

Factsheet 72 ● November 2011

Advance decisions, advance statements and living wills

About this factsheet

This information sheet explains the law on 'living wills'. A living will is a statement expressing your views on how you would or would not like to be treated if you are unable to make decisions about your treatment yourself at the relevant time in the future.

Advance decisions and advance statements are the formal names for the two different types of 'living will'. This factsheet explains the difference between the two types, how to make one and when they will be legally binding.

For information about the other parts of the *Mental Capacity Act 2005*, including Lasting Powers of Attorney, Deputies and Independent Mental Capacity Advocates, see Age UK's Factsheet 22 *Arranging for others to make decisions about your finances or welfare*.

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 15 for details.

For details of how to order other Age UK factsheets and information materials go to section 15.

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1 Advance decisions under the *Mental Capacity Act*

The *Mental Capacity Act 2005* provides a legal framework to help empower people to make their own decisions and to make clear what actions carers and family can take. It puts the law on advance decisions (or living wills) on a clear statutory basis for the first time. The rules relate particularly to advance decisions to refuse treatment, including refusal of life-sustaining treatment.

There is a Code of Practice to the *Mental Capacity Act*, which gives guidance on how it should work in everyday situations. Among other things, it explains how to assess whether someone lacks capacity to make a particular decision, and what it means to act in someone's best interests. Anyone dealing with an advance decision, especially medical staff providing care to someone who has made an advance decision, should have regard to the Code of Practice. See section 14 and the Office of the Public Guardian for more details.

2 'Living wills'

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 your own decisions about your treatment or communicate your wishes. This may happen, for example, if you have a car accident, a stroke or develop dementia. To use the legal term – you would 'lack mental capacity' to make an informed decision and/or communicate your wishes. In such situations, doctors have a legal and ethical obligation to act in your best interests. One exception to this is if you have made an advance decision refusing treatment. If this decision is valid and applicable to the circumstances, medical professionals providing your care are bound to follow it – whether or not they think it is in your best interests.

The term 'living will' doesn't have a legal meaning but can be used to refer to either an advance decision or an advance statement. An advance decision is a decision to refuse treatment; an advance statement is any other decision about how you would like to be treated.

Only an advance decision is legally binding, but an advance statement should be taken into account when deciding what is in your best interests.

3 What is an advance statement?

This is a general statement of your wishes and views. It allows you to state your preferences and indicate what treatment or care you would like to receive should you, in the future, be unable to decide or communicate your wishes for yourself. It can include non-medical things such as your food preferences or whether you would prefer a bath to a shower.

It could reflect your religious or other beliefs and any aspects of life that you particularly value. It can help those involved in your care to know more about what is important to you. It must be considered by the people providing your treatment, when they determine what is in your best interests, but they are not legally bound to follow your wishes.

Advance statements can also be used to let the people treating you know who you would like to be consulted when a decision has to be made, if you are unable to make that decision yourself.

If you create a Lasting Power of Attorney (LPA), you could record an advance statement in the LPA document. An LPA can be used if you want to give someone else, or more than one person, the power to make decisions about your care and treatment if you are not able to do so yourself. Your attorney(s) must take your advance statement into account when deciding what is in your best interests. See section 12 for more information about LPAs.

4 What is an advance decision to refuse treatment?

An advance decision to refuse treatment is the only type of living will that is legally binding.

An adult with mental capacity can refuse treatment for any reason, even if this might lead to their death. However, no one is able to insist that a particular medical treatment is given, if it conflicts with what the medical professionals providing the treatment conclude is in the patient's best interests. This is why an advance decision can only be a refusal of treatment.

An advance decision to refuse treatment must indicate exactly what type of treatment you wish to refuse and should give as much detail as necessary about the circumstances under which this refusal would apply. It is not necessary to use precise medical terms, as long as it is clear what treatment is to be refused in what circumstances.

