



Advance Statements, Advance Directives and Living Wills (October 2005)

Ref IS/5

Introduction

This information sheet is aimed at people over 60 and refers to the situation in England. Those living in Scotland, Wales or Northern Ireland may wish to contact:

Age Concern Scotland, Causewayside House, 160 Causewayside, Edinburgh EH9 1PR, tel: 0845 125 9732 (local call rate), website: www.ageconcernscotland.org.uk;

Age Concern Cymru, Units 13 & 14 Neptune Court, Vanguard Way, Cardiff CF24 5PJ, tel: 029 2043 1555 (national call rate); website: www.accymru.org.uk;

Age Concern Northern Ireland, 3 Lower Crescent, Belfast BT7 1NR, tel: 028 9032 5055 (national call rate) Monday to Friday 9.30am - 1pm.

Usually when you are ill, you are able to discuss treatment options with your doctor. You can then jointly reach a decision about any future treatment. As a mentally competent adult you cannot be given medical treatment without your valid consent.

However you may be admitted to hospital when unconscious or unable, on a temporary or permanent basis, to communicate your wishes. A time may come when you are not able to process information and understand

the implications of treatment being proposed. This may be the case if you have a car accident or a stroke or if you develop a form of dementia.

In these situations you would not be considered competent to participate in making a decision about your treatment. Another way of describing this would be to say that you 'lack mental capacity'.

Should such situations arise, doctors have a legal and ethical obligation to act in your best interests. BMA (British Medical Association) guidance states that it is good practice for relatives to be consulted when determining your best interests. However relatives do not have a legal right to be consulted or to make decisions on your behalf.

When trying to determine your best interests, it would help doctors if they had a copy of written information that reflects your views and wishes. You could prepare this in the form of an advance statement. Alternatively you could make an advance directive, which is also known as a 'living' will.

This information sheet relates to England and aims to:

- explain the terms mentioned in the title;
- draw attention to things you should be aware of if you would like to prepare valid documents.

It answers the following questions:

- What is an advance statement?
- What is an advance directive or 'living will'?
- Are there advantages or disadvantages in deciding in advance?
- Is an advance directive legally enforceable?
- What criteria apply for an advance directive to be valid?
- Are there requests that cannot be made in an advance directive?
- Who should be consulted prior to making an advance statement or an advance directive?
- How often does an advance directive need to be reviewed?
- Where should an advance directive or advance statement be kept?

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 forms of medical treatment you would or would not like to receive should you, in the future, be unable to decide or communicate your wishes for yourself.

This is sometimes called writing a 'values history'. It could reflect religious or other beliefs you have and any aspects of life which you particularly value. It can help those involved in your care to know more about what is important to you. It could also be used to inform health care professionals when making treatment decisions. However an advance statement would not bind doctors to a particular course of action if it conflicts with their professional judgment,

Advance statements can also be used to nominate someone who you would like to be consulted at a time a decision has to be made. At present, there is no right to insist this happens.

There is only one form of advance statement that is legally binding - an advance directive.

What is *an* advance directive or 'living' will?

An advance directive indicates:

- your specific wish to refuse all or some forms of medical treatment and
- the circumstances under which this refusal would apply.

It must be prepared when you are mentally capable and is only used once you have lost capacity to participate in the decision making process.

It does not have to be in writing but casual remarks about health care should not be used as the basis of an advance directive. Witnessed verbal instructions should be respected but it is possible that a refusal of treatment would be ignored unless the patient spoke to a senior member of the medical team.

A competent adult can refuse treatment for any reason, rational or irrational, even if this might lead to their death. However no one in the UK is able to insist that a particular medical treatment is given. This is why an advance directive can only be a refusal of treatment.

An advance directive is sometimes referred to as a 'living will'. This is a little misleading. An ordinary will allows you to indicate how you would like property, money or other valuables to be distributed once you are dead. An advance directive cannot include financial matters. However like an ordinary will, an advance directive allows you to indicate your future

wishes, while you are able to make decisions for yourself. This and the fact that it may be used while you are alive, could account for the term 'living' will.

Are there advantages or disadvantages in deciding in advance?

You may wish to make an advance statement or directive 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, a person may have been told they have a terminal illness or form of dementia. They may therefore wish to prepare an advance statement indicating the type of treatment they would find acceptable or prefer not to receive if they become unable to make their own treatment decisions. This would also provide an opportunity to talk to and ask questions of the medical team during the early stages of an illness rather than delaying it until it is more difficult to participate.

Preparing an advance statement or advance directive once an illness has been diagnosed, can provide an opportunity to discuss what may be difficult issues with family and friends. This could help to relieve them of some of the decision making at what may prove to be a very stressful time later on.

Is an advance directive legally enforceable?

Advance directives are recognised and must be upheld under common law.

A doctor is bound to comply with an advance directive if it meets the validity criteria explained in the next section. Common law will be the basis of the legality of advance directives until April 2007. From this date, The Mental Capacity Act 2005 will be implemented and becomes their legal basis.

The Mental Capacity Act 2005 clarifies the status of advance directives (which are known in the Act as 'advance decisions to refuse treatment') and introduces a new set of legal safeguards to help prevent abuse.

