Advance Decisions and Statements: A Guide

Making treatment decisions at the end of life can be an extremely difficult process. The situation can be complicated by patients losing the capacity to make decisions for themselves. In fact, this can happen well before a patient nears the end of life.

If a patient has advanced dementia or is in a permanently unconscious state, for example, and does not meet the requirements of mental capacity to make treatment decisions, doctors may need to act on their patient's behalf and make decisions based on the patient's good and what the patient would want or not want.

Thinking through such situations in advance can be difficult but it can also bring peace of mind, both to patients and to their loved ones who care for them, to plan in case decisions need to be made on their behalf. However, it also requires a considerable degree of knowledge and information, both medical and ethical.

The following guidance is meant to help patients think about their treatment and care options, especially when close to the end of life, or should they lose capacity to make decisions at any earlier time. They should think about these issues in conversation with their loved ones, chaplains, and with medical professionals.

The guidance will help you to make these decisions in a way that is consistent with the Catholic faith. This guidance should be used in conjunction with our Toolkit, which can be found on our project page: http://www.bioethics.org.uk/advance-decisions/

In This Guide

1 Why should I think about planning for my end of life care?

It is not a requirement to make any arrangements in case you lose mental capacity and some people prefer to trust the judgement of their doctors to make decisions about what treatments it would be in their best interests to give or withhold.

But it is important to know that if you lose mental capacity and do not have any arrangements in place for how you would like to be cared for as you approach the end of your life, then the doctors will use their judgement to decide what would be in your best interests. Your family or spouse will not have any right to make those decisions on your behalf instead of the doctors, unless you have previously made one or more of them attorneys for your health and welfare.

As a result, it is good to make your wishes and desires known in a clear way to avoid situations where your loved ones might think that the medical staff are making decisions on your behalf that you would not have wanted or that are not consistent with the Catholic faith.

If a patient does not make their choices and wishes known before they lose mental capacity, doctors are still obliged by law to make treatment decisions in the patient's best interests. This means taking into account both clinical and non-clinical factors to decide on what will help the patient best, all things considered. However, doctors will be better able to make a best interests decision if they have better knowledge of the patient's choices, wishes, values and preferences. That way, the risk of treatment being discontinued too soon or too late is reduced.

2 What does it mean to have or to lose 'mental capacity'?

'Mental capacity' is the term used by the law to refer to someone's capacity to make a decision. The law on mental capacity in England and Wales is known as the Mental Capacity Act (2005). According to the law, people must be assumed to have mental capacity unless it is proven otherwise. If a medical professional believes that you do not have the mental capacity to make decisions by giving or refusing your consent to certain forms of treatment, then they will assess whether you have lost mental capacity.

A person cannot be assumed to have lost mental capacity just because of their age, condition, or because their decisions are considered unwise. Furthermore, mental capacity is specific to a particular decision. Just because someone has been assessed as lacking the capacity to make a decision about a particular treatment, it does not mean they have lost the capacity to make other decisions about other treatments.

Lacking mental capacity means being unable to make decisions that concern you because of an impairment of, or a disturbance in the functioning of, the mind or brain.

The loss of mental capacity to make a decision is established if you are unable:

- to understand the information relevant to the decision,
- to remember that information,
- to use or weigh that information as part of the process of making the decision, or
- to communicate your decision (whether by talking, using sign language or any other means).

Continued overleaf →

This could be caused, for example, by dementia, a stroke, or an injury, or by some other physical or mental illness. The loss of mental capacity could be permanent or temporary. The important point is whether you lack capacity at the time when a decision needs to be made.

3 What are the different ways of planning for my end-of-life care in case I lose capacity?

There are three ways of planning your end-of-life care in advance in the event that you lose mental capacity to make decisions yourself.

You can choose to make:

- an Advance Statement,
- a Lasting Power of Attorney,
- or an Advance Decision to Refuse Treatment (ADRT or living will).

This guidance document will help you to think about which one is right for you. It is possible to use more than one at the same time.

4 What is an Advance Statement?

The Advance Statement is a document you can write to record your wishes and preferences for how you would prefer to be treated or not treated in case you lose mental capacity. It is not legally binding, but it will help medical staff take your preferences into account when making decisions. An Advance Statement can be as general or as precise as you like.

You can use it to let others know your beliefs about the value of human life, about any physical needs or disabilities you may have, which medications and treatments you would like to receive or refuse, which friends or family members you would like to be informed if you are admitted to hospital.

