

Advance decision

Explanatory information and form

People who have been diagnosed with dementia, or who are worried that they may develop dementia in the future, are often concerned about how decisions regarding their medical treatment might be made should they lose the ability to decide for themselves. They may fear that life-sustaining or life-prolonging treatments would be provided long after they were able to achieve a level of recovery, length of life or quality of life that the person would at present consider to be acceptable or tolerable.

The Mental Capacity Act 2005 gives people in England and Wales a statutory right to refuse treatment through the use of an 'advance decision'. An advance decision allows a person to state what forms of treatment they would or would not like should they become unable to decide for themselves in the future. The Alzheimer's Society is in support of the idea of advance decisions because they enable people with dementia to have a say in their future care.

This document explains what an advance decision is and what it can and cannot do. It also provides practical advice and a downloadable form to draft an advance decision.

Definitions of terms

An **advance decision** is intended to be a binding refusal of certain kinds of treatment as specified by the person making the advance decision.

An **advance statement** is a statement of general beliefs and aspects of life which a person values. It may reflect individual aspirations and preferences and is sometimes called a 'personal values history'. The statement can be used to help health professionals and others such as family members to decide what sort of treatment the person would want if they were unable to communicate their wishes. However an advance statement would not bind healthcare professionals to a particular course of action if it conflicted with their professional judgment.

An **analgesic** is a remedy that relieves or allays pain.

Capacity or **competence** is defined as the ability to understand the implications of a decision. A person is deemed to have capacity or competence if he or she:

- can understand and retain information relevant to the decision in question (the definition of 'to retain information' has to be assessed on an individual basis)
- believes it and can reflect on that information to arrive at a choice and use that information as part of the decision-making process
- can then express or otherwise communicate that choice.

A person diagnosed with dementia does not necessarily lack capacity. However, for people with dementia the loss of the ability to make informed decisions may be a gradual process, so the point at which they are no longer able to make a decision is quite difficult to pinpoint. Also, people may be quite capable of making their own decisions at times but at other times their dementia can significantly affect their capacity and abilities. In such cases of fluctuating or temporary capacity an assessment of the person's capacity must be made at the time the decision has to be made.

Cardiopulmonary resuscitation is a method of artificially restarting a person's heart.

A **health and welfare attorney** appointed under a Lasting Power of Attorney is an individual nominated and registered to make decisions on behalf of another person should that person lose capacity. (See the Society's Information sheet 472, *Enduring power of attorney, lasting powers of attorney and receivership*.)

What are the advantages of deciding in advance?

Creating an advance decision and/or advance statement can bring some reassurance to a person worried about their future healthcare.

When healthcare professionals are faced with difficult decisions about what treatment or care to give, an advance decision or advance statement will provide the best possible guide and will help to ensure that the person's wishes are taken into account.

Preparing an advance decision or advance statement can open up a dialogue with doctors and nurses that might otherwise be delayed until it is too late. The process can also stimulate conversation with family and close friends, relieving them of some of the burden of decision-making at what can be a distressing time.

Are advance decisions legally enforceable?

As long as an advance decision is valid and applicable it is legally enforceable in England and Wales.

Valid: it must be the case that the person who drew up the advance decision had mental capacity to do so at the time.

Applicable: the wording of the advance decision has to be relevant to the medical circumstances. If the wording is vague or there is a concern that the person was not referring to medical conditions and/or practices that they are actually experiencing, then the advance decision may not influence the doctors' decisions at all.

The advance decision must:

- be clear and unambiguous
- have been written when the person was over the age of 18 years, had sufficient mental capacity and been fully informed about the consequences of refusal of treatment, including the fact that it may hasten death
- have been intended to apply in the situation which has arisen
- not have been drawn up under the influence of other people.

If a health and welfare attorney has been appointed under a Lasting Power of Attorney, the health and welfare attorney should also be involved in discussions about the person's treatment, and healthcare professionals should take information provided by him or her into account. An advance decision overrides a Lasting Power of Attorney unless a Lasting Power of Attorney prepared after the advance decision specifically confers authority on the attorney. (See again

Information sheet 472.)

The British Medical Association supports the principle of advance decisions and recognises that healthcare professionals may be legally liable if they disregard the contents of a valid advance decision.

What an advance decision cannot do

An advance decision cannot be used to:

- refuse basic nursing care essential to keep a person comfortable, such as washing, bathing and mouth care
- refuse the offer of food or drink by mouth
- refuse the use of measures solely designed to maintain comfort, for example painkillers
- demand treatment that a healthcare team considers inappropriate
- ask for anything which is against the law such as euthanasia or assisting someone in taking their own life.

How to draw up an advance decision

The content of an advance decision can be as simple or as complex as you wish. It is up to you to decide how detailed you wish your statement to be. You can draft an advance decision yourself using your own words, or you can use the attached form. If the form does not cover everything you wish to say you can use it as a guide and add extra wording to ensure it includes all your views and wishes.

Discuss your advance decision with your general practitioner (GP)

Because an advance decision concerns healthcare, the Society strongly recommends that you discuss it with your GP before drafting it. As well as providing information on how your illness is likely to affect you as it progresses, your GP can help you understand the advantages and disadvantages of choosing or refusing medical procedures in advance. He or she can advise on some of the problems that may arise from an unclear statement. Your GP will also be able to confirm that you had sufficient mental capacity at the time that you drafted your advance decision.

