

Factsheet 72

Advance decisions, advance statements and living wills

April 2020

About this factsheet

There are things you can do to make sure others know which medical treatments you would want to refuse and how you would like to be cared for, should a time come when you cannot make or communicate these decisions yourself.

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

If you want to know how to make arrangements for other people to manage your financial affairs, or make health and care decisions on your behalf, should you be 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 are at the back of this factsheet

Contact details for any organisation 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 usually discuss treatment options and their pros and cons with the doctor, to help you reach a decision. If you have mental capacity to make such a decision, a doctor must have your consent before providing treatment.

However, a time may come, on a temporary or permanent basis, when you are unable to make or communicate a decision about medical treatment at the time it needs to be made. For example, you may be unconscious following an accident or stroke, or develop Alzheimer's or other form of dementia. If concerned such a situation may arise in future, you can ensure your wishes are known and followed by making one or both of the following legally binding documents:

- an **advance decision to refuse treatment**
- a **Lasting Power of Attorney (LPA) for health and care decisions**.

You can also prepare an **advance statement of wishes and care preferences**. People caring for you could refer to this non-legally binding document, if they want to know your preferences and what you value, if you cannot tell them yourself.

1.1 The role of the *Mental Capacity Act 2005*

The *Mental Capacity Act 2005* (*'the Act'*) aims to empower and protect people who cannot make decisions for themselves. By giving legal status to an advance decision to refuse treatment, to a LPA for health and care decisions, and to a LPA for financial decisions, the *Act* supports people who have mental capacity to plan for the future. It also provides a legal framework and process to be followed by anyone making a *'best interests'* decision on your behalf.

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

- assess if someone lacks mental capacity to make a particular decision
- identify support that would help them make or communicate a decision
- reach a *'best interests'* decision as an appointed Attorney; as a health or social care professional when you must make a health or care decision on behalf of someone who lacks mental capacity without a valid LPA; or as family member or care worker who must make day-to-day decisions on their 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.

For information about the five principles on which the *Act* is based, see section 3.1 of factsheet 22, *Arranging for someone to make decisions on your behalf*.

2 What is an advance decision to refuse treatment?

An advance decision to refuse treatment lets you, while you have mental capacity, choose and explain which medical treatments you do not want doctors to give you, if a time comes when you lack capacity and cannot make the decision or communicate your wishes. If you want to refuse *life-sustaining* treatment, you must put this in writing, sign and date it in presence of a witness. See section 5.4 for more information.

Note

An advance decision to refuse treatment is time and decision-specific. It is only acted upon once it is decided, by following *Mental Capacity Act* principles, that you lack capacity to make a specific decision at the time it needs to be made.

It is legally binding if it complies with the *Act*, is valid and applicable.

For brevity we use '*advance decision*' throughout. You may hear the term '*living will*' but it is not a legally recognised term.

3 What is an advance statement?

An advance statement allows you to make 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 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 prefer a bath or a shower. You can say who you would like to visit you, or be consulted about your care.

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

When creating a Lasting Power of Attorney (LPA) for health and care decisions, let your chosen attorney(s) know if you have an advance statement. This alerts them to what you would want, if they must make decisions on your behalf. See section 10 for information about LPAs.

Note

An advance statement is not legally binding but those making a '*best interests*' decision on your behalf should take its contents into account when you cannot tell them what you would like.

4 Reasons to record your wishes in advance

You may want to record your health and care wishes in an advance decision, in an advance statement, or both:

- when thinking about and planning for the future
- if you have a life-limiting illness and are discussing your goals for care, and for managing foreseeable issues as your illness progresses
- if you want to maintain control over your medical treatment or hold strong religious or other views about a situation that may arise, such as needing to be fed by tube, have a limb amputated, or require a blood transfusion.
- to guide your Attorney should they need to make decisions on your behalf or to guide a partner, family, close friends, or care workers if they are asked what you would want.

5 Making an advance decision

To make an advance decision, you must:

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

Test to determine mental capacity

The law says you must be assumed to have capacity, unless it is proven otherwise. If there are concerns about your mental capacity to make a *particular* decision, the *Code* sets out a two stage test of capacity:

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

Being able to answer 'yes' to both questions and give reasons, would support a reasonable belief that you '*lack capacity*' to make the decision.

