Advance planning for medical treatment and care

It’s natural to be concerned about what the future holds. What would happen if we were unable to make decisions because of an illness or accident?

Living wills, advance statements, advance decisions - all describe documents which could be used in the future to convey your wishes relating to your care or treatment, should you lack the mental capacity (ability) to decide at the relevant time. These are not simply different terms to describe the same document. Advance planning can be a very confusing topic – this factsheet aims to describe and clarify some of the ways in which you can record your wishes.

The term ‘living will’ does not have a specific legal meaning and it is often used to refer to both advance decisions and advance statements.

Advance statements of wishes and care

An advance statement (sometimes called statement of wishes) can be used to record your wishes and preferences about future treatment and care. Although it can specify what treatments you would like to have or to refuse, doctors would not be bound to comply with your wishes if they conflicted with their professional judgement.

Advance statements can also cover other topics particularly important to you which may influence your care such as your religion, your dietary needs or welfare of your pets. The contents of advance statements, unlike advance decisions, are not legally binding.

Advance decisions (or living will)

An advance decision (or living will) only applies to refusal of medical treatment. Provisions of the Mental Capacity Act 2005, which came into force in 2007, include the right to refuse specific treatment, even if this might result in death. Although advance decisions can relate to a physical or mental disorder, refusal of treatment for a mental illness can be overruled by the Mental Health Act.

Your advance decision could also include a refusal of life-sustaining treatment, even if your life is at risk.

Advance decisions cannot be used to:

- ask for a specific medical treatment or anything which is against the law, such as requesting help to commit suicide or euthanasia.
- request that someone else makes decisions regarding treatment (see section on Lasting Power of Attorney).
- refuse basic care essential to keep a person comfortable such as washing, mouth care, treatment with painkillers.
- refuse food and drink by mouth (it can be used to refuse being tube fed).
How to make an advance decision

- Discuss your intentions with health professionals involved with your care. This will provide vital information as to how an illness is likely to affect you in the future and the advantages and disadvantages relating to future medical procedures.
- Your local health providers may have their own advance decision forms and their own guidance to ensure advance decisions are easily accessible if needed.
- An advance decision must state very clearly which treatments you wish to refuse and in what circumstances your refusal would apply.
- You can make allowances for new treatments in your advance decision even if you wish to refuse those which are currently available.
- Discuss your wishes with your relatives and friends.
- You may also want to take legal advice. Citizens Advice and national support organisations such as MIND or Alzheimer’s Society offer further information.

Who can make an advance decision and what should it include?

Your advance decision can only be valid and legally acceptable if you:
- are at least 18 and have full mental capacity when it is made.
- have set out exactly which treatments you wish to refuse.
- have explained the circumstances under which you want to refuse specific treatment.
- have made the advance decision of your own free will – without harassment or influence from anyone else.
- have not said or done anything which contradicts the advance decision since it was made.

Decisions to refuse life-sustaining treatment

A decision to refuse treatment to keep you alive, must, by law:
- be in writing.
- be signed, dated and witnessed.
- state clearly that you are refusing treatment even if your life is at risk.

Can doctors refuse to carry out my wishes?

A doctor may not follow an advance decision if:
- the advance decision is not absolutely clear about your wishes.
- you have done something which contradicts the advance decision – changing your faith to a religion which does not allow refusal of treatment, for example.
- he/she thinks new circumstances would have affected your decision – a new treatment which could have a major effect on your condition, for example.
What steps should I take to ensure my wishes are carried out?

- Keep a copy of your advance decision.
- Provide a copy for your GP to be kept with your medical records.
- Provide a copy for a CPN (Community Psychiatric Nurse), if applicable.
- Provide a copy for hospital records.
- Provide a copy for family and friends.
- Provide a copy for Attorney(s) if you already have arranged a Health and Welfare Lasting Power of Attorney (LPA). Your latest advance decision will overrule any previous directions which you have included with the LPA.
- Any decisions included with an LPA made after an advance decision will overrule the earlier advance decision – see below.

What happens if I change my mind?

- An advance decision can be cancelled or altered at any time, provided you still have the capacity to do this.
- It is advisable to put a cancellation or alterations in writing.
- Ensure everyone who knows about your advance decision is informed about any changes or cancellation.

Health and Welfare Lasting Power of Attorney (LPA)

Since April 2007 it has been possible to arrange a Health and Welfare LPA. This is a legal process which enables you to appoint someone (known as an Attorney) to manage your health and personal welfare affairs if you no longer have the capacity to make your own decisions. It is important to appoint someone you trust to carry out your wishes and act on your behalf. To find out more please refer to our Lasting Power of Attorney factsheet.

Appointment of an Attorney under a Health and Welfare LPA, after you have made an advance decision, can invalidate the advance decision. This happens if you have given your Attorney power to make the same decisions about the same treatment which you specified in your advance decision.

Similarly, if an advance decision is made after an appointment of an Attorney, the advance decision would overrule the Attorney’s decision.

Understandably, it can be very difficult to make detailed plans for a time when you may be unable to make your own decisions or convey your wishes. Many people make general comments about future treatment but unless they make formal arrangements there is a real danger their wishes cannot be met. Once the formalities have been completed there can be reassurance for all concerned.

We strongly advise you to consult your healthcare professionals when planning and drawing up legally binding documents.
References used in preparing this factsheet:
Age UK: Advance decisions, advance statements and living wills.
www.nhs.uk/conditions/end-of-life-care/
Compassion in dying: Making decisions and planning your care.

Further Reading:
Age UK: Advance decisions, advance statements and living wills (FS72).
Available from Age UK Orderline: 0800 678 1602; www.ageuk.org.uk
Alzheimer’s Society: Advance decisions and advance statements (463)
Available from www.alzheimers.org.uk; Tel: 0300 303 5933
Making decisions and planning your care and Advance Decision Pack
Available from www.compassionindying.org.uk

Disclaimer

Please note: inclusion on our list does not imply recommendation by Carers’ Resource.

If you need further information or would like to discuss any aspect of your caring role,
please contact your local Carers’ Resource:
Harrogate 01423 500555
11 North Park Road, Harrogate, HG1 5PD
Bradford 01274 449660
15 Park View Court, St Paul’s Road, Shipley, BD18 3DZ
Ripon 01765 690222
Community House, Sharow View, Allhallowgate, Ripon, HG4 1LE
Skipton 01756 700888
Ronaldsway House, 36 Brook St, Skipton, BD23 1PP

info@carersresource.org www.carersresource.org

We can provide this information in another format. Please contact us to discuss your requirements.

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