

Factsheet 72

Advance decisions, advance statements and living wills

April 2017

About this factsheet

There are things you can do to make sure others know how you would like to be cared for and which medical treatment(s) you would want to refuse, if you are ever unable to make or communicate those decisions yourself.

Preparing an advance statement and an advance decision to refuse treatment (often simply called an advance decision or referred to as a *'living will'*) are two things you can do. This factsheet explains what they are, why you might want to prepare them, requirements for drawing them up and ways to ensure people know they exist.

If you want to know how to make arrangements for others to manage your affairs or make decisions on your behalf, should the time come when you are unable to do this yourself, see factsheet 22, *Arranging for someone to make decisions on your behalf*.

The information in this factsheet is applicable in England and Wales. If you are in Scotland or Northern Ireland, please contact Age Scotland or Age NI for their version of this factsheet.

Contact details for organisations mentioned in this factsheet can be found in the Useful organisations section.

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1 Making decisions about treatment and care

When you are ill, you can usually discuss treatment options with the doctor and jointly reach a decision.

However, there may be a time - on a temporary or permanent basis - when you are unable to make a treatment decision and/or express your wishes. For example you may be unconscious following an accident or a stroke, have a learning disability, or have Alzheimer's disease or other form of dementia.

You can make plans in advance for such eventualities by:

- making an **advance decision to refuse treatment** and/or
- making and registering a **Lasting Power of Attorney for health and care decisions**.

Similarly you may want to prepare an **advance statement of wishes and care preferences** to enable others to know what you would want and take it into account, if they must make decisions when caring for you and you are not be able to tell them yourself.

1.1 The role of *Mental Capacity Act 2005*

The *Mental Capacity Act 2005* (*the Act*) provides a legal framework to empower and protect people who cannot make specific decisions for themselves. It supports those with mental capacity to plan for the future, by giving legal status to an **advance decision to refuse treatment** and a **Lasting Power of Attorney**.

The supporting *Code of Practice* (*the Code*) gives guidance on applying *the Act* in everyday situations including how to:

- assess if someone lacks capacity to make a particular decision
- offer support that could help them make or communicate a decision
- reach a decision when a doctor, healthcare professional, family member or professional carer must make a best interests decision or act on another person's behalf.

You can find *the Act* at www.legislation.gov.uk/ukpga/2005/9/contents and *the Code* at www.gov.uk/government/publications/mental-capacity-act-code-of-practice

2 What is an advance decision to refuse treatment?

An advance decision to refuse treatment lets you, while you have mental capacity, make a decision about medical treatment(s) you would want to refuse, should you at some time in the future, '*lack mental capacity*' to decide and/or express your wishes when the decision needs to be made. An advance decision does not have to be in writing unless you want to refuse *life-sustaining* treatment. In this case it must be in writing, signed and witnessed, and state clearly that you wish it to apply, even if your life is at risk.

Note

An advance decision is legally binding as long as it complies with the *Mental Capacity Act* and is valid and applicable. See section 5.

For brevity we say 'advance decision' throughout the factsheet.

Others may use the term 'living will' but this is not a legally recognised term.

3 What is an advance statement?

An advance statement allows you to make more general statements, describing your wishes and preferences about future care should you be unable to make or communicate a decision or express your preferences at the time. You may want it to reflect your religious or other beliefs and important aspects of your life. You can include things such as food and drink preferences; type of clothes you like to wear; music, TV or DVD preferences or whether you like a bath to a shower. You can say who you would like to visit you or be consulted about your care.

It is helpful to write such information down, so people can refer to it if they want to know what is important to you and what you like.

You should state you have an advance statement when creating a Lasting Power of Attorney (LPA) health and care decisions, so your attorney(s) take it into account when deciding what is in your 'best interests'. See section 10 for more information about LPAs.

Note

An advance statement is not legally binding but should be taken into account by those making a 'best interests' decision on your behalf because you cannot tell them what you would like.

