For many people with dementia, there will come a time when you aren’t able to make decisions for yourself, such as choices about your care and treatment. There are a number of things you can do now to make sure your wishes are taken into account. These are often referred to collectively as ‘advance care planning’ or planning ahead.

Advance decisions and advance statements are two of these ways. This factsheet explains how advance decisions and advance statements work, and what they can and cannot do. It also provides practical advice and a form to help you to draft an advance decision.

Contents

- What is an advance decision?
- What is an advance statement?
- Why should I consider making an advance decision or advance statement?
- Will the doctor have to follow my advance statement?
- Will the doctor have to follow my advance decision?
- What an advance decision cannot do
- How to make an advance decision
- Frequently asked questions
- Other useful organisations.
Advance decisions and advance statements

For many people with dementia, there will come a time when you aren’t able to make decisions for yourself. This ability is known as ‘mental capacity’. There are a number of ways that you can ensure that your wishes are taken into account in the future, if you lack mental capacity.

Advance decisions and advance statements are two of these ways. They can ensure that you are not given treatment that you do not wish to receive, or that your family have power to act on your behalf if you wish them to.

This factsheet is for people living in England and Wales. It is not intended for those living in Northern Ireland, where the laws about advance decisions do not apply. For information about the laws that relate to Northern Ireland see factsheet NI467, Financial and legal tips.

What is an advance decision?

An advance decision allows you to decide now about specific treatments that you do not want to receive in the future. Its purpose is to ensure that, if you are not able to make decisions at the time, you are not forced to receive treatment that you would not want.
Treatment that you can refuse includes life-sustaining treatment. For example, some people may make an advance decision to refuse a blood transfusion for religious or spiritual reasons. You can do this even if it will hasten your own death.

Advance decisions are legally binding as long as they meet certain conditions. This means that they must be followed by doctors and other medical professionals. This factsheet details these requirements so that you can be sure that any advance decision you make will be valid.

**What is an advance statement?**

Advance statements are similar to advance decisions, but are not the same thing. An advance statement gives you the option to make general statements about your wishes and views for the future, rather than refusing certain specific treatments. Often an advance statement is referred to as a ‘statement of wishes and care preferences’.

You could use an advance statement to express your wishes on future care options, such as where you wish to live, or the type of care and support you wish to receive. You could also use it to express other wishes and preferences not directly related to care, such as the food you would like.

If you have particular religious or spiritual views, an advance statement provides an opportunity to ensure that your values are taken into account by the people who make decisions for you. You can also include a list of people, such as your partner, family or friends, whom you wish to be consulted by health and social care professionals when they are making decisions about your care.

An advance statement gives you the option to make general statements about your wishes and views for the future, rather than refusing certain specific treatments.

An advance statement can be made verbally, or you can write it down. It is better to put it in writing because then it is a permanent record of your wishes.
It is also important to note that you can make both an advance statement and an advance decision.

**Why should I consider making an advance decision or advance statement?**

There are a number of reasons why you may wish to make an advance decision or advance statement:

- It can be reassuring to know that you will not be given treatment in the future that you do not want.
- It ensures your views and wishes are taken into account.
- It can help to start conversations about your future care with doctors and nurses that you may not have otherwise.
- It can also help to prompt discussions with your family about your wishes, and what you would like to happen in the future.
- It can take the burden away from your family, who otherwise may be asked to make these decisions for you.

**Will the doctor have to follow my advance statement?**

An advance statement – unlike an advance decision – is not legally binding. This means doctors and medical professionals do not have to follow it. However, doctors, nurses and all other health and social care professionals should take an advance statement into account when making decisions about your care and treatment. This means they should try to follow it where possible, and if they do not, it must be because they have a good reason.

**Will the doctor have to follow my advance decision?**

Advance decisions, when they meet certain criteria, are legally binding. This means all medical professionals, including doctors, have to follow them. This is only true when your advance decision is both ‘valid’ and ‘applicable’.

- **Valid** – In order to be valid, an advance decision must have been made at a time when you were capable of making the decision. This is referred to as having ‘mental capacity’. For more information see factsheet 460, *Mental Capacity Act 2005*. 
**Applicable** – In order for the advance decision to be applicable, the wording has to be specific and relevant to the medical circumstances. This means you have to choose what you say carefully. If the advance decision is vague or if it isn’t clear that it refers to a particular medical condition, treatment or practice, the doctor may not have to (or be able to) follow it.

The advance decision must also:

- have been made when you were over 18 and fully informed about the consequences of refusing treatment, including the fact that it may hasten death
- not have been made under the influence of other people
- be written down and be signed and witnessed (if it relates to refusing life-saving treatment).

An advance decision can be as simple or as complex as you want it to be. It is up to you to decide how much detail you include.

