

Advance Decisions and Statements: An Ethical and Practical Toolkit

What is this toolkit for?

Many of us are concerned with how decisions would be made about our medical care and treatment, in the event that we lose capacity to make those decisions due to illness or injury. This toolkit is designed to help you find the best tool available under the law in England and Wales, to ensure that decisions are made in the best possible manner in case of loss of capacity. This toolkit has been designed in accordance with Catholic moral values, but it can be used by people of all faiths and none.

How should I use this toolkit?

Making decisions about future care and treatment is often a process, not a single event. Our thoughts and wishes may develop and change as we begin to think about them.

This toolkit is meant to be:

- A guide for personal reflection and discussion, as well as discussion with others, e.g. healthcare professionals, family, friends, chaplains/ministers of religion.
- A place where your thoughts and decisions are recorded and updated, which those involved in your care and treatment decisions can access easily.

Produced by the Anscombe Bioethics Centre,
a Catholic research institute in Oxford.

For more resources on this topic, please visit:
www.bioethics.org.uk/advance-decisions/

This toolkit has been designed for use in
England and Wales only. There are legal
differences in Scotland and in Northern
Ireland pertaining to some of the contents
in this document.



Step 1: What tool do I need?

Mental capacity is the ability to make decisions in an informed way. A person can lose the capacity to make decisions about healthcare due to illness or injury, such as through a stroke or dementia. (This does not mean that everyone who has a stroke or who has dementia has necessarily lost mental capacity.) Mental capacity is decision-specific, so someone could lose the capacity to make a particular decision about one type of treatment, but still have capacity to make other treatment-related decisions. Under the Mental Capacity Act 2005 of England and Wales, there are three different tools you can use to guide treatment decisions, if you lose mental capacity:

	Advance Statement: Setting out your preferences, wishes, feelings, values	Lasting Power of Attorney: Empowering someone else to make treatment decisions for you	Advance Decision to Refuse Treatment: Refusing specific treatments in specific circumstances
Legally binding	No	Yes	Yes
Specific to treatments and circumstances	Depends on wording	Depends on wording	Yes
Others make final decision	Yes	Yes	No

What happens if I don't make use of any of these tools?

Some people prefer not to make their decisions or preferences known, and would rather trust in the judgement of healthcare professionals. You are presumed to have mental capacity unless it is proven otherwise, and doctors will continue to discuss treatment options with you.

If you lose capacity and have not communicated any decisions or preferences in advance, all decisions must still be made according to your best interests. This is a legal requirement.

Best interest decisions mean decisions that are the best for you, all things considered. Both clinical and non-clinical factors will be taken into account. But your family or

spouse will not have an automatic right to make decisions on your behalf, unless you have made any of them an attorney for your healthcare. Nor are healthcare professionals required to follow your wishes to refuse certain treatments, unless you have an Advance Decision to Refuse Treatment.

However, a best interest decision will still take into account your wishes and values. If these are set out in a non-binding Advance Statement, this will help give your healthcare team more information for their best interests assessment.

It can also give your family and loved ones a clearer idea of how to communicate your likely preferences in response to a specific situation.



Pause and Think

How well each tool works depends on an individual's circumstances and needs. Which tool suits you best? There may be more than one:

- **An Advance Statement** allows you to set out your preferences, wishes, feelings and values. It is not legally binding, but it enables those making healthcare decisions for you to work out what course of action would be in your best interests.
- **A Lasting Power of Attorney** allows the nominated person(s) to exercise discretion in consenting to or refusing treatment, subject to the specific instructions of the document. This allows for more flexibility, and may be more suitable if there is someone you can trust to make treatment decisions on your behalf.
- **An Advance Decision to Refuse Treatment** must specify the treatment(s) being refused, and the specific circumstances to which the decision would apply. It is generally best suited to someone who has (or expects to have) a progressive condition, where likely scenarios and treatment options can be predicted. It is legally binding, meaning there is no flexibility once an Advance Decision is judged valid and applicable to the circumstances.



Step 2: Explore the tools further.

Find out more about the different options and record your decisions.

To learn about making an **Advance Statement**, please visit page 6.

To learn about making a **Lasting Power of Attorney**, please visit page 10.

To learn about making an **Advance Decision to Refuse Treatment**, please visit page 12.



We Recommend

Anyone concerned about treatment decisions at the end of life should make an Advance Statement.

Advance Decisions to Refuse Treatment and/or Lasting Powers of Attorney can be added on if you have concerns about specific treatments, especially in relation to a pre-existing condition.

Step 3: Let your healthcare team know about these documents.

