

View this article online at: patient.info/end-of-life-care

End of Life Care

End of life care is a term used to cover the issues you need to think about and plan for, when you are approaching death. It is a very wide area that covers many topics. This leaflet deals with advanced care planning in the UK. In particular, it covers three subjects:

- Lasting power of attorney (LPA).
- Advance decisions (previously known as advance directives).
- Advance statements.

Clinical Editor's Note

(September 2017) Dr Hayley Willacy notes a recent change to the definition of advanced care planning with an emphasis on having conversations that communicate people's wishes:

'Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness'^[1]. Further high-quality information can also be accessed at the Gold Standards Framework website^[2].

What is a lasting power of attorney?

This is a legal document in which you ('the donor') appoint one or more people ('the attorney(s)') to take decisions for you.

In general, decisions about your health and social care can be taken by the professionals looking after you. Your relatives will usually be able to look after your best interests when it comes to general decisions about your daily living.

However, there may be circumstances when you feel it would be best to appoint someone you trust on an official basis to take these decisions for you. This is done by completing and registering a lasting power of attorney (LPA) form. This is a legal document in which you ('the donor') appoint one or more people ('the attorney(s)') to take decisions for you.

An LPA differs from an ordinary power of attorney (OPA) in that it is intended for people who are likely to lose their mental capacity. An OPA is most commonly used by people who have a physical illness and want someone to look after their financial affairs.

An LPA can be drawn up to cover decisions about your health and welfare. If you want to appoint someone to take decisions about your finances and property, this will require a separate LPA. You can have both types of LPA drawn up if you wish.

Typical decisions you may allow a person with a health and welfare LPA to take include:

- Your daily diet
- What medical treatment you receive
- Whether you should go into a care home

You need to be 18 or over in order to make a LPA. You also need to be able to make your own decisions at the time the LPA is drawn up.

Your attorney can be a family member, an acquaintance or a professional (for example, a solicitor). When choosing an attorney think about how well you know them and how much you trust them. How well do they look after their own affairs? Would they be happy to accept the responsibility?

You cannot appoint someone who is under 18 or who is unable to make their own decisions.

You do not need to involve a solicitor in completing the forms although some people prefer to do so. You can fill in the forms on the internet, download and print them out or get them sent to you in the post. You can get further information and download the forms from the GOV.UK website (see below).

Once you have completed the forms you need to register them with the Office of the Public Guardian (see below). A fee is payable (currently £110, reductions available in certain circumstances). You do not need to register the LPA straight away but you should do so well before it is needed. Your appointed attorney(s) can register on your behalf at any time. However, if you feel that the registration is not in your best interests at the time and you have mental capacity, you can object to this.

What is an advance decision?

An advance decision is a statement which explains what medical treatment you would not want to have in the future if ever you are not able to make decisions for yourself. This statement would come into play if it was decided that you lacked capacity as defined by the Mental Capacity Act 2005. It is different from a lasting power of attorney (LPA) which concerns what sort of care you *do* want.

It is popularly known as a 'living will' but unlike a proper will it is not concerned with property or finances, only with healthcare.

It can deal with all future treatment, not just that which may be immediately life-saving. Types of treatment which you may want to cover in an advance decision if you lose mental capacity include:

- Whether you want fluids or feeding (nutrition) through a drip.
- Whether you want to be revived (resuscitated) if your heart stops beating (cardiopulmonary resuscitation, or CPR).
- Whether you want life-saving treatment if you have brain damage from a stroke, head injury or dementia.
- Any other types of treatment prohibited by your culture or religion (for example, blood transfusion for a Jehovah's Witness).

The legal position

An advance decision is legally binding in England and Wales in the sense that if a doctor gave you treatment against the wishes you expressed, they would face legal action. Except in the case where you decide to refuse life-saving treatment, it does not have to be written down. However, most are written down and a written document is less likely to be challenged.

In Scotland and Northern Ireland the situation is somewhat different. Advance decisions are governed by common law rather than legislation. However, providing the decision was made by an adult with capacity and clearly sets out the person's intentions, it is highly likely that a court would consider it legally binding.

