factsheet

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Age Concern and Help the Aged

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Advance decisions, advance statements and living wills

About this factsheet

Advance decisions (sometimes referred to as 'living wills') and advance statements are two ways to make sure others, including doctors, know your wishes about your health and care. Drawing up one or both can provide reassurance in case a time comes when you cannot make choices and decisions about them yourself. This factsheet explains the difference between them, how to draw them up and the legal status of an advance decision to refuse treatment under the *Mental Capacity Act 2005*.

See Age UK's Factsheet 22, *Arranging for someone to make decisions on your behalf* for other information about 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.

The information given in this factsheet is applicable in England and Wales only. Different rules apply in Northern Ireland and Scotland. Readers in these nations should contact their respective national Age UK organisation for information specific to where they live – see section 13 for details.

For details of how to order other Age UK factsheets and information materials go to section 13.

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1 The *Mental Capacity Act 2005*

The *Mental Capacity Act 2005* provides a legal framework to empower and protect people who, on a permanent or temporary basis, cannot make specific decisions for themselves. It also describes the process that doctors and other healthcare staff, family and professional carers should follow when they must make decisions or act on another person's behalf.

The Act also enables you to plan ahead, in case you are unable to make important decisions about medical treatment in the future. One way you can do this is to make an 'advance decision' or as it is formally known 'an advance decision to refuse treatment'.

The *Mental Capacity Act Code of Practice* gives guidance on how the Act should work in everyday situations. Among other things, it explains how to assess whether someone lacks capacity to make a particular decision, how to provide support that could help them make or communicate a decision and what it means to act in the 'best interests' of someone unable to make a decision for themselves.

2 Mental capacity to make your own treatment decisions

When you are ill, you can usually discuss treatment options with your doctor and then jointly reach a decision about your future care.

However, you may be admitted to hospital when unconscious or unable, on a temporary or permanent basis, to make treatment decisions or communicate your wishes. This may be the case if you have a learning disability, or are unconscious following a car accident or a stroke or have Alzheimer's disease or another form of dementia. To use the legal term – you would 'lack mental capacity'[1] to make an informed decision and/or communicate your wishes. If a doctor is confident that you lack mental capacity to make a particular decision at the time it needs to be made, he or she has a legal and ethical obligation to act in your 'best interests'.

[1] A person lacks capacity if he or she is unable to make or communicate a decision about a particular matter because of an impairment of, or a disturbance in, the mind or the brain.

One exception to this is if you have made an 'advance decision to refuse treatment'. The other is if you have made a Lasting Power of Attorney (health and welfare). The latter is explained in Age UK's Factsheet 22, *Arranging for someone to make decisions on your behalf.* See section 13.

3 What is an advance decision?

An advance decision offers a way for you to make a decision now, about a specific medical treatment you would want to refuse in the future.

If you prepare an advance decision according to the requirements of the *Mental Capacity Act 2005*[2] and it is found to be valid and to apply to the current circumstances, medical professionals providing your care are bound to follow your wishes. This is the case regardless of whether the doctors believe it is in your best interests. See section 6 for information about preparing an advance decision.

An advance decision does not have to be in writing but if you want to refuse life-saving treatment, it must be in writing, must be signed and witnessed, and state clearly that you wish it to apply, even if your life is at risk.

3.1 What an advance decision cannot do

An advance decision cannot be used:

- to refuse treatment when you still have the capacity to make the decision yourself
- to demand specific medical treatment. No one - at the time or in an advance decision - can insist on being given medical treatment that healthcare professionals consider clinically unnecessary, futile or inappropriate
- to refuse treatment for a mental disorder should you be detained under the *Mental Health Act 1983*
- to refuse basic care that is essential to keep you comfortable, such as washing

[2] http://www.legislation.gov.uk/ukpga/2005/9/contents

- to refuse the offer of food or drink by mouth. You can refuse being given food or fluid by tube, referred to as artificial nutrition and hydration, as this is a form of medical treatment
- to refuse measures such as pain relief that simply aim to keep you comfortable
- to ask for anything that is against the law such as euthanasia or help to take your own life.