At the time you need to make a decision, you must to be able to understand it, why it needs to be made, and the consequences of making or not making it. You must be able to understand and retain information long enough to use it to make a decision and tell people what you want verbally, or by using a method appropriate to you. It is important people consider and offer you appropriate support to do this.

If you have not made an advance decision or appointed a LPA for health and care decisions, and are unable to make a particular decision at the time it needs to be made, it is the doctor responsible for your treatment who must decide what is in your '*best interests*'. In reaching a '*best interests*' decision, they must seek evidence of your beliefs and past wishes, including by talking to family, friends and carers.

5.1 Are there things an advance decision cannot include?

You cannot:

- choose to refuse basic care that is essential to keep you comfortable, for example nursing care, pain relief, keeping you warm
- choose to refuse the offer of food or drink by mouth
- ask for anything unlawful e.g. euthanasia or help to take your own life
- demand specific treatment. Healthcare professionals do not have to give treatment they consider clinically unnecessary, futile, or inappropriate
- refuse treatment for a mental disorder if you meet relevant criteria to be detained under the *Mental Health Act 1983*.

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, and
- help you phrase your wishes, so you avoid making unclear statements that could raise doubts about its applicability in the future.

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

You do not have to take legal advice but a solicitor could help you express your wishes clearly, using wording that complies with provisions of the Act. Check whether you will be charged if you do request assistance from a doctor or a solicitor before taking action.

Terminal illness

If you have a terminal illness, talking to your medical team can help you:

- look at specific treatments in the light of the likely course of your illness
- understand the consequences of refusing or opting for a particular treatment, and
- verify you had mental capacity when you prepared the advance decision.

Insurance policies

If you intend to make an advance decision to refuse *life-sustaining treatment* and have a life insurance policy, check with the insurance company, as there is a risk it may affect your policy. If you have any doubts or concerns, it is advisable to take appropriate legal advice.

5.3 Does an advance decision need to be in writing?

If the treatment you want to refuse is not life-sustaining, you can create a valid advance decision simply by telling your doctor which treatments and under what circumstances you would not want them in the future. An advance decision only needs to be in writing if you want to refuse '*life-sustaining*' treatment, see section 5.4.

It is best practice, for the doctor to confirm you understand the consequences of what you are asking and record the conversation in your records, along with details of other people present and their role in the conversation. Recording it in this way increases the likelihood that any doctor treating you is alerted to it, and avoids uncertainty over whether what you have directed is valid. As explained in section 6, you should review it to ensure it continues to reflect your wishes.

There is no dedicated form to use if you want to put an advance decision in writing. There is a free online tool at <https://mydecisions.org.uk> that can help you draft an advance decision. The *Code* advises it is helpful to include the following in a written advance decision:

- 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
- a statement that the document should be used if you ever lack the capacity to make treatment decisions yourself
- a clear statement of the decision, stating precisely what treatments you want to refuse and the circumstances under which the decision is to apply. Aim to make it clear to anyone reading the document what your wishes are. A statement with a general desire not to be treated is not enough. It is helpful to give as much detail as possible to support any discussion about the '*applicability of your advance decision*' as explained in section 5.5. Avoid using words like '*unbearable*' or '*severe*' that are open to interpretation.
- date the document was written (if reviewing it, see section 6)
- 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, 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

Remember to keep a record of people you give a copy to.

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. Describe any distinguishing features, such as a birthmark or tattoo, if this helps 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, signed, and witnessed.

Life-sustaining treatment is treatment that, in the view of the person providing your healthcare, is necessary to keep you alive.

Examples of *life-sustaining* treatment include: being given food or drink by tube if you cannot take it by mouth (doctors call this '*artificial nutrition and hydration*'); kidney dialysis; organ transplant; chemotherapy or other cancer treatment; using a machine to help you breathe; restarting your heart using CPR (cardiopulmonary resuscitation).

