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 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 they can set out your wishes for your family to act on your behalf.

This factsheet is for people living in England and Wales. In Northern Ireland the laws about advance decisions are different. For information about the laws that relate to Northern Ireland see factsheet NI467, Financial and legal tips.

Advance decisions and advance statements are just one aspect of planning ahead. You might also want to give someone ‘power of attorney’, so they can make decisions on your behalf, or to think about putting your finances in order and making or updating a will. For more information on these see factsheets 472, Lasting power of attorney, and NI472, Enduring power of attorney and controllership.

For more on mental capacity and the ability to make decisions see factsheets 460, Mental Capacity Act 2005, and 484, Making decisions and managing difficult situations.
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 explain 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.

An advance statement provides an opportunity to ensure that your values and wishes 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 explain 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 difficult decisions away from your family, who otherwise may be asked by doctors for information about your wishes and values without having specific guidance from you.

For more information on planning for the future and a sample template for an advance statement, see booklet 1510, Planning ahead.
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 18 or over
- not have been made under pressure from other people
- if it relates to refusing life-saving treatment, be written down, be signed and witnessed and include a statement that it applies even if your life is at risk.
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.

Unless you want your advance decision 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.
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.

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, include the following information:

- your full name
- your address
- your date of birth
- any distinguishing features (e.g., 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 aged 18 or over. 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. It’s a good idea to state their relationship to you
- an explanation of the circumstances where you want your advance decision to apply – for example, it may say that you want to refuse the specified treatment only if you have a terminal illness
- the specific treatment/s 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 pressure from other people
- 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.
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 properly reflects your intentions. However, you must have mental capacity to make any changes.

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 your decision, 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 pressure from others, and so it was not valid
- you have done something clearly inconsistent with your advance decision
- there are reasonable grounds for believing that circumstances exist that you didn’t anticipate at the time of the advance decision and that would have affected your decision.

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.