Understanding Advance Directives – Scotland

This factsheet explains what an Advance Directive is, what it can and cannot be used for, and the steps involved in completing one. This is applicable to people living in Scotland, if you live England, Wales or Northern Ireland please see our factsheets ‘Understanding Advance Decisions – England and Wales’, or ‘Your Rights in Northern Ireland’. If you would like further information about your end-of-life rights and choices call our free Information Line on 0800 999 2434

Advance Directive is a Scottish term, but in other parts of the UK these documents are also called Advance Decisions or Living Wills.

This factsheet uses the term Advance Directive, unless it refers specifically to the form that Compassion in Dying provides, which is called an Advance Decision. The Compassion in Dying Advance Decision form can be used in Scotland.

What is an Advance Directive?

An Advance Directive is a document that allows you to make a refusal of treatment in advance of a time when you can’t communicate your wishes, or don’t have the capacity to make a decision. It only comes into effect if either of these situations occurs.

You can use an Advance Directive to refuse any treatment, including life-sustaining treatment such as resuscitation, artificial nutrition and hydration, or breathing machines. An Advance Directive enables healthcare professionals to know what your wishes are even if you cannot tell them yourself, e.g. if you had severe dementia or were in a coma.

You can also use an Advance Directive to set out the treatments that you do wish to consent to if you lose capacity. There is no legal obligation for healthcare professionals to give you this treatment, but it is a good idea to include the treatment you would want as it helps your healthcare team to gain a better understanding of exactly how you want to be treated.
Are Advance Directives legally binding, and how does the law in Scotland differ to the rest of the UK?

An Advance Directive is not legally binding in Scotland (whereas an Advance Decision is legally binding in England and Wales). However, if a medical decision was ever challenged in the courts, provided the Advance Decision was valid and applicable, it is likely that a judge would rule in favour of respecting it.

One of the general principles of the Adults with Incapacity (Scotland) Act 2000 is that if someone lacks capacity to make a decision for themselves and needs medical treatment, the wishes of the adult should be taken into consideration when making a decision on their behalf. So although Advance Directives aren't legally binding in Scotland, health professionals should take them into account when deciding on how to treat you. Family and friends can also use them as evidence of your wishes.

What does capacity mean?

Mental capacity is the ability to make decisions for yourself about a particular matter. Having ‘capacity’ means having the ability to understand and retain information relating to the decision, understanding the consequences of any choice you make, taking that information into account, and being able to communicate your wishes. You might ‘lack capacity’ because, for example, you have:

- dementia
- a mental health problem
- a brain injury
- had a stroke
- been given end-of-life sedation

If you are an adult (over 16) with mental capacity you have the legal right to refuse any medical treatment, and the law assumes that individuals have the capacity to make decisions unless it is proven otherwise. For decisions about your health, care and consent to or refusal of treatment, a doctor or other healthcare professional will need to decide whether 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 whether you want to be cared for in hospital or at home, but not have capacity to decide whether you want to refuse life-sustaining treatment. You might lose capacity to make a decision for a short time (for instance, if you are knocked unconscious) or for the indefinite future (for instance, if you were in a persistent vegetative state).
What can an Advance Directive not do?

You cannot use an Advance Directive to:

- ask for your life to be ended, because assisting suicide is against the law
- refuse the offer of food and drink by mouth or refuse basic care that attends to your comfort, pain and/or personal hygiene. This is because these things are a basic human right that no one can decline in advance.
- nominate someone else to decide about treatment on your behalf. Nominating another person to make decisions about your health and care is done by making a Welfare Power of Attorney.
- 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 Directive?

If you lose the ability to communicate or the capacity to make a decision then Advance Directives are a direct communication between you and the doctors treating you. This allows you to speak for yourself and means that other people will not have the responsibility of making life and death decisions on your behalf.

If you have ideas about what kind of treatment you would want to refuse in specific circumstances then an Advance Directive will help to ensure your wishes are followed.

Preparing an Advance Directive can open a dialogue between you and your friends or family, enabling you to talk about what you want and to make your wishes known.

If you cannot make a decision about your medical treatment and you have not made an Advance Directive or Welfare Power of Attorney, then your doctor will decide what treatment to give you. They will base their decision on what they believe would ‘benefit’ you, but this may not be what you would have wanted. Your doctor should speak to your family or next of kin, but does not legally have to follow what they say. This means that if you have no Advance Directive or Welfare Power of Attorney, the doctor has the final say about what treatments you receive. You can challenge their decision in the courts, but this can be costly and time consuming, and ultimately the final decision will then lie with the judge.
Can I change my mind?

If you change your mind you can change your Advance Directive to reflect this. If you have mental capacity and can communicate your wishes then your Advance Directive will not apply.

How do I make an Advance Directive?

1. Compassion in Dying provides free Advance Decision forms. Although they are called an ‘Advance Decision’, they serve the same purpose as an Advance Directive and can therefore be used in Scotland.
2. Think about what you want and the situations in which you would want to refuse certain treatments.
3. Speak to your loved ones about your wishes.
4. Speak to your doctor about your Advance Directive. They will be able to talk to you about which treatments to include and you can ask them to witness your mental capacity by signing the declaration within the form.
5. Fill in the Advance Directive. Then sign and date it, and have your signature witnessed. Your witnesses must then sign and date the document.
6. As there is currently no central record of Advance Directives, it is important that people around you know if you have one.

How will people know about my Advance Directive?

It is important that your loved ones and the healthcare professionals treating you know about your Advance Directive. There are a few things you can do to make sure people are aware that you have one:

- Ask your doctor to keep a copy of your Advance Directive with your medical records.
- Carry the ‘Notice of Advance Decision’ card (which comes with Compassion in Dying’s Advance Decision pack) or keep a copy of your Advance Directive on your person.
- Give a copy of your Advance Directive to those who would be contacted in an emergency. There is space to put their name and telephone number on the ‘Notice of Advance Decision’ card.
- Give a copy of your Advance Directive to everyone else who is regularly involved in your care. For example, a consultant, health visitor or local hospital.
- Keep a copy of your Advance Directive yourself and make sure other people know where it is.
- You could also use the pull out form in Compassion in Dying’s Advance Decision Guidance Notes to join MedicAlert. They can provide jewellery designed to alert the emergency services to the fact that you have an
Advance Directive. They also store a copy of your Advance Directive electronically and can send this to a healthcare professional if it is needed.

**Reviewing and updating your Advance Directive**

We strongly recommend updating your Advance Directive if your health changes, or if you are going into hospital for serious treatment or surgery. It is important to talk to your doctor about your preferences for treatment, as they will be able to explain the implications of any decision you make.

It is a good idea to review your Advance Directive regularly, even if your health is stable. If you lose mental capacity and your Advance Directive was reviewed and updated in the last two years, the doctor treating you can be more confident that what you have said in your Advance Directive is still what you want.

**How can we help?**

- Compassion in Dying can send you a free Advance Decision form
- We provide information and support to make an Advance Directive or Welfare Power of Attorney
- We provide a free and comprehensive guide to *Your Rights at the End of Life*
- The following Compassion in Dying factsheets may be helpful:
  - *Reviewing and Updating Your Advance Decision*
  - *Helpful Questions to Consider When Making an Advance Decision*
  - *Understanding the General Medical Council’s Guidance ‘Treatment and Care Towards the End of Life’*
  - *Understanding Welfare Powers of Attorney – Scotland*

If you would like any of the factsheets mentioned here or want information about end-of-life rights more generally please call our free **Information Line** on **0800 999 2434** or visit our website [www.compassionindying.org.uk](http://www.compassionindying.org.uk).