4 Why record your wishes in advance?

You may record your wishes in an advance decision, in an advance statement or in both. You may want to do this:

- when thinking about and making decisions about the future, in the same way as you might decide to make a will
- if you have a life-limiting illness and are discussing foreseeable healthcare problems as the illness progresses with your medical team or family
- to give you peace of mind and guide family members who may need to make decisions on your behalf or be consulted by a doctor who must make a 'best interests' decision on your behalf
- if you hold strong views about a situation that might arise in the future - such as having a limb amputated or medical treatment you would not want for religious reasons such as a blood transfusion.

You do not have to make an advance decision. You can leave it to the doctor to decide what is in your 'best interests'. In reaching a 'best interests' decision, a doctor should take account of evidence of your beliefs and past wishes and talk to your friends, family and carers where appropriate.

5 Making an advance decision

To make an advance decision, you must:

- be aged 18 or over and
- have the mental capacity to make an advance decision about treatment.

Test to determine mental capacity

For most people, there is no doubt about their capacity to make an advance decision. There is a two stage test if there are concerns about capacity:

- Stage 1 Do they have an impairment of the mind or brain, or is there some sort of disturbance affecting the way their mind or brain works?
- Stage 2 If so, does that impairment or disturbance mean they are unable to make the decision in question at the time it needs to be made after all practical and appropriate support to help them make the decision has been tried?

Answering 'yes' to both questions and recording why you believe this, would support a reasonable belief that someone 'lacks capacity' to make treatment decisions.

5.1 Are there things you cannot include in an advance decision?

You cannot include the following:

- to refuse basic care that is essential to keep you comfortable, such as nursing care, pain relief, keeping you warm
- to refuse the offer of food or drink by mouth
- to ask for anything that is against the law such as euthanasia or help to take your own life
- to demand specific medical treatment – no one can insist on treatment that healthcare professionals consider clinically unnecessary, futile or inappropriate
- to refuse treatment for a mental disorder if you are to be detained under the *Mental Health Act 1983*
- to refuse treatment when you still have capacity to make a decision.

5.2 Do I need to involve a doctor or solicitor?

You do not have to involve a doctor when making an advance decision but a doctor can:

- help you understand the consequences, advantages and disadvantages of what you are proposing
- help you phrase your wishes, so you avoid making unclear statements that could raise doubts in future about its applicability.

If you have a terminal illness, you may wish to talk to the medical team involved in your care. They can help you relate specific decisions to the likely course of your illness, understand the consequences of refusing or opting for a particular treatment and verify you had mental capacity at the time you prepared the advance decision.

Involving your GP or medical team means they record your wishes in your medical notes. Reviewing your advance decision as your illness progresses will ensure your notes accurately reflect your wishes. This can form part of a wider on-going discussion about your future care and preferences, often referred to as 'advance care planning'.

You do not have to take legal advice but a solicitor could help you express your wishes clearly.

5.3 Does an advance decision need to be in writing?

An advance decision only needs to be in writing if you want to refuse *life-sustaining* treatment. If you are not wanting to refuse *life sustaining treatment*, you would create a valid advance decision simply by telling your doctor you would not want a particular type of treatment in certain circumstances in the future. It is best practice for the doctor to confirm you understand the consequences of what you are asking and record this conversation in your medical records, along with details of anyone else present who heard what you said and their role in the conversation.

Putting it in writing and recording it in your medical notes avoids uncertainty over the validity of your advance decision and increases the likelihood that any doctor treating you is alerted to it.

There is no dedicated form to use if you want to put an advance decision in writing. Official guidance advises it is helpful to include the following:

- your full name, date of birth and address
- name, address and phone number of your GP and whether they have a copy of the document
- include a statement that the document should be used if you ever lack the capacity to make treatment decisions yourself
- clear statement of the decision, stating precisely what treatment(s) is to be refused. A statement with a general desire not to be treated is not enough. You may set out circumstances when the refusal should apply, as it is helpful to give as much detail as possible
- date the document was written (or reviewed)
- your signature or that of someone you directed to sign it in your presence, on your behalf and the date
- dated signature of person who witnessed your signature. If you cannot sign the document yourself, ask a second witness to sign to say they witnessed you asking someone else to sign on your behalf and saw this person sign the document in front of you.