An advance decision can only be made by someone over the age of 18 who has the mental capacity to make the decision. This means they must be able to understand, weigh up and retain the relevant information to make the decision to refuse treatment; and they must then be able to communicate that decision.

4.1 **How to make an advance decision to refuse treatment**

An advance decision does not have to be in writing, unless it is a decision to refuse life-sustaining treatment (see the next section below for the legal requirements for this type of decision).

Verbal instructions can amount to a valid advance decision but there is more risk that a verbal refusal of treatment would not be carried out. The person providing treatment may not be aware of it, or there could be uncertainty about its validity or applicability.

For example, a statement made by a patient during a discussion with their doctor that they would not wish to have a particular type of treatment in certain circumstances in the future can be a valid advance decision even if it is not put in writing. It would be best practice for the doctor to record the statement in the patient's medical records, but it can still be valid if this is not done. Even if you are putting your advance decision in writing yourself, it is a good idea to discuss it with your doctor.

To avoid uncertainty over the validity of an advance decision you should put it in writing, or ask someone else to write it down for you if possible. The following guidelines could be helpful.

- Put the decision in writing.
- Include your name, date of birth, address and details of your GP.
- Include a statement that you wish the advance decision to apply if you lack the capacity to make the decision yourself at the relevant time.
- Specify what kind of treatment is to be refused and in what circumstances, giving as much detail as possible.
- Sign and date the document.
- Ask someone to witness your signature.

- You could ask your doctor or another relevant professional to sign a statement on the document stating that they have carried out an assessment of you and, in their opinion; you have the mental capacity to make the decision.

Remember that the above points are not legal requirements, but they can help to avoid uncertainty over the validity and applicability of your advance decision. There are legal requirements if you are making an advance decision to refuse life-sustaining treatment. See below for details of these.

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

If you want to make an advance decision to refuse life-sustaining treatment, it must meet certain requirements set out in the *Mental Capacity Act*. Life-sustaining treatment is defined in the Act 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.

The legal requirements for a valid advance decision to refuse life-sustaining treatment are as follows.

- The decision must be in writing. You can ask someone else to write it down if you can't do it yourself.
- You must sign the document. You can instruct someone to sign it on your behalf in your presence if you can't sign it yourself.
- Your signature (or the signature of the person signing on your behalf) must be witnessed. The witness must also sign the document in your presence.
- You must include a written statement that the advance decision is to apply to the specific treatment even if your life is at risk.

5 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 that date can still be valid if it meets the requirements set out in the Act.

If you made an advance decision refusing life-sustaining treatment before 1 October 2007, you should review it to make sure it meets the requirements of the *Mental Capacity Act* (see the previous section). It is likely that many such advance decisions will not meet those requirements; in particular, your decision must include a statement that it is to apply even if your life is at risk. You should remake your decision if your original decision does not meet the requirements of the *Mental Capacity Act*.

There are transitional arrangements for people who made an advance decision to refuse life-sustaining treatment before 1 October 2007 but who have since lost the mental capacity to remake that decision.

A decision made before 1 October 2007 which does not meet the requirements (to be signed and witnessed and to include a statement that it will apply even if your life is at risk) can still be valid and applicable if:

- it is in writing
- the person providing the treatment has a reasonable belief that the advance decision was made before 1 October 2007, and
- the person providing the treatment has a reasonable belief that the person making the advance decision has lacked capacity to amend it since 1 October 2007.

The normal requirements regarding validity and applicability (see below) must also be met.

6 Deciding if an advance decision is valid and applicable

You should take steps to make sure that the people providing your treatment will be aware of your advance decision at the relevant time. This could mean discussing it with your GP, or other treating doctors, while you still have capacity to do so, and making sure that a copy of your decision is kept in your medical notes. It would also be helpful to make sure that your family and friends are aware of the decision. If the person providing your treatment is aware of your advance decision, they must then consider whether it is valid and applicable to the particular circumstances.

