situation, as to whether it meets the stated directive. This, unfortunately, may well not include the patient as they would be in the very situation that they have listed in their directive.

The most common situation that has caused this issue to be discussed is that of patients with dementia and wasting diseases. For that group there is a fear of a degrading and drawn-out death process. It is felt, in many cases, that the medical profession is not prolonging life but rather prolonging death. The situation that has developed with the provision of good palliative care, especially in the hospice movement, has removed so much of the fear of the dying process, that it has been virtually banished, and it is entirely likely that the same effect can be expected in the sort of scenarios considered in this context.

One of the most difficult issues to deal with, if Advance Directives are in force, is dealing with temporary changes in status especially in the dementing patient, who may in the early stage have quite lucid periods but through an infection becomes totally demented, and has specified no antibiotic therapy if they should get an infection, but if treated will return to their previous state. There is a problem then of interpreting the patient's desires; there is the problem of defining terminal, incurable and irreversible, terms usually used in a document of this type. The patient is

terminal, maybe in a period of years, and the underlying condition is both incurable and irreversible, but not the present acute state. Studies using this scenario have produced quite a spread of opinions, in focus groups asked to debate this scenario, in how to respond to the Advance Directive i.e. Thomson et al 2003 had as many treating as not, and each side was able to cogently argue their case.

Do we therefore ask for a looser indicative type of format? Whatever type, there will be a subjective element in it, as decisions are made on value items, such as severity, doing good, trying to decide what the patient would want in a particular situation. Is there a role for a proxy? If so, should it be a non-family member?

There is already an issue of signed directives where a person wishes to either leave their organs for transplant after death or their body for medical research, but these can be over-ruled by the family. What influence should family members have in the final decision making? If the document is legally binding, then they could expect not to have any.

There are many philosophical arguments that can be considered both in the secular world as well as by Christians, but many will have a special weight for the latter group when considering issues such as the place of suffering; quality decisions of a “good life versus a bad”; and whether those decisions are either “right or wrong”. If the argument is based only on the perceived good and bad quality of life then the resulting decision made might well be to kill someone who was felt not to be having a good life, but that would not be a right decision. As Christians, who are we to make judgements as to the wholeness of a person, even one with severe dementia.

For people as they get older their desires are to remain independent, that is preserve freedom and dignity and not be a burden. But Christian belief raises hard questions about our present ideas, attitudes and practices in respect to chronic illness, dying and death.

First of all we cannot elevate autonomy to its present secular level, of total centrality. Through our creation, though we have autonomy, it is limited both by our belonging to God and as humans we are dependant both on God and on each other as social animals. It is impossible for us to claim the autonomy of personhood in all dimensions of life especially at the hour of death. We cannot escape the dependence and interdependence that is a part of the good life given us by God, and it is through death that we enter into eternal salvation.

Second Christian belief holds that all believers are bound together in Christ as one body - St Paul's “if one suffers, all suffer”. The members owe one another appropriate care in all dimensions. Finally in respect of our redemption, though we see death as the final and great enemy, we believe that through Christ and his Resurrection death no longer has dominion over life.

Therefore in making arrangements for our final times we would be better to think of simple Advance Directives and powers of attorney that place us in the hands that care for us and not try to extend our autonomy. They should be less expressions of our autonomy and more provisions that can guide those who care for us. They are aids for those who are caring for us, when no longer fully autonomous, to allow them to refuse to prolong our dying for the sake of prolonging our lives. Let us look at them, Advance Directives, as expressions of love, not autonomy, for those who love us to provide proper care at these stages of our lives.

In all these arguments we must be careful not to let the agenda be hijacked by those who would use hard case examples to argue to the general situation, but rather let the argument be based on the normal situation and then extended outwards. We must be careful in how compassion is used without any thought as to its implications. Does our compassion say that that is no longer a life that is good to God? We must avoid the compassion that says there must be no suffering at whatever the cost even if it should mean the taking of life. We do not have the right to take life. Rather we must fight for adequate palliative care. It may be perceived as compassionate to kill or aid the suicide of a sufferer, but it is without awareness of God's dominion over human life, its sanctity, its goodness, of Christ's victory.

How are the older members of society going to feel, as they get frailer, if there is a change in attitude over caring when they are amongst the weakest members of that society, as to the care that they might receive? The slippery slope of no quality of life, then economic burden and a feeling of pressure from family, and rapidly there will be a swing from advance refusals to physician-assisted suicide or euthanasia.

Compassionate witness is more compelling than argument, and the commitment of Christians to the development of a caring community is the best possible counter to these dangerous demands.

Saunders said, "When someone asks for euthanasia or turns to suicide, I believe in almost every case someone or society as a whole has failed that person". The same applies to Advance Directives.

Summary

As members of the Church of Ireland we feel that, with appropriate communication between patients, their families and the health professions, there should be no need for formal Advance Directives.

If there are to be Advance Directives, then:

1. they should apply to conditions that are terminal, incurable and irreversible.
2. they should be to list treatments that should not be carried out, in the event of certain events.
3. they should not be to force any particular treatment to be carried out.
4. they should not be legally binding.
5. they should not require an illegal action by others.
6. there should be a presumption that the wishes expressed will be carried out.
7. but, at the same time, are seen as indicative of a wished course of action.
8. they should be time limited.
9. they should need positive renewal.
10. there is a great need for more palliative care physicians and nurses, and other appropriate care workers, to meet the needs of these patients.

For Christians:

1. life is God given and determined.
2. killing another is wrong.
3. it is not our decision as to whether the value of any life is "good or bad".

4. compassion based on our assessment of poor quality of life may produce a wrong decision.
5. we are not totally autonomous people, but dependent and interdependent on others.
6. Christian love will produce the right compassionate care.

Problems:

1. Should all age groups be able to sign Advance Directives?
2. Should they only apply to certain situations?
3. How are the terms “terminal, incurable and irreversible” to be defined?
4. How does a person give fully informed consent to an action or inaction, for an abstract situation in the future?
5. Is artificial nutrition and hydration a medical intervention, (*when carried out at home, by family*)? If commenced then how is it to be withdrawn, and by whom?
6. What is the role of a proxy?
7. If a written signed directive, can family over-rule it?

Discussions about Advance Directives must not be allowed to be used as a “back door” route, by certain pressure groups, to patient-assisted suicide or euthanasia.

8th June 2006.