You can ask your doctor or another relevant professional to sign a statement saying, in their opinion, you have mental capacity to make the decision. You may want to say you were not under any pressure to make the advance decision.

You could describe any distinguishing features such as a birthmark or tattoo as this would help identify you quickly if necessary.

5.4 If you want to refuse life-sustaining treatment

To be legally valid, an advance decision to refuse *life-sustaining* treatment must be in writing. *Life-sustaining* treatment is described as ‘*treatment that, in the view of the person providing health care to the person concerned, is necessary to sustain their life*’. Examples of *life-sustaining* treatment include being given food or drink by tube if you cannot take it by mouth, described by medical professionals as ‘artificial nutrition and hydration’; ventilation to help you breathe using a mechanical ventilator; or restarting your heart using cardiopulmonary resuscitation (CPR).

Although not compulsory, the Code states it is very important to discuss decisions to refuse *life-sustaining* treatment with a health professional.

As well as the recording details described in the list in section 5.3, it must include:

- a clear, specific written statement that the advance decision is to apply to the specific treatment even if life is at risk.

If you make the statement to refuse *life-sustaining* treatment at a different time or in a separate document to an advance decision, you (or someone you direct) must sign and date it in the presence of a witness, who must also sign it.

5.5 Must a doctor always follow an advance decision?

If you prepare an advance decision according to the requirements of *the Act*, it is legally binding and medical professionals must follow it, regardless of whether they believe it is in your ‘best interests’, if

- they are aware of it
- it is valid and
- it applies to the current situation.

For it to be **valid** – you must have been aged 18 or over and had mental capacity at the time you made it. Doctors must be sure you have not withdrawn it or clearly said or done something that goes against it which would suggest you have changed your mind.

They must be sure that since you made it, you have not made a Lasting Power of Attorney (LPA) for health and care decisions giving your attorney the power to make the same treatment decisions described in your advance decision. See section 10 for more about the relations between advance decisions and LPA’s.

For it to be **applicable** – it must apply to the situation in question and in current circumstances.

Doctors should consider whether there are new developments you did not anticipate at the time, which could have affected your decision; for example new developments in medical treatment or changes in your personal circumstances.

If there is doubt over the existence, validity or applicability of an advance decision, doctors can provide treatment they believe is in your 'best interests' while seeking further clarification. See section 8.

5.6 Ensuring others are aware of an advance decision

The Code says it is your responsibility to take steps to ensure your advance decision will be drawn to the attention of your GP and other doctors who treat you and where they can find it, and if it is written down.

There are several things you can do:

- let relatives or close friends know you have one and where it is
- ask for a copy to be placed in your GP and hospital records
- ask for a copy to be included in your Summary Care Record. You have one if you agreed for the NHS to create one from your GP record
- carry a card in your wallet that says you have one and where it is
- become a member of MedicAlert. Wearing ID specific jewellery alerts emergency professionals that you have vital information stored in a secure emergency personal record and how they can access it.

6 Reviewing your advance decision

Regularly reviewing your advance decision ensures it continues to reflect your views. Your particular circumstances and state of health may influence how frequently you do this. The doctor providing treatment must feel confident you have not changed your mind since making it. If there are new or improved medical treatments or your personal circumstances have changed, the doctor may question its validity if you signed it many years ago.

You can change an advance decision at any time while you have mental capacity to do so. Even if you do not change it, it is advisable to sign and date it to indicate that you have reviewed it and give a copy of the reviewed document to everyone who has an earlier copy.

7 How to withdraw an advance decision

You can cancel an advance decision at any time while you have capacity to do so. There is no formal process, so you can cancel it verbally or in writing and should destroy any written document. Tell everyone who knows you have an advance decision that you have cancelled it and put this in writing to avoid uncertainty. Healthcare professionals should record any verbal cancellation in your records for future reference.

8 Dealing with disagreements about an advance decision

The senior doctor or healthcare professional treating you is responsible for deciding whether there is a valid, applicable advance decision related to the current situation. If there is a dispute between professionals or between professionals and family members, this responsible person must consider all available evidence.