3.2 Does a doctor always have to follow an advance decision?

Healthcare professionals must follow an advance decision if they are aware of it and it is valid and applicable to the current situation. So it is important to take steps to make sure that your GP or other doctors who might treat you will be aware of it at the relevant time. You could ask for a copy of your decision to be placed in your medical records.

Valid – this means you must have been over 18 and had mental capacity to make the advance decision at the time you made it. Doctors must be sure that you have not withdrawn it or clearly done something that goes against it and so suggests you've changed your mind. They must also be sure that since you made it, you have not made a Lasting Power of Attorney (health and welfare) that gives your attorney the power to make the same treatment decisions described in your advance decision.

Applicable – this means an advance decision must apply to the situation in question and in the current circumstances.

Doctors should consider whether there are any new developments that you didn't anticipate when you made your decision, which could have affected your decision; for example new developments in medical treatment or changes in your personal circumstances.

Professionals can provide treatment they believe is in your best interests if they are in doubt over the existence, validity or applicability of an advance decision.

The *Mental Capacity Act 2005 Code of Practice*[3] explains in more detail how doctors should decide if an advance decision is valid and applicable.

[3] https://www.gov.uk/government/collections/mental-capacity-act-making-decisions

4 What is an advance statement?

An advance statement allows you to make more general statements describing your wishes and preferences about future treatment and care. It can reflect your religious or other beliefs or any aspects of life that you particularly value.

Note: An advance statement is not legally binding but staff should take it into account if they need to make a 'best interests' decision on your behalf when you are unable to tell them what you would like.

An advance statement can describe where you would prefer to live and how you would like to be supported if unable to care for yourself. It could include things such as the type of clothes you like to wear, your food preferences, your music, TV or DVD preferences or whether you prefer a bath to a shower.

It can be made verbally but if you write it down, it can act as a permanent record for people treating you to refer to, so they know what you like. You could also say who you want to be consulted if a time comes when you are unable to make or communicate a decision or express a preference yourself.

If you create a Lasting Power of Attorney (LPA) health and welfare, you could state that you have prepared an advance statement. Your attorney(s) must take your advance statement into account when deciding what is in your best interests. See section 11 for more information about LPAs.

5 Why record your wishes in advance?

There are a number of reasons why you may wish to record your wishes in advance:

- as part of thinking about and making decisions about the future, in the same way as you might decide to make a will
- to give you peace of mind and take the burden away from family members who may need to make such decisions on your behalf or maybe asked by those charged with making a 'best interests' decision on your behalf

- if you hold strong views about a particular situation that might arise in the future - such as the need to have a limb amputated, or medical treatment you would not wish to be given for religious or other reasons such as a blood transfusion
- if you have been diagnosed with a life-limiting illness and you are discussing the future with your medical team or your family.

You do not have to make an advance decision to refuse treatment. You may want to leave it to the healthcare professionals to decide what is in your 'best interests' should you be unable to make such decisions yourself. When deciding this, they should take account of any evidence of your past wishes, your beliefs and values and they should consult your friends, family and carers where appropriate.

6 Making an advance decision to refuse treatment

You can only make an advance decision if you are over the age of 18 and have the mental capacity to do so. To have mental capacity means you must be able to understand, weigh up and retain the relevant information to make the decision to refuse treatment and be able to communicate that decision, with support if necessary. In most cases it will be obvious that you have capacity but the *Mental Capacity Act 2005* describes a test to use if there is any doubt.

6.1 Do I need to involve a doctor or solicitor

As you want to make a decision about refusing certain medical treatment in the future, it is advisable to discuss this with your GP. A GP can help you understand the consequences, advantages and disadvantages of what you are proposing. A GP can help you phrase your wishes, so you don't make unclear statements that raise doubts about its applicability in the future.