Whilst you still have mental capacity, your views overrule anything you may have put in an advance decision.

Advance statement

You may sometimes see the term 'advance statement'. This is an expression of a person's desires and may refer to your values, principles and religious beliefs. It is not legally binding but may act as a guide to a doctor who has to make a decision on a patient's behalf at a time when the patient lacks mental capacity

What are the limits of an advance decision?

You cannot use an advance decision to:

- Ask for a particular medical treatment.
- Ask for something that is illegal (for example, assisted suicide).
- Choose someone to make decisions for you, unless that person is given lasting power of attorney (LPA).
- Refuse treatment for a mental health condition.

A doctor may not follow an advance decision if:

- You make changes which make the decision invalid (for example, a change to a religion which prohibits the refusal of treatment).
- Better treatment has been discovered since the decision was issued (unless you say in it that you don't want to benefit from such advances).
- The wording is not relevant to your current illness.

A decision may not be valid:

- If it is written but not signed.
- If there is reason to doubt that it is authentic (for example, if it was not witnessed).
- If it is felt that you were under pressure when you made it
- If there is doubt about your state of mind at the time you made it.

Advance Decision Example

I, (name) of (address) wish the following to be considered in the event of my incapacity to give or withhold consent for medical intervention:

If ever I am unable to communicate and have an irreversible condition and I am expected to die in a matter of days or weeks, or if I am in a coma and not expected to regain consciousness, or if I have brain damage of disease that makes me unlikely ever to recognise or relate to people then I want treatment only to provide comfort and relieve distress, even if this may shorten my life. I do not want treatment that can only prolong dying.

I consent to any acts or omissions undertaken in accordance with my wishes and I am grateful to those who respect my free choice. I reserve the right to revoke or vary these conditions but otherwise they remain in force.

If I am certified brain dead, should any of my organs be of value to others, I give consent to their removal for the purpose of transplantation.

Note:

- State where copies may be lodged.
- The person must sign and date the document.
- Beneath this may be two signatories, also with dates below a statement to the effect that the above signed in their presence and was, to the best of their knowledge, under no duress and of sound mind. They also believe that they will not benefit from the estate.

Who should make an advance decision?

An advance decision can be made by anyone who is aged over 18 years (16 in Scotland), is of sound mind and cares about the issues involved. Some people may be especially likely to choose the option. For example, those with cancer which cannot be cured, those with a progressive disease of the nervous system and those with early dementia who are still of reasonably sound mind.

Useful resources

Lasting Power of Attorney, GOV.UK

Office of the Public Guardian

Telephone: 0300 456 0300; Textphone: 0115 934 2778; From abroad: +44 300 456 0300
Monday to Friday 9 am-5 pm (except Wednesday, 10 am-5 pm).

Further reading & references

- **Menon S**; The mental capacity act: implications for patients and doctors faced with difficult choices. *Ann Acad Med Singapore*. 2013 Apr;42(4):200-2.
 - **Advance decision (Living wills)**; Alzheimer's Society
1. **Rietjens JAC, Sudore RL, Connolly M, et al**; Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol*. 2017 Sep;18(9):e543-e551. doi: 10.1016/S1470-2045(17)30582-X
 2. **Gold Standards Framework**

Disclaimer: This article is for information only and should not be used for the diagnosis or treatment of medical conditions. Patient Platform Limited has used all reasonable care in compiling the information but makes no warranty as to its accuracy. Consult a doctor or other healthcare professional for diagnosis and treatment of medical conditions. For details see our [conditions](#).

Author: Dr Laurence Knott	Peer Reviewer: Dr Hannah Gronow	
Document ID: 28839 (v2)	Last Checked: 10/07/2017	Next Review: 09/07/2020

View this article online at: patient.info/end-of-life-care

Discuss End of Life Care and find more trusted resources at [Patient](#).

Ask your doctor about Patient Access

- 🔑 Book appointments
- 🔑 Order repeat prescriptions
- 🔑 View your medical record
- 🔑 Create a personal health record (iOS only)



Simple, quick and convenient.
**Visit patient.info/patient-access
or search 'Patient Access'**