Talk to a solicitor if you wish

You do not need to consult a solicitor to draw up an advance decision, but if you are uncertain, a suitably qualified solicitor can help you to ensure that your views are clearly expressed.

Important information to include in your advance decision

If you choose to draft your own advance decision, this is the minimum information you must include:

- your full name
- your address
- the name, address and telephone number of your GP
- whether advice was sought from a healthcare professional
- the date
- your signature
- the dated signature of at least one witness over the age of 18. Your witness should not be a partner, spouse, relative, nor anyone who stands to benefit under your will. Nor should the witness be your attorney under a Lasting Power of Attorney
- a clear statement of your wishes and values
- if you have nominated a person to be consulted about treatment decisions (your health and welfare attorney under a Lasting Power of Attorney for health and welfare) then supply the name, address and telephone number of that person
- where relevant, the date that you reviewed and, if necessary, revised your advance decision, accompanied by your signature
- if the advance decision is applicable to lifesustaining treatment, a statement must be included to verify that the decision applies to that treatment even if it might put your life at risk.

You should include a statement to identify the circumstances under which the advance decision would come into effect. For example it may specify that it would come into effect only in the case of terminal illness, or in a situation where you are unable to make a decision for yourself. You may wish to include a statement of your wishes regarding specific treatments such as cardiopulmonary resuscitation or artificial feeding and hydration.

The advance decision should include a statement to acknowledge that it was drawn up without influence or pressure from other people.

Make copies of your advance decision

As well as keeping a copy of the document for yourself you will need to make several copies of your advance decision and give it to the following people:

- your GP, to keep with your medical records
- your hospital team to place in your case notes
- a close relative or friend
- your health and welfare attorney under a Lasting Power of Attorney (if you have one).

Review your advance decision regularly

We recommend that you review and, if you so wish, revise your advance decision or advance statement regularly, perhaps every six months. If you wish to make changes you can either start afresh and complete a new form or amend your existing document, making sure you sign and date the form again to confirm the changes. Whether the original form is revised or a new form completed you must ensure an independent witness also signs the new version. Make sure you give copies of the revised version to all the holders of the original version.

You can download a pdf form to help you draft an advance decision [here](#).

Frequently asked questions

1 Is my advance decision legally enforceable?

Yes, it is valid in England and Wales as long as it was drawn up when you were over 18 and had the required mental capacity, is clear and is relevant to the medical circumstances that arise.

2 Is there equivalent legislation for people in Northern Ireland and Scotland?

The Mental Capacity Act 2005 does not apply to people living in Scotland or Northern Ireland. People living in Scotland should refer to the Adults with Incapacity Act 2000. There is currently no legislation in Northern Ireland covering the use of advance decisions. See below for some organisations that can advise further.

3 How long is my advance decision valid for, and do I have to renew it?

Your advance decision will be valid from the date you sign it. It is advisable to review and, if necessary, revise it every six months to ensure that it continues to reflect your views. However failure to do this will not invalidate it.

If you do revise your advance decision remember to sign and date it with the current date. Make sure you know who has copies of your advance decision so that you can give them the revised version.

4 Do I have to give my advance decision form to my solicitor?

No. An advance decision is entirely separate from other legal documents such as your will. However you may want your solicitor to hold it for safekeeping.

5 Does my GP have to sign the advance decision form?

This is not necessary but it is useful. If you discuss your advance decision with your GP and ask him or her to sign it, he or she will understand your wishes and can also be called upon if necessary to confirm that you had capacity at the time you made these decisions. It is also important to make sure that a copy of your advance decision is placed with your medical records and to ensure that the relevant people know that it is there.

6 Can my family overturn an advance decision?

No. An advance decision is a statement of your wishes and cannot be overturned by anyone unless:

- you have signed a Lasting Power of Attorney to appoint a health and welfare attorney after the advance decision and given authority to the attorney to accept or refuse treatment to which the advance decision relates
- you revoke the advance decision yourself at a time when you have the required mental capacity
- you made your advance decision at a time when you did not have the required mental capacity
- you were unduly influenced by others to make the advance decision.

7 I have already written a living will. Is this still valid under the new Act?

Living wills written before the Mental Capacity Act 2005 was passed will continue to have standing in statute law as long as they are valid and applicable to the circumstances that arise.

Where to find out more

Alzheimer's Society

Gordon House
10 Greencoat Place
London
SW1P 1PH

Alzheimer's Society helpline: 0845 300 0336 (8.30am - 6.30pm weekdays)
Website: <http://www.alzheimers.org.uk/>

Alzheimer Scotland - Action on Dementia

22 Drumsheugh Gardens
Edinburgh
EH3 7RN

Helpline: 0808 808 3000 (24 hours)
Website: <http://www.alzscot.org/>

Public Guardianship Office

Archway Tower
2 Junction Road
London
N19 5SZ

Customer services phone: 0845 330 2900
Email: custserv@guardianship.gov.uk
Website: <http://www.guardianship.gov.uk/>

Customer services provide free booklets on enduring power of attorney and receivership. Their phoneline is available from 9am to 5pm on weekdays. The court of protection is at the same address.

Information sheet 463

Last updated: June 2007
Last reviewed: June 2007