If you have a terminal illness, you may wish to discuss making an advance decision with the medical team involved in your care. They can help you understand the consequences of refusing or opting for a particular treatment and relate specific decisions to the likely course of your illness. They can also help you express your wishes clearly and verify you were competent at the time you prepared it.

If you send a written copy of your advance decision to your GP and/or medical team, they can include it in your notes. You can revisit it as your illness progresses to ensure it still reflects your wishes. See section 7.

You do not have to involve a solicitor when drawing up an advance decision. While not having the expertise to help you understand the consequences of what you are proposing, a solicitor could help ensure you express your wishes clearly.

6.2 Does an advance decision need to be in writing?

An advance decision does not have to be in writing, unless it is a decision to refuse life-sustaining treatment.

Verbal instructions can amount to a valid advance decision but there is more risk that they would not be carried out. The person providing treatment must know you have one, at the time a treatment decision needs to be made.

If you say during a discussion with your doctor that you would not want a particular type of treatment in certain circumstances in the future, this can be a valid advance decision. It would be best practice for the doctor to confirm you understand the consequences and to record this in your medical records, along with details of anyone else present who heard what you said and their role in the conversation.

Putting your advance decision in writing will avoid uncertainty over its validity. You could ask someone else to write it down for you if you cannot do it yourself.

There is no dedicated form for making an advance decision because contents will vary depending on an individual's wishes and situation. The *Mental Capacity Act Code of Practice* says it is helpful to include the following:

- your full name, date of birth and address;
- the 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 decision yourself;
- a clear statement of the decision, the treatment to be refused and circumstances in which it will apply, giving 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;
- the 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 could ask your doctor or another relevant professional to sign a statement in the document stating that in their opinion, you have the mental capacity to make the decision. You may also want to say that you were not under any pressure to make the advance decision.

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

6.3 How to make an advance decision to refuse life-sustaining treatment.

To make an advance decision to refuse life-sustaining treatment, it must meet requirements set out in the *Mental Capacity Act*. The Act describes life-sustaining treatment as 'treatment that, in the view of the person providing health care to the person concerned, is necessary to sustain their life'. This could include artificial nutrition and hydration to someone who cannot eat or drink by mouth.

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

To be legally valid, an advance decision to refuse life-sustaining treatment must be in writing. As well as the details given in the bulleted list in section 6.2 it must also 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 this statement to refuse life-sustaining treatment is made at a different time or in a separate document to an advance decision to refuse treatment, you (or someone you direct) must sign it in the presence of a witness, who must also sign it.

7 Reviewing your advance decision

It is important for the people providing your treatment to feel confident that you have not changed your mind since you made your advance decision. If new or improved medical treatments are now available or your personal circumstances have changed, its validity may be questioned if you signed it many years ago. You will also want to check it on a regular basis to be sure it continues to reflect your views.

It is therefore advisable to review your advance decision and make changes if you wish. You can change your advance decision at any time while you still have capacity to do so. Even if you don't change it, you should sign and date it and indicate that you have reviewed it. Your particular circumstances and state of health could influence how frequently you do this. Make sure you give a copy of the reviewed document to all who have an earlier copy.

8 How to withdraw an advance decision

You can cancel or alter an advance decision at any time while you still have capacity to do so. There is no formal process to follow. You can cancel it verbally or in writing and can destroy any written original document. Where possible you should tell all who knew you had made one that you have cancelled it. Putting this action in writing will avoid any uncertainty.

9 Dealing with disagreements about an advance decision

The senior healthcare professional treating you is responsible for making the decision as to whether there is a valid, applicable advance decision that relates to the current situation. If there is a dispute over this – and for example an urgent decision about treatment is required without delay - the doctor can make an application to the Court of Protection.

The Court of Protection can make a declaration on:

- whether the person has mental capacity to make the decision themselves at the time it must be made (in which case, 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. Therefore it cannot order that treatment should be provided, if this has been refused in a valid advance decision.

See Age UK's Factsheet 22, *Arranging for someone to make decisions on your behalf* for details of how to make an application to the Court of Protection. See section 13.