In our Practical and Ethical Toolkit, we have prepared an Advance Statement (General Instructions) which outlines Catholic principles on the value of life and how decisions regarding medical treatment should be made. Read through it carefully and tick the 'Yes' box if you would like it to be included in your Advance Statement. This will ensure that medical staff take everything in those instructions into account when making decisions on your behalf.

An Advance Statement is not legally binding but we recommend that anyone with concerns about treatment decisions at the end of life should make an Advance Statement to ensure that your beliefs and values are taken into account when medical staff are considering what is in your best interests.

Remember that an Advance Statement is principally for helping you make your preferences known.

5 What is a Lasting Power of Attorney?

A Lasting Power of Attorney (LPA) for health and welfare allows you to give someone else the legal power to make decisions on your behalf regarding medical treatment and care. You can nominate more than one attorney.

You can have an LPA and an Advance Decision to Refuse Treatment (ADRT) at the same time, but if they concern the same treatment and/or circumstances, then the more recent document takes precedence. This means that if you make an LPA after an ADRT, then your attorney could choose to override the instructions in the ADRT. To prevent this, you must make it clear in the LPA that your attorney must follow the instructions in the ADRT.

You must make and register an LPA with the Office of the Public Guardian.

More information about how to do this is available here: https://www.gov.uk/power-of-attorney

Continued overleaf →

6 What is an Advance Decision to Refuse Treatment?

An Advance Decision to Refuse Treatment (or ADRT, sometimes also called a living will) is a document you can make to refuse certain kinds of treatment in case you lose the mental capacity to make those decisions in the future.

It is a legally binding document in England, Wales, and Northern Ireland. In Scotland an ADRT is known as an Advance Directive and is not legally binding in exactly the same way but it is treated in a similar way by medical professionals and courts.

An ADRT only applies when you lose mental capacity to make decisions yourself. As stated in Question 2, mental capacity is always considered in relation to a particular decision. Even if you have already made an ADRT about a particular treatment, as long as you have mental capacity to make a decision about that treatment in the circumstances stated in your ADRT, you are free to make a decision that is different from or even contradictory to your ADRT.

But if you lose mental capacity after making an ADRT, then the medical staff are legally required to follow the instructions in it. No one can prevent them from withholding or withdrawing a treatment that you have explicitly refused in the ADRT.

The ADRT must make it clear which specific treatments you want to refuse and in which situations or circumstances you want to refuse them. The ADRT will be followed only if those circumstances come about and if you lack mental capacity.

You must sign the document by hand and have a witness be physically present to watch you sign it. The witness must then sign and fill in the appropriate section as well.

Furthermore, for each refusal that involves treatment which might be life-sustaining for you, you must include a statement such as 'I confirm that this refusal applies even if my life is at risk as a result'. Otherwise, the refusal of life-sustaining treatment will not be legally valid.

If you just wish to convey your general views about how you want to be treated, it would be better to make an Advance Statement (see question 4). If you do choose to make an ADRT, we recommend that you also provide an Advance Statement. You cannot use an ADRT to ask for or to demand particular treatments. You cannot use it to give someone else the power to make decisions on your behalf. For that, you would need to make a Lasting Power of Attorney.

7 Which one is right for me?

Thinking about how to plan for your future care is something that should be done over a period of time in conversation with those closest to you, your GP, your chaplain, your parish priest, and with anyone else who might be involved in your care.

If there is someone you trust, you might prefer to make an LPA. Your attorney will be able to use his or her judgement to make treatment decisions on your behalf if you lose capacity. This offers more flexibility. You can make your wishes and preferences known to the attorney personally. You can also put them in writing in the form of an Advance Statement.

The Advance Statement allows you to express generally how you want to be treated and why, so that your medical team and/or your attorney are not left to guess what you would have wanted. However, the Advance Statement is not legally binding on your doctors or on your attorney (if you have one).

Continued overleaf →

The Advance Decision to Refuse Treatment (ADRT) is a much more precise document: you must state exactly in which circumstances you want to refuse a particular treatment. This would be more appropriate if you have a progressive condition with a fairly predictable trajectory. An Advance Decision allows you to decide in advance which interventions and treatments you want to refuse in case you lose the capacity to refuse them yourself.

The more specific your ADRT is, the better. You should discuss with your doctor how your illness is likely to develop, what the potential treatment options are and their potential risks and benefits. This will allow you to understand which treatments you might want to refuse in an ADRT because you might decide that they would be excessively burdensome. Please see Question 8 for more information about what to consider when thinking about refusing treatment.

We recommend that if you have any concerns about losing mental capacity, you should make an Advance Statement. If you have particular concerns about specific treatments, then an LPA or Advance Decision could also be made, following the right principles (see Questions 8 and 9).

