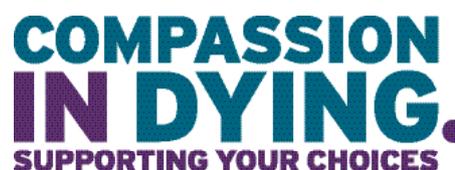


Information Line: 0800 999 2434

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Advance Decisions (Living Wills)

An introduction

This factsheet explains what an Advance Decision is, what it can and cannot be used for, and how to make one. It is for people living in England and Wales. If you live in Scotland or Northern Ireland, or you would like more information about planning ahead for your future care and treatment, please contact us.

What is an Advance Decision?

An Advance Decision allows you to write down any medical treatments that you do not want to have in the future, in case you later become unable to make or communicate decisions for yourself. It will only be used if you cannot make or communicate a decision for yourself. The legal name is an Advance Decision to Refuse Treatment, and it is also sometimes called a Living Will or an Advance Directive.

Advance Decisions are legally binding in England and Wales, as long as they meet certain requirements. This means that if a healthcare professional knows you have made an Advance Decision, they have to follow it. If they ignore an Advance Decision then they could be taken to court. See our factsheet *Advance Decisions (Living Wills) – Is my form legally binding?* for more information on the requirements an Advance Decision needs to meet.

Why might I be unable to make decisions for myself?

There are many reasons why you might be unable to make decisions for yourself. For example, you could become unconscious or have dementia, a mental health condition, a brain injury or a stroke. If you cannot make decisions for yourself, it is called not having 'capacity'. You lack capacity to make a decision if you cannot do one of these things:

- understand information relating to the decision;
- retain that information for long enough to make the decision;
- take that information into account when making the decision; or
- communicate the decision.

The Mental Capacity Act says that people must be assumed to have capacity unless it is proven otherwise. However, if a decision needs to be made about your health or care and a healthcare professional thinks that you might lack capacity, then they will need to assess whether or not you have the capacity to make that decision.

Whether or not you have capacity is decided on a decision-by-decision basis. For example, you might have capacity to decide what you want to eat every day but not have capacity to understand what will happen if you refuse life-sustaining treatment.

You might lose capacity to make a decision for a short time (for example, if you are knocked unconscious) or for a long time (for example, if you are in a vegetative state).

What can I refuse in an Advance Decision?

You can use an Advance Decision to refuse any medical treatment including

life-sustaining treatment, such as:

- cardiopulmonary resuscitation (CPR) if your heart stops;
- being put on a ventilator if you cannot breathe on your own;
- being given food or fluids artificially, for example through a drip, a tube through the nose or through a tube directly into the stomach; and
- antibiotics for a life-threatening infection.

What can I not use an Advance Decision for?

You cannot use an Advance Decision to:

- ask for something illegal, such as assistance to end your life;
- refuse to be offered food and drink by mouth or to refuse care that keeps you clean and comfortable. This is because these things are part of basic care, which healthcare professionals have a duty to provide;
- choose someone else to decide about treatment on your behalf. Choosing another person to make decisions about your health and care is done by making a Lasting Power of Attorney for Health and Welfare; or
- demand certain treatments. This is because doctors do not have to give you treatment just because you ask for it. Doctors decide whether treatment is medically appropriate for your condition and then you decide whether or not you want that treatment.

Why would I want to make an Advance Decision?

If there are treatments that you would not want to have in the future then making an Advance Decision will help to make sure your wishes are followed.

Making an Advance Decision can:

- Help you to make informed decisions in your own time by considering

your options.

- Give you control over the care and treatment you receive, whether that is tomorrow or further in the future.
- Give you peace of mind that you have taken steps to make sure your wishes are known about, recorded and respected.

The process of making an Advance Decision can help to initiate conversations between you and those close to you about your wishes for future treatment and care.

If you cannot make a decision about your medical treatment, and you have not made an Advance Decision or a Lasting Power of Attorney, then your doctor will decide what treatment to give you. They will base their decision on what they think is in your ‘best interests’, and they must take into account the views of your family members or others close to you. However, legally, they do not have to follow what the people close to you say. This means that if you have not made an Advance Decision or Lasting Power of Attorney, the doctor has the final say about what treatments you receive. For more information about how ‘best interests’ decisions are made, see our factsheet *What happens if I cannot make decisions about my care and treatment?* If you would like to know more about *Lasting Power of Attorney*, see our factsheet *Lasting Power of Attorney for Health and Welfare – An introduction*.

How do I make an Advance Decision?

Any adult with capacity can make an Advance Decision. You can write an Advance Decision yourself, or Compassion in Dying provides free forms that have space for you to record your wishes and all your details.