10 Advance decisions made before 1 October 2007

The part of the *Mental Capacity 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) will be valid if it meets requirements set out in the Act, as described in 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.

The normal requirements regarding validity and applicability must be met.

11 Lasting powers of attorney

The *Mental Capacity Act 2005* brought in a new system of Lasting Powers of Attorney (replacing Enduring Power of Attorney).

In July 2015, the two power of attorney names were changed to:

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

Note: You may still see the old names used in various places: LPA for property and financial affairs and LPA for health and welfare.

If you **create an advance decision to refuse life-sustaining treatment and later create a LPA health and care** that gives your attorney the authority to make treatment decisions that are the same as those covered by the advance decision it will make that advance decision invalid.

If you **create a health and care LPA and later make an advance decision to refuse treatment or to refuse life-sustaining treatment,** the advance decision overrules any powers you gave your attorney to refuse medical treatment or lifesaving medical treatment, if it is decided that this advance decision is 'valid and applicable. See section 3.2.

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

The fact you may have made an advance decision is recognised when you complete an LPA for health and care decisions application form (LP1H). This is discussed in section A5 of the separate guidance notes (LP12). The notes say if you have made an advance decision that your doctors or attorneys should take into account, you should refer to it when completing section 7: Preferences and instructions, on the form. You must also include a copy of the advance decision when you send your LPA to the Office of the Public Guardian (OPG) to be registered.

For information about powers of attorney see factsheet 22*, Arranging for others to make decisions on your behalf* for details of how to make an LPA. Contact the Office of the Public Guardian for an LPA application pack or go to their website to make your application online. See 'useful organisations'.

12 Useful organisations

Alzheimer's Society

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.

Devon House, 58 St Katherine's Way, London, E1W 1LB
Helpline: 0300 222 1122
Tel: 020 7423 3500
Email: enquiries@alzheimers.org.uk
Website: www.alzheimers.org.uk

Office of the Public Guardian

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*.

PO Box 16185, Birmingham B2 2WH
Tel: 0300 456 0300
Email: customerservices@publicguardian.gsi.gov.uk
Website: www.gov.uk/government/organisations/office-of-the-public-guardian

13 Further information from Age UK

Age UK Information Materials

Age UK publishes a large number of free Information Guides and Factsheets on a range of subjects including money and benefits, health, social care, consumer issues, end of life, legal, employment and equality issues.

Whether you need information for yourself, a relative or a client our information guides will help you find the answers you are looking for and useful organisations who may be able to help. You can order as many copies of guides as you need and organisations can place bulk orders.

Our factsheets provide detailed information if you are an adviser or you have a specific problem.

Age UK Advice

Visit the Age UK website, www.ageuk.org.uk, or call Age UK Advice free on 0800 169 65 65 if you would like:

- further information about our full range of information products
- to order copies of any of our information materials
- to request information in large print and audio
- expert advice if you cannot find the information you need in this factsheet
- contact details for your nearest local Age UK

Age UK

Age UK is the new force combining Age Concern and Help the Aged. We provide advice and information for people in later life through our, publications, online or by calling Age UK Advice.

Age UK Advice: 0800 169 65 65
Website: www.ageuk.org.uk

In Wales, contact:
Age Cymru: 0800 022 3444
Website: www.agecymru.org.uk

In Scotland, contact:
Age Scotland: 0845 125 9732
Website: www.agescotland.org.uk

In Northern Ireland, contact:
Age NI: 0808 808 7575
Website: www.ageni.org.uk

Support our work

Age UK is the largest provider of services to older people in the UK after the NHS. We make a difference to the lives of thousands of older people through local resources such as our befriending schemes, day centres and lunch clubs; by distributing free information materials; and taking calls at Age UK Advice on 0800 169 65 65.

If you would like to support our work by making a donation please call Supporter Services on 0800 169 87 87 (8.30 am–5.30 pm) or visit www.ageuk.org.uk/donate

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