When deciding whether an advance decision is **valid**, the person providing the treatment should try to find out:

- if you have withdrawn the decision since you made it, at a time when you had the mental capacity to do so
- if you have done anything which is inconsistent with the decision and suggests that it no longer represents your wishes or
- if you have since made a Lasting Power of Attorney, giving someone else the authority to make the decision consenting to or refusing the particular treatment.

When deciding whether an advance decision is **applicable** to the particular circumstances, the person providing the treatment must:

- assess whether you actually still have mental capacity to make the particular decision about your treatment at the time it has to be made (they must start from the assumption that you have capacity and the advance decision will only be relevant if there is evidence that this is not the case)
- check that the treatment and circumstances are the same as those referred to in the decision
- 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 providing your medical treatment are protected from liability for not providing treatment if they reasonably believe there is a valid and applicable advance decision.

They can provide treatment if they are in doubt over the existence, validity or applicability of an advance decision, and they are again protected from liability.

7 Why make an advance decision?

You may wish to make an advance decision if you have strong feelings about a particular situation that could arise in the future. This might relate to having a limb amputated following an accident or having a blood transfusion.

More commonly, you may have been told that you have a terminal illness or form of dementia. You may wish to prepare an advance decision indicating the type of treatment you would not want to receive in the future. Making an advance decision may give you peace of mind knowing that your wishes should not be ignored if you are unable to take part in the decision-making process at the relevant time.

Considering making an advance decision provides an opportunity to talk to and ask questions of your medical team during the early stages of an illness rather than delaying it until it is more difficult to participate. It can also provide an opportunity to discuss what may be difficult issues with family and friends.

You do not have to make an advance decision. You may decide to leave it to the healthcare professionals providing your treatment to decide what is in your best interests. When deciding this, they should take into account any evidence they have of your past wishes, your beliefs and values; and they should consult your friends, family and carers where appropriate. They may decide that what is in your best interests is not the same as what you would have decided to do yourself.

8 What an advance decision cannot be used for

An advance decision cannot be used to:

- ask for anything that is illegal such as euthanasia or help to commit suicide
- demand care the healthcare team considers inappropriate in your case
- refuse the offer of food and drink by mouth
- refuse the use of measures solely designed to maintain your comfort such as providing appropriate pain relief, warmth or shelter
- refuse basic nursing care that is essential to keep you comfortable such as washing, bathing and mouth care.

9 Who to consult about an advance decision

It is not necessary to involve a solicitor, although you may wish a solicitor to confirm that your views are clearly presented in the document.

It is always advisable to discuss your intentions with a medical professional, such as your GP, and your family and friends.

If you have a terminal illness, you may wish to speak to the doctor involved in your care about making an advance decision. He or she 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. This doctor can also help you express your wishes clearly and verify you were competent at the time you prepared and signed the document.

10 **Reviewing your advance decision**

It is important for the people providing your treatment to feel confident that you have not changed your mind since your advance decision was made. 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.

Therefore a regular review, after which you sign and date that you have reviewed it, is advisable. The frequency with which you do this will depend on your particular circumstances and state of health. Make a note of who has copies of your advance decision so you can tell them if you revise it.

You can change your advance decision at any time while you still have capacity to do so. This can either be verbally or in writing (unless it is a decision to refuse life-sustaining treatment), but to avoid uncertainty it is advisable to record the changes in writing if possible. Any changes to an advance decision to refuse life-sustaining treatment must be in writing and follow the legal requirements mentioned above.

11 How to cancel an advance decision

You can cancel an advance decision at any time while you still have capacity to do so. The cancellation does not have to be in writing; a verbal statement cancelling the decision should be respected. To avoid the risk that the relevant people do not know you have cancelled your decision, it is advisable to put the cancellation in writing, if possible, and to inform everyone who was aware of the decision's existence. You should destroy the original document, or mark on it that it has been withdrawn.