This means consulting relevant colleagues and others familiar with you, such as your GP. If they must make an urgent decision without delay, a doctor can apply to the Court of Protection. The Court of Protection can make a declaration on:

- whether you have mental capacity to make the decision at the time it must be made (if you do, the advance decision does not come into play)
- whether the advance decision is valid
- whether the advance decision is applicable to the particular treatment and circumstances.

The Court of Protection cannot overturn a valid and applicable advance decision. It cannot order treatment to be provided, if it has been refused in a valid advance decision.

For more on applying to the Court of Protection, see factsheet 22, *Arranging for someone to make decisions on your behalf*.

9 Advance decisions made before 1 October 2007

The part of *the Act* relating to advance decisions came into force on 1 October 2007. An advance decision made before then (often called an advance directive or living will) remains valid if it meets requirements described in section 5 and section 6. If it includes a wish to refuse *life-sustaining* treatment, it must include a statement that it is to apply even if your life is at risk.

10 Lasting powers of attorney

The *Mental Capacity Act 2005* replaced the Enduring Power of Attorney with a new system of Lasting Powers of Attorney (LPA).

In July 2015, the names of the two LPAs changed to:

- LPA for financial decisions and
- LPA for health and care decisions.

Note

You can still register an existing Enduring Power of Attorney.

You may still see references to the pre-July 2015 terms - LPA for property and financial affairs and LPA for health and welfare.

If you have or intend to have an advance decision to refuse treatment and a LPA for health and care decisions, it is important to consider their inter-relationship.

If **after creating an advance decision, you create a LPA for health and care decisions** that gives your attorney the authority to make treatment decisions that are the same as specified in the advance decision, the most recent document takes precedence. This means your advance decision, as it relates to the treatment in question, is invalid.

If you **create an LPA health and care decisions and later make an advance decision**, your attorney cannot give consent to any treatment refused in the advance decision, if it is decided the advance decision is valid and applicable, as described in section 5.

Making an LPA for health and care decisions

The fact you might have made an advance decision is recognised when you complete an LPA for health and care decisions application form (LP1H). Accompanying guidance notes (LP12) state if you have an advance decision you want doctors or your attorney(s) to take into account, you should refer to it when completing section 7 of the form. You must include a copy of the advance decision when you send your LPA to the Office of the Public Guardian to be registered.

You must specify in your LPA for health and care decisions if you want your attorney(s) to make decisions about *life-sustaining* treatment.

For information about LPA's, see factsheet 22, *Arranging for others to make decisions on your behalf*.

Useful organisations

Alzheimer's Society

www.alzheimers.org.uk

Telephone Helpline 0300 222 1122

Offers advice, information and support in England and Wales to people with dementia and their family. You can download their information sheet on preparing an advance decision together with a sample advance decision form from their website.

Court of Protection

www.gov.uk/courts-tribunals/court-of-protection

Telephone 0300 456 4600

It's role is to protect individuals who lack capacity and make rulings on difficult decisions about their care and welfare.

MedicAlert

www.medicalert.co.uk

Telephone 01908 951045

A registered charity that offers a way for emergency services to access medical information from a secure database when you are unable to share this information with them yourself.

Office of the Public Guardian

www.gov.uk/government/organisations/office-of-the-public-guardian

Telephone 0300 456 0300

The Office of the Public Guardian protects people in England and Wales who may not have the capacity to make certain decisions for themselves including about their health and finances. It supports the Public Guardian in carrying out the legal functions of the *Mental Capacity Act 2005*.

Age UK

Age UK provides advice and information for people in later life through our Age UK Advice line, publications and online. Call Age UK Advice to find out whether there is a local Age UK near you, and to order free copies of our information guides and factsheets.

Age UK Advice

www.ageuk.org.uk

0800 169 65 65

Lines are open seven days a week from 8.00am to 7.00pm

In Wales contact

Age Cymru

www.agecymru.org.uk

0800 022 3444

In Northern Ireland contact

Age NI

www.ageni.org

0808 808 7575

In Scotland contact

Age Scotland

www.agescotland.org.uk

0800 124 4222

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