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

As well as recording details described in section 5.3, you must include:

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

If you make an advance decision to refuse *life-sustaining* treatment at a different time, or in a separate document to another advance decision, you (or someone you direct) must sign and date it in the presence of a witness, who must also sign and date 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. If medical professionals believe you lack capacity to make a decision about treatment covered in your advance decision, having followed the process in section 5 to determine mental capacity, they must follow your wishes, regardless of whether they believe it is in your '*best interests*', if:

- they are aware of your advance decision
- it is valid, and
- it applies to the current situation.

Valid

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 created a Lasting Power of Attorney (LPA) for health and care decisions that gives your attorney the power to make the same treatment decisions described in the advance decision. See section 10 for more about the relationship between advance decisions and LPA for health and care.

Applicable

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 clarification. See section 8 for more information.

5.6 Ensuring others are aware of an advance decision

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

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 added to your Summary Care Record (SCR) as additional information. You have a SCR if you agreed for the NHS to create one from your GP record. Staff in A&E departments can securely access your SCR if you arrive there unable to speak to them
- carry a card saying you have an advance decision and where it is
- become a member of MedicAlert. Wearing their 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

You should regularly review your advance decision to ensure it continues to reflect your views, and to help doctors providing treatment feel confident you have not changed your mind since making it. Your state of health and circumstances may influence how frequently you do this.

A doctor may question the validity of an advance decision signed many years ago, if there are new or improved treatments, or your personal circumstances have significantly changed.

Even if you do not change the contents, it is advisable to say 'you have reviewed it', and sign and date it.

If you want to change the contents, it is advisable to write, sign, and date a new document, saying it overrides any previous document. To amend a refusal of *life-sustaining treatment*, you must make the change in front of a witness, who must sign and date the document in front of you. If you review your advance decision, give a copy of the latest document to anyone with an earlier copy and ask them to destroy the old one.

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. You should destroy any written document.

Tell everyone who knows you have an advance decision that you have cancelled it. Put this in writing to avoid uncertainty. Healthcare professionals should record a verbal cancellation in your records for future reference.

8 Dealing with disagreements

The senior doctor or healthcare professional treating you is responsible for deciding whether there is a valid, applicable advance decision relating 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)
- the advance decision is valid
- 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 section 11 of 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 sections 5 to 5.5. 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.

If you made an advance decision before or around the time the *Act* came into force and have not reviewed it, it is important to review, sign and date it as described in section 6. This ensures it reflects your current wishes and reduces the risk of a doctor questioning its validity.

10 Lasting powers of attorney

The *Mental Capacity Act 2005* introduced the system of Lasting Powers of Attorney (LPA) which replaced the Enduring Power of Attorney (EPA). Under *the Act* you can make a

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

Note

An EPA only covers money and property but you can still register an EPA made and signed before 1 October 2007. After that date, you were required to make a LPA for financial decisions.

You may see the terms LPA for property and financial affairs and LPA for health and welfare. These terms were in use until July 2015.

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

Advance decision created after LPA

If you **create an advance decision after creating an LPA for health and care**, your attorney cannot 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.

Advance decision created before LPA

If you **create an LPA for health and care after creating an advance decision**, whichever was made more recently takes priority should they deal with the same decision.

Making an LPA for health and care decisions

It is recognised you might have made an advance decision when completing LPA for health and care decisions application form (LP1H).

Part A5 in accompanying guidance notes (LP12) states if you have an advance decision you want doctors or your attorney(s) to take into account, you must 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 section 4 of 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.

Court of Protection

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

Telephone 0300 456 4600

Its role is to protect individuals who lack capacity. This includes making rulings on urgent or emergency decisions or contested 'best interests' decisions about their care and welfare, and appointing deputies to act on their behalf.

Macmillan Cancer Support

www.macmillan.org.uk

Telephone 0808 808 0000

Provides information, advice and financial support for people facing cancer, their carers and loved ones. They produce an advance decision to refuse treatment document and a booklet '*Planning ahead for the end of life*'.

MedicAlert

www.medicalert.org.uk

Telephone 01908 951045

A non-profit, membership organisation 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 Advice

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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