Send photocopies or scanned copies of your documents to at least the first two, and others that may apply:

My GP surgery

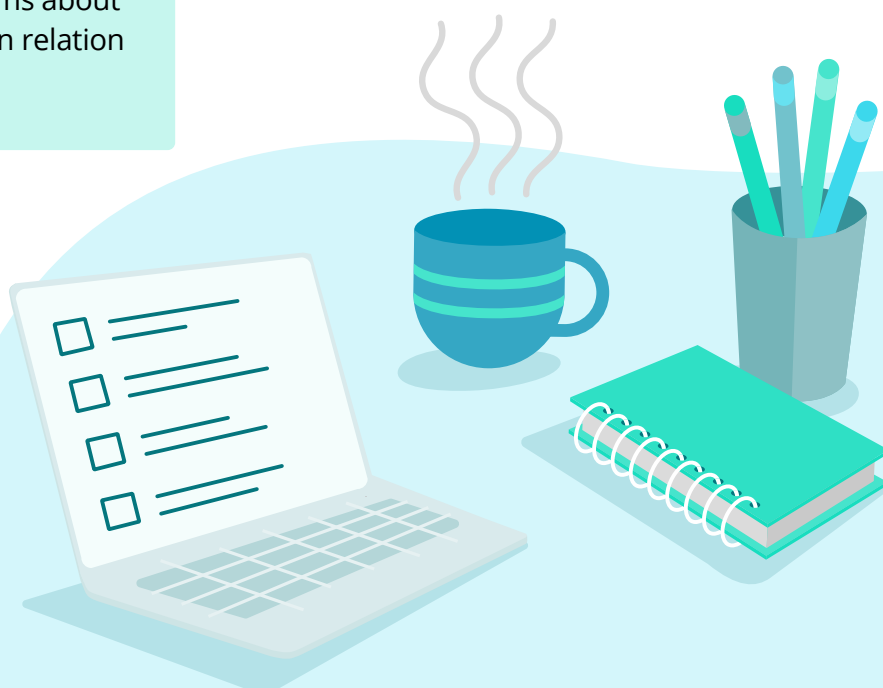
A trusted friend/family member

My care home/hospice/hospital

My healthcare chaplain/parish priest

The person(s) given Lasting Power of Attorney

Always have a copy ready to bring with you **every time** you are admitted to hospital.



Personal Information

Type directly into the PDF, or print out and complete using black ink and block capitals.

About me

Name:

Address:

Date of Birth:

NHS Number:

Next of Kin:

I would like my Next of Kin* to be consulted by healthcare staff on matters to do with my treatment and care (optional).

*Your nominated Next of Kin should be someone you feel close to. It does not have to be a blood relative or spouse.

GP details

Name of GP:

Name of Surgery/GP Practice:

Address:

Phone Number:

Making an Advance Statement

An Advance Statement is not legally binding, but you can use it to set out your preferences, wishes, feelings and values. These will be considered carefully by your healthcare team, in consultation with you, or your loved ones where necessary.

Your healthcare team will assess both your clinical condition and this statement to determine care and treatments for you, if you lose capacity to make decisions. An advance statement need not be limited to treatment preferences; it can also include information about preferences in daily life (e.g. food, leisure, religious practices).



Remember

How general or specific your statement should be is your choice. Healthcare professionals are not obliged to follow instructions in it, but they will take your statement into account when making decisions in your best interests.

Record your advance statement on page 7 and continue on page 8 if needed.

You can also opt to include our suggested Advance Statement (General Instructions) on page 9.



Name: _____

My Personalised Advance Statement

Type directly into the PDF, or print out and complete using black ink and block capitals.

I have included an additional page for my Advance Statement (see page 8).

Name: _____

My Personalised Advance Statement (continued)

Type directly into the PDF, or print out and complete using black ink and block capitals.

Name: _____

My religion or faith tradition is: _____

(Optional)

I have read and understood the following Advance Statement (General Instructions), and I wish to include it as part of my Advance Statement because I agree with its values.

Yes No

Advance Statement (General Instructions)

In the light of the Catholic faith

- 1 I have read and understood the following Advance Statement (General Instructions), and I wish to include it as part of my Advance Statement because I agree with its values.
- 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.
- 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.
- 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.
- 5 I ask that I be given adequate palliative treatments to manage uncomfortable or distressing symptoms, while maintaining as much function as possible, especially lucidity, during the dying process. If the only way to manage my distress is with treatments that have the side effect of reducing lucidity or even shortening life, then I am prepared to accept these consequences.
- 6 In no situation whatsoever must my life be ended by an act or omission that is either intended to cause or hasten my death, or is motivated by a desire to bring about my death.
- 7 As a Catholic, or as someone who respects the Catholic faith, I wish my treatment and care decisions to be informed by the teachings of the Catholic Church, and for appropriate expertise on these teachings to be consulted where necessary.
- 8 If I am in danger of death, please inform a Roman Catholic priest/minister of my religion who is able to take care of my spiritual needs.