**What an advance decision cannot do**

There are some limits to the kinds of treatments and situations an advance decision covers. It cannot be used to:

- refuse treatment if you still have the capacity to give or refuse consent
- refuse basic care that is essential to keep you comfortable, such as washing or bathing
- refuse food or drink by mouth (although it can be used to refuse feeding by tube)
- refuse the use of measures designed solely to maintain comfort – for example, painkillers (which relieve pain but do not treat the underlying condition)
- demand specific treatment
- refuse treatment for a mental disorder in the event that you are detained under the Mental Health Act 1983. For more see factsheet 459, *Mental Health Act 1983 and guardianship*.

- request something that is against the law, such as euthanasia or assisting you in taking your own life.

### How to make an advance decision

An advance decision can be as simple or as complex as you want it to be. It is up to you to decide how much detail you include.

You can draft an advance decision yourself using your own words. There is also a template at the end of this factsheet that you can use if you want some guidance. If this does not cover everything you want to say, use it as a guide. Add to it or delete from it to ensure that it covers everything you want it to.

Unless you want your advance statement to cover life-sustaining treatment, you can make it verbally – that is, you can say what you want to happen. There is no set format for making a verbal advance decision as it depends a lot on the circumstances when it is made. There are a few things that you can do to ensure that it is still valid, however.

Your verbal advance decision should still be recorded in your medical records by a medical professional as this can help avoid confusion later. The record should include:

- a clear note of the treatment(s) to be refused if you lack the capacity to make the decision at the time

- details about the person who witnessed your decision

- whether or not the health professional heard your decision themselves.

It is always better to make your advance decision in writing, if possible. This ensures that medical professionals are aware of your wishes and that they are correctly understood.
Talk to your GP
It is strongly recommended that you discuss an advance decision with your GP before drafting it. They will be able to explain how your condition is likely to affect you as it progresses, and what treatment you may need. They can help you understand the advantages and disadvantages of choosing or refusing treatment in advance. They can also explain some of the problems that may arise from an unclear statement, and will be able to confirm that you had mental capacity at the time that you wrote your advance decision.

Consider talking to a solicitor
You don’t need to consult a solicitor to make an advance decision, but it can be a good idea. If you are uncertain about what you want to include or how to say it, a qualified solicitor can help make sure that your views are clearly expressed. However, be aware that a solicitor may not be able to advise you on how your condition might progress and the treatments and interventions that may be available. For this you should talk to your GP.

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

- your full name
- your address
- your date of birth
- any distinguishing features (eg tattoos, birthmarks)
- the name, address and telephone number of your GP
- the date you made the advance decision
- your signature
- the dated signature of at least one witness over the age of 18. Ideally this should not be a partner, spouse, relative, anyone who stands to benefit under your will, or your attorney under a Lasting power of attorney
the name, address and phone number of the people you have nominated to be consulted about treatment decisions, if anyone. This might be your attorney under a Lasting power of attorney for health and welfare, for example

where relevant, the date that you reviewed – and, if necessary, revised – your advance decision, along with your signature

if the advance decision applies to refusing life-sustaining treatment, a very clear statement that the advance decision applies to the treatment in question even if your life is at risk.

Although you don’t have to, it is also a good idea to include the following:

an explanation of when the advance decision should come into effect – for example, it may specify that it comes into effect only if you have a terminal illness

any specific treatments that you want to refuse, such as cardiopulmonary resuscitation (CPR) or artificial feeding and hydration – for more information on medical treatments that you could include, speak to your GP

a statement that says your advance decision was drawn up without influence or pressure from other people.

Make copies of your advance decision
You should make a copy of the document for yourself and keep it somewhere safe, You should also make several other copies and give them 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 attorney under a Lasting power of attorney for health and welfare, if you have one.
Review your advance decision regularly
You should review your advance decision regularly to make sure that it still matches your wishes and preferences. If you want to, you can make changes to it.

To do this, you can start afresh and complete a new form. Or you can make changes to your existing document, making sure you sign and date it again to confirm the changes.

Whether you amend the original form or complete a new one, you must make sure that an independent witness also signs and dates the new version. Be sure to give copies of the revised version to everyone who held a copy of the original version.

Frequently asked questions

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 a good idea to review it regularly and, if necessary, revise it to make sure that it still reflects your views. However, your advance decision will continue to be valid even if you don't review it. If you do revise your advance decision, remember to sign and date it with the current date and get it witnessed again. Make sure you know who has copies of your advance decision so that you can give them the revised version.

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.

Does my GP have to sign the advance decision form?
No. It is not necessary for your GP to sign your advance decision, but it is useful. If you discuss your advance decision with your GP and ask them to sign it, they will understand your wishes better, and can then be called upon if necessary to confirm that you had mental capacity at the time you made the decision. It is also important to make sure that a copy of your advance decision is placed with your medical records and to make sure that the relevant people know that it is there.
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 health and welfare Lasting power of attorney after you made the advance decision, and gave the attorney the power to accept or refuse treatment that the advance decision relates to
- you decide for yourself not to follow the advance decision at a time when you have the mental capacity to do so
- you made your advance decision at a time when you did not have the mental capacity to do so
- you made the advance decision under the influence of others, and so it was not valid.