12 Lasting powers of attorney

The *Mental Capacity Act* brought in a new system of Lasting Powers of Attorney (replacing the Enduring Power of Attorney). An Enduring Power of Attorney could only relate to your financial affairs, whereas there are two types of Lasting Powers of Attorney (LPA) – a LPA property and affairs and a LPA personal welfare. If you set up an LPA personal welfare, you can choose who should make decisions about your care or treatment if you are not able to do so yourself. There is a section in the personal welfare LPA document where you can specify if you want your attorney(s) to have the power to make decisions about life-sustaining treatment.

If you have made an advance decision refusing treatment this will become invalid if you later create a personal welfare LPA giving someone else the power to refuse medical treatment on your behalf.

If you make an advance decision after creating a personal welfare LPA, this will overrule the LPA. Your attorney cannot make a decision about treatment that you have made an advance decision to refuse, as long as the advance decision was made after you signed the LPA.

For more information about LPAs see Age UK's Factsheet 22 *Arranging for others to make decisions about your finances or welfare*.

13 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. If there is a dispute over this, an application can be made to the Court of Protection. See Age UK's Factsheet 22 *Arranging for others to make decisions about your finances or welfare* for details of how to 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; so it cannot order that treatment should be provided if this has been refused in a valid advance decision.

14 Useful organisations

Alzheimer's Society

Produces a free information sheet and guidance on preparing an advance decision. This information sheet together with a sample advance decision form can be downloaded from their website.

Devon House, 58 St Katherine's Way, London E1W 1JX

Helpline: 0845 300 0336

Tel: 020 7423 3500

Website: www.alzheimers.org.uk

Email: enquiries@alzheimers.org.uk

MIND (National Association for Mental Health)

Offers support for people in mental distress and their families.

Advice line: 020 8519 2122

Mindinfo line: 0845 766 0163

Website: www.mind.org.uk

Office of the Public Guardian

Office of the Public Guardian

PO Box 15118

Birmingham

B16 6GX

Phone number: 0300 456 0300 - Phone lines are open Monday - Friday 9am - 5pm (Except Wednesday 10am - 5pm)

Fax number: 0870 739 5780

The OPG publishes the Code of Practice to the Mental Capacity Act. The Code of Practice provides guidance on Advance Decisions and other areas of the Mental Capacity Act and can be downloaded from the OPG website. It can also be ordered from the Stationary Office for £15 by calling their orderline 0870 600 5522 or ordering through their online shop www.tsoshop.co.uk

A series of six Mental Capacity Act booklets is available to download from the additional publications section of OPG website:

Booklet 1: About your health welfare or finance – who decides when you can't?

Booklet 2: For family friends and unpaid carers

Booklet 3: For people who work in health and social care

Booklet 4: For advice workers

Booklet 5: The Mental Capacity Act – Easyread

Booklet 6: The Independent Mental Capacity Advocate (IMCA) service

PO Box 15118, Birmingham B16 6GX

Tel: 0845 330 2900

Website: www.publicguardian.gov.uk

Patients Association

Produces information for patients on living wills.

PO Box 935, Harrow, Middlesex HA1 3YJ.

Tel: 0845 608 4455

Website: www.patients-association.org.uk

15 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, issues 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 169 65 65

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 80 80 (8.30 am–5.30 pm) or visit www.ageuk.org.uk/donate

Legal statement

Age UK is a registered charity (number 1128267) and company limited by guarantee (number 6825798). The registered address is 207–221 Pentonville Road, London, N1 9UZ. VAT number: 564559800. Age Concern England (charity number 261794) and Help the Aged (charity number 272786) and their trading and other associated companies merged on 1 April 2009.

Together they have formed Age UK, a single charity dedicated to improving the lives of people in later life. Age Concern and Help the Aged are brands of Age UK. The three national Age Concerns in Scotland, Northern Ireland and Wales have also merged with Help the Aged in these nations to form three registered charities: Age Scotland, Age Northern Ireland, Age Cymru.

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