Making a Lasting Power of Attorney

Making a Lasting Power of Attorney (LPA) for Health and Welfare means that someone is given the ability to make decisions about your treatment and care if you lose the capacity to make those decisions yourself.

A Lasting Power of Attorney allows the nominated person(s) – the attorney(s) – to use their judgement in consenting to or refusing treatment. This allows for more flexibility, and may be more suitable if there is someone you can trust to make treatment decisions on your behalf.

Your attorney(s) will be obliged to make decisions in your best interests, that is to say, taking into account all relevant factors. In your LPA, you may wish to include instructions or recommendations regarding your beliefs and preferences, or point to your Advance Statement, as these will help inform the best interests decision-making process.

Please read the following carefully:

- When you nominate an attorney for healthcare, it is up to you to decide:
 - How broad or how narrow the circumstances or range of conditions are in which the Attorney can make treatment decisions for you.
 - The range of treatments about which the Attorney is empowered to make decisions. This can, but need not, include life-sustaining treatment.



Remember

You can have a Lasting Power of Attorney and an Advance Decision to Refuse Treatment at the same time, but if they concern the same treatment and/or circumstances, then the more recent document takes precedence.

For example, if you give an Attorney the power to refuse or consent to ventilation, and then you subsequently make an Advance Decision to refuse ventilation in certain circumstances, then the Advance Decision will take precedence in those circumstances.

If you make an Advance Decision after making an LPA, please ensure that they do not conflict, or else amend your LPA accordingly. If you make an LPA after an Advance Decision, then you can either specify that the attorney must follow the Advance Decision, or you can specify that you are giving the attorney power to override the Advance Decision.

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- If the attorney is not given the power to refuse or consent to life-sustaining treatment, then the doctors will make those decisions about life-sustaining treatment. In that case:
 - Doctors could make the decision to withdraw clinically-assisted nutrition and hydration, even though it is life-sustaining, on the grounds that it is in the best interests of a patient. From a Catholic perspective, there is a danger that the doctors might want to withdraw it too soon or at an inappropriate moment, as nutrition and hydration is considered basic care in Catholic teaching except in special circumstances.
 - For that reason, we recommend stating clearly in the ‘instructions’ section of the LPA that you do not want clinically-assisted nutrition and hydration to be discontinued, except when it is significantly burdensome or is no longer able to nourish the body. Your attorney will be obliged to follow your instructions and advocate for this course of action.

You can make a Lasting Power of Attorney for Health and Welfare with the Office of the Public Guardian. More information about how to do this is available here:

<https://www.gov.uk/power-of-attorney>

If you choose to make a Lasting Power of Attorney, you can record the details of your attorney(s) below:*

Type directly into the PDF, or print out and complete using black ink and block capitals.

The details of my attorney(s) are:

Name:

Email:

Phone number:

Name:

Email:

Phone number:

*Complete this section only if you have already made a Lasting Power of Attorney for Health and Welfare with the Office of the Public Guardian. Filling in this box alone will not constitute a valid Lasting Power of Attorney.

Making an Advance Decision to Refuse Treatment

Please read the following carefully:

- An Advance Decision to Refuse Treatment is a legally binding document.
- It should set out the future circumstances in which you wish to refuse specified treatments.
- It will only apply if the specified circumstances materialise, the specified treatment(s) are under consideration, and you lack capacity to make that specific decision at that time.
- If you still have capacity, you will be able to refuse or consent to treatment, even treatment mentioned in an Advance Decision.
- However, if you are judged to lack capacity for a particular decision, and an Advance Decision you made has been judged valid and applicable to the circumstances, then nobody can legally prevent the specified treatment(s) from being refused/withdrawn.



We Recommend

An Advance Decision should, in general, only be used when you have been diagnosed with a progressive condition.

Anyone thinking of making an Advance Decision should consult a doctor to understand the likely trajectory of their condition or health status, possible treatment options, and their risks and benefits.

This will help make an Advance Decision more precise and better tailored to one's individual needs, and less likely to be judged inapplicable.



Pause and Think

Focus on the burdens and benefits of possible treatment options, not on 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.

Be clear about the reasons why you wish to refuse a specific treatment in the circumstances stated. Though not necessary for validity, it will give others and yourself a better idea of your values and thought processes.

Consider the Risks

The more specific an advance decision, the better it will respond to someone's needs. There are risks associated with adopting advance decisions that are too broad or that adopt a blanket approach.