The Act addresses other issues that can affect those who lack capacity and their carers and will give them increased legal rights. Before the Act

can be implemented, there are a number of major tasks to be completed – hence the implementation date of April 2007. Tasks include consulting on and drawing up codes of practice to guide professionals and carers on the workings of the Act; appointing a Public Guardian and establishing a new Office of the Public Guardian; establishing a new Court of Protection. More information will be available from the Department of Constitutional Affairs (DCA) as implementation date approaches. A summary of The Mental Capacity Act 2005 can be found on the DCA website. See Further information section.

What criteria apply for advance directives to be valid?

You:

- must have been 18 or over at the time the document was prepared and signed;
- must have been mentally competent and not suffering from any mental distress at the time the directive was drawn up;
- must not have been influenced or harassed by anyone else when preparing the advance directive;
- must appear to have been fully informed about the treatment options and their implications when the advance directive was made;
- must not have modified the advance directive verbally or in writing since it was signed and dated.

An advance directive does not have to be in writing. This was discussed earlier in answer to the question ‘what is an advance directive’. However you will be better able to ensure all issues affecting validity have been addressed by having a written document.

The resulting document should be dated and signed by at least one witness over the age of 18. This person should not be a spouse, partner, relative or anyone who stands to benefit from your ordinary will.

It is also important to explain the circumstances under which you would wish refusals of treatment to apply.

No required wording or official guidance has been issued to help you when preparing an advance directive. Several organisations have produced their

own versions of a form that would meet the criteria required to produce a valid advance directive. For details of these organisations see the Further Information section at the end of this information sheet.

A doctor presented with an advance directive will need to verify that it is referring to the actual situation that has arisen.

Are there requests that cannot be made in an advance directive?

They cannot be used to:

- ask for anything that is illegal such as euthanasia or for 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;
- refuse basic nursing care that is essential to keep you comfortable such as washing, bathing and mouth care.

Who should be consulted prior to making an advance statement or advance directive?

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. He / 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. If this doctor or your GP co-signs the document, it will show he or she fully understands your wishes.

How often does an advance directive need to be reviewed?

It is important for doctors, who need to access your advance directive, to feel confident that you have not changed your mind since it was prepared. If new or improved medical treatments are now available, 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 directive so you can tell them if you revise it.

Where should an advance statement or advance directive be kept?

It does not need to be kept with your ordinary will. However an up to date copy should be placed in your medical records and if appropriate, kept with your hospital case notes. Your family and relevant medical professionals need to be aware of its existence and have an up to date copy.

Further information

Information is also produced by the following organisations:

Alzheimer's Society, Gordon House, 10 Greencoat Place, London SW1P 1PH, Helpline 0845 300 0336; website www.alzheimers.org.uk produces a free information sheet and guidance on preparing an advance directive - *Future medical treatment: advance statements and advanced directives or living wills*. This information sheet together with a sample advance directive form can also be downloaded as a pdf file from their website.

Department of Constitutional Affairs, Selborne House, Victoria Street, London SW1E 6QW, tel: 020 7210 8614 website: www.dca.gov.uk The DCA produces a series of booklets on mental capacity issues including: *Making Decisions: a guide for family and friends*. This can be obtained from the website at: www.dca.gov.uk/capacity/index.htm under 'Information Booklets'. You will find a summary of the Mental Capacity Act 2005 on their website at www.dca.gov.uk/menincap/legis.htm If you do not have access to the internet, you can request a copy of this summary from the Mental Incapacity Team on 020 7210 8337.

Patients Association, P.O. Box 935, Harrow, Middlesex HA1 3YJ.
Helpline 0845 608 4455; website: www.patients-association.com
produces a booklet: *Living Wills – a guide for patients*. This booklet is free
to download as a pdf file from their website.

Mind information line: 0845 766 0163; website: www.mind.org.uk
produces a free information sheet - *Advance Directives*, or telephone
publications department on 0844 448 4448.

Useful books

Their Rights – advance directives and living wills explored by Kevin
Kendrick and Simon Robinson, published by Age Concern 2002. Price
£9.99. ISBN 0-86242-244-2.

To order, please telephone our hotline (9am-7pm Monday to Friday, 9am-
5pm Saturday and Sunday): **0870 44 22 120** (national call rate), or visit our
website: www.ageconcern.org.uk/bookshop (secure online bookshop).

If ordering by post, please send a cheque or money order, payable to Age
Concern England, for the appropriate amount plus p&p to Age Concern
Books, Units 5 & 6, Industrial Estate, Brecon, Powys LD3 8LA.

(Postage and packing: mainland UK and Northern Ireland: £1.99 for the
first book, 75p for each additional book up to a maximum of £7.50. Free
on orders over £250. For customers ordering from outside the mainland
UK & NI: credit card payments only; please telephone the hotline for
international postage rates or **email: sales@ageconcernbooks.co.uk**).

Further information from Age Concern

All Age Concern Factsheets and Information Sheets are available free of
charge (maximum five copies per request) by calling the Information Line
free on:

- 0800 00 99 66, 8am - 7pm daily or writing to
Age Concern FREEPOST (SWB 30375), Ashburton, Devon TQ13 7ZZ

Alternatively, they can be downloaded free of charge from the Age
Concern website:

- www.ageconcern.org.uk and clicking on 'Information & Advice'

If you would like

- to receive this information in large print

phone 0800 00 99 66 (free call) or write to Age Concern FREEPOST (SWB 30375), Ashburton, Devon TQ13 7ZZ. Find out more about Age Concern England online at www.ageconcern.org.uk

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SD/October 2005