8 How should I decide which treatments to refuse?

This depends very much on the specific circumstances of each person, on the nature of their disease, and on what they would find burdensome.

It is sometimes appropriate to refuse certain treatments when approaching the end of life. For Catholics, there are two things that should be kept in mind:

1 Life is a precious gift of God that we are given to cherish and preserve.

2 We are mortal and we should not try to resist death at all costs.

What this means is that where there are particular treatments available that are likely to be effective in treating one's illness or at least extending life, then accepting such treatment would ordinarily be part of our general duty to preserve life.

But this duty is not absolute. When the potential benefits of treatment are outweighed by its potential risks or burdens, then the Catholic Church teaches that such treatment could be legitimately refused or discontinued. The burdens of treatment could be physical, emotional or psychological. Whether the burdens of a treatment outweigh its benefits is often a very personal decision. We do not all have the same ability to cope with a treatment's burdens. One person might wish to discontinue chemotherapy because its side effects have become too severe, even though it would still extend life a little longer. Another person might feel that they can cope with the burdens of treatment well and hence find it reasonable to continue preserving life by those means.

When planning treatment decisions in advance, these same principles apply, but there is the added dimension of thinking about the benefits and burdens of treatment in advance. It can be hard to predict what we will find burdensome at a different stage in life, or even what treatments we may need, as this will depend on the exact progression of an illness or condition. For this reason, it is not wise to refuse all forms of treatment in advance, as this may result in life being shortened even when an effective treatment with minimal burdens is available.

Because of the difficulty of predicting these matters, an Advance Statement will often be very helpful as it provides flexibility to doctors or your health attorney(s) (if you have any) when making decisions for you, while keeping them informed of your values and preferences. Hence, in the Advance Statement (General Instructions) which

Continued overleaf →

we have prepared in the Toolkit, we have included the following:

1 **I believe that my life is a gift from God. I acknowledge its intrinsic dignity, which means it must always be valued and cherished. I ask that decisions always be made with the presumption of life. I wish to receive treatment that is appropriate to my condition, beneficial, and not excessively burdensome.**

2 **I acknowledge that I do not need to preserve life at all costs, and that treatment that is excessively burdensome may be legitimately withdrawn or refused, even if that treatment is life-sustaining.**

An Advance Decision to Refuse Treatment (ADRT) may be appropriate in cases where the trajectory of a disease and the likely treatment options can be more easily predicted. If you want to refuse certain forms of treatment in advance, it is important that you think about it in terms of the burdens and benefits of the treatment, not in terms of how you imagine what life with a particular condition might be like. This can be hard to imagine, and our preferences often change to adapt and accept our new health status.

Quality of life assessments can sometimes help doctors and patients determine whether the benefits of a proposed treatment will be great or small. However, we should be careful not to use 'poor quality of life' itself as a reason to refuse treatment. From a Catholic perspective, Advance Decisions should always be about whether a particular treatment is worthwhile or not, and not about whether life with a certain quality is worthwhile or not. Our dignity does not depend on how physically able or free from discomfort we are, and someone with 'poor quality of life' can still find meaning and hope through relationships and the care shown by others. It is best to make this stance regarding quality of life clear to one's medical team.

For this reason, the Advance Statement (General Instructions) includes the following statement:

3 **I ask that all decisions about my treatment be made solely in relation to the benefits and burdens of the treatments in question, without considering my actual or anticipated quality of life as a burden of the treatment.**

The danger of using the language of 'quality of life' is that it can make us too quick to assume that we would not want to live a life of disability or of being dependent on others for care and support. Our dignity can never be lost, because we are all made in the image of God, including those who have physical or mental disabilities, and everyone is dependent on others for care at different points in life.

9 Are there any treatments that it would be wrong to refuse as a Catholic?

We can imagine many situations in which certain forms of treatment could be refused for the perfectly acceptable reason that would it be too burdensome on the physical and mental well-being of the dying person and would not offer many benefits to extend or improve his or her health.

But food and drink should be treated as ordinary and basic care, and in general should not be refused or discontinued, even if it has to be administered by clinically assisted means. Only when the administration of food and fluids causes significant burdens, or is no longer able to nourish the body, should it be discontinued.

Continued overleaf →

This is because providing someone with food and drink is one of the most basic ways of showing love and care towards another human being's needs. Refusing to provide that for a person who is unable to feed himself or herself may lead to that person's life being ended by starvation or dehydration. This is contrary to the dignity of the human person and the basic care that each person deserves. Similarly, to refuse to be given food and drink, except in those special circumstances mentioned above, would be gravely wrong.