The NHS National End of Life Care Programme guide to Advance Decisions

gives three examples of the risk involved in making advance decisions that are not sufficiently tailored to the circumstances:

- An advance decision refusing treatment other than comfort measures after a stroke might prevent good treatment and rehabilitation opportunities, with the result that, rather than dying, the person is left with worsened long-term disability.
- A patient with very severe unstable asthma might refuse mechanical ventilation but such refusal might result in survival with hypoxic brain damage rather than death.
- A person with dementia (lacking capacity to make decisions about medical treatment) can be physically reasonably well. This person could have a urinary tract infection which could be treated easily with a short course of antibiotics. If a refusal of antibiotics has been made this might prevent appropriate treatment and lead to distress.

If you would prefer to communicate your preferences in a general way, and leave the decision-making to your healthcare team or a nominated person please go to page 6 to make an Advance Statement, or page 10 to learn more about making a Lasting Power of Attorney.

Is an Advance Decision to Refuse Treatment equivalent to euthanasia?

Not necessarily. First of all, the Mental Capacity Act expressly states that it does not change the legal prohibition on euthanasia and assisted suicide.

Secondly, Catholic moral teaching has long recognised that life-sustaining treatment can, in some circumstances, be legitimately discontinued. Although there is always a presumption in favour of life, we are not obliged to preserve life at all costs.

When treatment is disproportionate because it is overly burdensome in comparison with its limited benefits, then it can be refused or withdrawn.

At all times, such a decision must be made on the basis of whether the treatment is worthwhile, not whether life lived with a particular condition, disability or level of quality is worth living.

It follows that a decision to refuse or discontinue treatment can also be made in advance, following the same moral principles.

However, particular care must be taken to make such a decision with sufficient knowledge of one's future situation and the risks and benefits of different treatment options, and without being influenced by negative perceptions about life lived with disability or dependence.

1. My Advance Decision to Refuse Treatment

Type directly into the PDF and print out, or print out and complete using black ink. You must sign it physically in the presence of a witness.

Important note: If the treatment you wish to refuse might be life-sustaining for you, please include the words 'I confirm that this refusal applies even if my life is at risk as a result.' in the 'I wish to refuse' box, for **each** refusal where this applies.

In relation to my condition,

(Optional)

if I develop

(Mandatory – specify circumstances)

I wish to refuse

(Mandatory – specify treatment)

This is motivated by my concern(s) that

(Optional)

I confirm that the information and decisions within this Advance Decision are entirely my own and made with full capacity.

Signature: _____

Name: _____

Date: _____

You must have a witness who is physically present when you sign the Advance Decision. **The witness must see you sign the document physically.**

Signature: _____

Name: _____

This is essential for the document to have legal validity if it involves refusing treatment that could be life-sustaining. Your witness must sign and date it.

Date: _____

Review Dates: Regularly reviewing your Advance Decision gives your healthcare team confidence that your wishes have not changed recently.

Signature: _____

Name: _____

I have reviewed this Advance Decision and confirm that what is written reflects my current wishes.

Date: _____

2. My Advance Decision to Refuse Treatment

Type directly into the PDF and print out, or print out and complete using black ink. You must sign it physically in the presence of a witness.

Important note: If the treatment you wish to refuse might be life-sustaining for you, please include the words 'I confirm that this refusal applies even if my life is at risk as a result.' in the 'I wish to refuse' box, for **each** refusal where this applies.

In relation to my condition,

(Optional)

if I develop

(Mandatory – specify circumstances)

I wish to refuse

(Mandatory – specify treatment)

This is motivated by my concern(s) that

(Optional)

I confirm that the information and decisions within this Advance Decision are entirely my own and made with full capacity.

Signature: _____

Name: _____

Date: _____

You must have a witness who is physically present when you sign the Advance Decision. **The witness must see you sign the document physically.**

Signature: _____

Name: _____

This is essential for the document to have legal validity if it involves refusing treatment that could be life-sustaining. Your witness must sign and date it.

Date: _____

Review Dates: Regularly reviewing your Advance Decision gives your healthcare team confidence that your wishes have not changed recently.

Signature: _____

Name: _____

I have reviewed this Advance Decision and confirm that what is written reflects my current wishes.

Date: _____

After Your Advance Decision

Remember to send it out to those may be involved in future decisions – see page 4. An advance decision cannot take effect if it is not known in time by those treating or caring for you.

Choose dates for a regular review of your Advance Decision, and note them in your diary or email/phone calendar. A review every year or six months might be appropriate.

Your Advance Decision will remain valid unless:

- You cancel it. It is recommended to make such a cancellation in writing and inform all those who previously received your Advance Decision of your cancellation.
- You give someone else Lasting Power of Attorney in relation to a treatment that your Advance Decision relates to, after the Advance Decision was made.
- You have done something clearly inconsistent with the Advance Decision remaining your fixed decision.



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

Registered Charity No. 274327

www.bioethics.org.uk

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