To make an Advance Decision, you should:

1. Think about what you want and the situations in which you would want to refuse certain treatments.
2. Speak to those close to you about your wishes.
3. Speak to your doctor about your Advance Decision. Your doctor can help you to understand your treatment options and explain the consequences of any decisions you want to make.
4. Fill in your Advance Decision form. If you want to refuse life-sustaining treatment, you must include a sentence which states that your refusals apply even if your life is at risk or shortened as a result (Compassion in Dying's Advance Decision form includes this wording).
5. Sign and date your Advance Decision form, and get it witnessed. Your witness must also sign and date the form.
6. Make sure your GP and those close to you know you have made an Advance Decision. There is more information about how to do this below.

You do not need a solicitor to write an Advance Decision. As long as it meets certain requirements then it is a legally binding refusal of treatment. For more information about the requirements an Advance Decision must meet, please see our factsheet *Advance Decision (Living Wills) – Is my form legally binding?*

How will people know about my Advance Decision?

Currently, there is no national register of Advance Decisions, so it is very important that those close to you, your GP, and anyone else involved in your care, know about your Advance Decision. There are a few things you should do to make sure people are aware of your Advance Decision:

- Ask your doctor to keep a copy of your Advance Decision with your medical records.

- Give a copy of your Advance Decision to anyone who would be contacted in an emergency.
- Give a copy of your Advance Decision to anyone else who is regularly involved in your care; for example, your consultant, carer or district nurse.
- Ask your GP to add the fact that you have an Advance Decision to your Summary Care Record. A Summary Care Record is an electronic record of important information about your health that is accessible to any health or care professional 24 hours a day. The presence of your Advance Decision will only be added if you specifically ask your GP to do so.
- Carry the 'Notice of Advance Decision' card (which comes with Compassion in Dying's Advance Decision pack) or keep a copy of your Advance Decision on your person.

What if I already have a Living Will?

A Living Will is the old name for an Advance Decision. If you made your Living Will before October 2007 (when the Mental Capacity Act came into force and made Advance Decisions legally binding) then it may not meet the criteria that an Advance Decision needs to meet. For more information on these requirements see our factsheet *Advance Decisions (Living Wills) – Is my form legally binding?*

What if my family disagree with my wishes?

In England and Wales, as long as your Advance Decision meets certain requirements then it is legally binding and cannot be overruled by anyone.

The only exception to this is if you have made a Lasting Power of Attorney for Health and Welfare after your Advance Decision was completed. See our

factsheet *Advance Decisions and Lasting Power of Attorney for Health and Welfare*
– *What is best for me and can I have both?* for more information.

Can I change my mind about my Advance Decision?

While you still have capacity you can change your mind or cancel your Advance Decision at any time. If you want to change it you should make a new form and give copies to the people close to you and anyone involved in your care (instructing them to destroy the old version). You can cancel your Advance Decision by destroying it (and any other copies you have made).

Remember that your Advance Decision will only come into effect when you lack capacity. So if you still have capacity to make decisions about medical treatment, your Advance Decision will not apply.

Reviewing and updating your Advance Decision

We strongly recommend updating your Advance Decision every two years, or sooner if your health changes, or if you are going into hospital. It is important to talk to your doctor about your wishes for treatment, as they will be able to explain the consequences of any decision you make.

If you lose capacity and your Advance Decision was reviewed or updated in the last two years, the doctor treating you can be more confident that what you have said in your Advance Decision is still what you want.

See our factsheet *Advance Decisions (Living Wills) – Reviewing and updating* for more information.

How can we help?

Compassion in Dying can send you a free Advance Decision form and guidance notes that explain how to complete it. We can also support you to complete your form over the phone.

If you have any questions about Advance Decisions, Lasting Powers of Attorney, planning ahead or decision making more generally then please contact our Information Line (our contact details are on the next page).

We can send you a copy of *Planning Ahead: Making Choices for the End of Life*, a free and comprehensive guide to planning ahead for your future care and treatment

The following Compassion in Dying factsheets may also be helpful:

- *Advance Decisions (Living Wills) – Is my form legally binding?*
- *Advance Decisions (Living Wills) – Reviewing and updating*
- *Advance Decisions (Living Wills) – Helpful questions to consider*
- *Lasting Power of Attorney for Health and Welfare – An introduction*
- *Advance Decisions and Lasting Power of Attorney for Health and Welfare – What is best for me and can I have both?*

Every effort has been made to ensure that the information provided in this factsheet is accurate and up-to-date, but information can change over time. Compassion in Dying does not accept any liability arising from its use, and it should not be used as an alternative to legal or medical advice. You can find the latest version of this publication on our website.

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Compassion in Dying supports people to plan ahead to ensure their wishes for treatment and care are respected.

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A list of references is available on request