Hence, the following is given in the Advance Statement (General Instructions) found in our Toolkit:

4 **I consider eating and drinking to be ordinary and basic care, and I ask that such care be given for as long as is possible. I also consider the medically assisted administration of food and fluids ordinary and basic care in principle. If I require food and fluids administered in this way because of my condition, I ask that my nutrition and hydration levels are monitored and kept adequate. I do not wish for the clinically assisted administration of food and fluids to be discontinued unless it becomes significantly burdensome, or can no longer nourish me.**

If your doctors inform you that your condition may cause you to lose the ability to drink or to feed yourself, it is important to make a statement, such as the one we have provided, to ensure that food and water are not withdrawn, even if they are clinically administered.

10 What about Do Not Resuscitate (DNR) notices?

This project on Advance Decisions and Ethical Choices focuses on Advance Statements, Lasting Powers of Attorney, and Advance Decisions to Refuse Treatment, because these are tools that patients can use to express their decisions and preferences. By contrast, a Do Not Resuscitate (DNR) notice is the decision of the doctor, not the patient, regarding Cardio-Pulmonary Resuscitation (CPR). These are also sometimes referred to as Do Not Attempt CPR (DNACPR) notices.

A DNR notice is only put in place when the doctor has assessed that CPR is not in the patient's best interests. A DNR notice is not a sign that a patient will no longer be treated or cared for. It is a decision made by a doctor that a specific intervention, which is CPR, is no longer appropriate for a particular patient given their condition. Very often, this will be because the patient's condition indicates that CPR is very unlikely to succeed in resuscitating them, or that its burdens (e.g. broken bones) will be disproportionate in comparison with very marginal benefits or a low chance of success.

A DNR notice is needed because, unlike most other treatments, CPR is always an emergency procedure. Typically, when it is needed, there will be no time for deliberation or discussion about whether or not to give it. Hence, it is helpful to have a decision made in advance. If there were no DNR decisions, then everyone whose heart stopped in hospital would get CPR, and this would mean futile and painful treatment for some patients.

From a Catholic moral perspective, the decision regarding a DNR notice should follow the same principles as whether or not a patient should refuse treatment (see Question 8). The assessment behind

Continued overleaf →

the decision should focus on whether the potential benefits of CPR outweigh its burdens or not.

A DNR notice should only be put in place after the doctor has consulted the patient and explained the rationale for the decision. It must be put in place only on the basis of an individual assessment, and never as a blanket decision on a group of patients. If you are not sure whether you have had a DNR notice put in place, please speak to your doctor about this.

11 How does this Guide relate to ReSPECT forms?

ReSPECT stands for 'Recommended Summary Plan for Emergency Care and Treatment' and it is a resource produced by the Resuscitation Council UK.

Some hospitals and other healthcare organisations have opted to adopt ReSPECT forms, which means that ReSPECT forms are used to record a patient's care and treatment preferences. This will be done through a conversation with a healthcare professional, and is meant to produce an agreed plan that can be followed for that patient's care and treatment, especially in the event of an emergency.

It is a good idea to engage with the ReSPECT process, if offered to you by a healthcare professional, as it is meant to establish a shared understanding between a patient and the healthcare team about values, preferences, and treatment options. ReSPECT forms are often used to record decisions about Do Not Resuscitate/Do Not Attempt CPR notices (see Question 10). They may also be used to help decision-making about other treaments besides CPR in an emergency.

If you have made an Advance Statement, Lasting Power of Attorney, and/or an Advance Decision to Refuse Treatment, you should let the healthcare professional know about these and ask for the fact that you have an Advance Statement, Lasting Power of Attorney, and/or an Advance Decision to Refuse Treatment to be recorded on your ReSPECT form.

In addition to this, it would be good idea to use these documents as a basis for your conversation regarding the ReSPECT form. This will help ensure that the ReSPECT form will reflect the preferences and decisions you have already thought about and recorded in any of these documents.

The same principles, regarding the value of treatment and the place of 'quality of life' in assessing treatment options, apply to ReSPECT forms as they do to the documents covered by our resources (see Question 8).

Anscombe Bioethics Centre

Catholic bioethics for the common good.
Promoting research, public debate and education since 1977.

82–83 St Aldate's
Oxford OX1 1RA
United Kingdom

Registered Charity No. 274327

www.bioethics.org.uk

This project on *Advance Decisions and Ethical Choices* was made possible by the generous support of the Sisters of the Holy Cross Charitable Trust.

Design: Fizog Design, Oxford