Other useful organisations

Office of the Public Guardian (OPG)
PO Box 16185
Birmingham B2 2WH

0300 456 0300 (customer services, 9am–5pm weekdays)
customerservices@publicguardian.gsi.gov.uk
www.gov.uk/office-of-public-guardian

The OPG supports and promotes decision-making for those who lack capacity or would like to plan for their future, within the framework of the Mental Capacity Act 2005. It provides free booklets on Enduring and Lasting powers of attorney and deputyship.
Factsheet 463LP
Reviewed January 2013 by Natalie Melling, Approved Mental Health Professional (Mental Health Act), Independent Social Worker, Best Interests Assessor (Mental Capacity Act) and Irene Chenery, Partner, Chenery Maher Solicitors; member of Solicitors for the Elderly
Reviewed April 2016 by Alzheimer’s Society
Next review due: April 2019
This factsheet has also been reviewed by people affected by dementia.
A list of sources is available on request.

Alzheimer’s Society National Dementia Helpline
England, Wales and Northern Ireland:
0300 222 1122
9am–8pm Monday–Wednesday
9am–5pm Thursday–Friday
10am–4pm Saturday–Sunday

This publication contains information and general advice. It should not be used as a substitute for personalised advice from a qualified professional. Alzheimer’s Society does not accept any liability arising from its use. We strive to ensure that the content is accurate and up to date, but information can change over time. Please refer to our website for the latest version and for full terms and conditions.

© Alzheimer’s Society, 2017. All rights reserved. Except for personal use, no part of this work may be distributed, reproduced, downloaded, transmitted or stored in any form without the written permission of Alzheimer’s Society.

alzheimers.org.uk
Alzheimer’s Society is the UK’s leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.
Advance decision

To my family, my GP, my health and welfare attorney (where applicable) and all other persons concerned, this advance decision has been made by me, entirely without influence from any other person, whether they might stand to gain from my death or otherwise.

Full name in capitals: ........................................................................................................................................................

Of [address]: ........................................................................................................................................................

........................................................................................................................................................

Date of birth: ........................................................................................................................................................

I declare that if at any time:

- I am unable to participate effectively in decisions about my medical care and
- two independent doctors (one a consultant) are of the opinion that I am unlikely to recover from illness or impairment and
- the gravity of my condition/suffering is such that treatment seems to be causing distress beyond any possible benefit,

then in those circumstances my directions are as follows:

- that I am not subjected to any medical intervention or treatment aimed at prolonging or sustaining my life such as those in ‘Detailed instruction’ below, even if this means my life is at risk. This does not necessarily mean withdrawal of life enhancing medication, as I would not want the withdrawal of any treatment which may reduce distress, provide pain relief or may adversely affect my quality of life.
- that any distressing symptoms, including any caused by inability to eat, drink or simply receive nutrition, are to be fully controlled by appropriate analgesic or other treatment, even though that treatment may shorten my life.
Detailed instruction

Insert your personal requests here in relation to the types of medical intervention you would find unacceptable (for example, artificial resuscitation and/or an artificial feeding tube inserted through the stomach wall). Continue on a separate sheet if necessary.

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................

........................................................................................................................................................
These problems may arise through a dementia related illness (which may or may not have been formally diagnosed) or any other condition of comparable gravity.

I consent to anything proposed to be done or omitted in compliance with the directions expressed above and I absolve my medical attendants from any civil liability arising out of such acts or omissions, provided they take due care in exercising their responsibility.

I reserve the right to revoke this decision at any time, but unless I do so it should be taken to represent my continuing directions.

My health and welfare attorney is/are (cross out if not applicable):

Name: ..........................................................................................................................................

Address: ......................................................................................................................................

Name: ..........................................................................................................................................

Address: ......................................................................................................................................

[Continue on a separate sheet if necessary]:

My general practitioner is:

Name: ..........................................................................................................................................

Address: ......................................................................................................................................

Postcode: ............................................ Telephone: .................................................................

Before signing this form I discussed these matters with my GP □:

Signed: .................................................. Dated: .................................................................
Witness statement

I testify that the maker of this advance decision signed it in my presence and made it clear to me that he/she understood what it meant. I do not know of any pressure being brought on him/her to make sure an advance decision and I believe it was made by his/her own wish. So far as I am aware I do not stand to gain from his/her death.

Witnessed by:  
Signed: ..............................................................
Dated: ..............................................................
Name: ..............................................................
Address: ..............................................................

Witnessed by:  
Signed: ..............................................................
Dated: ..............................................................
Name: ..............................................................
Address: ..............................................................