

Common words and phrases

This is a guide to some words and phrases you may hear when planning or discussing end-of-life care and treatment. If you would like further information about your end-of-life rights and choices you can call our free Information Line on **0800 999 2434**

Advance Care Plan: A plan for your end-of-life care which follows conversations with your healthcare team and can include an Advance Decision or details of your Lasting Power of Attorney

Advance Care Planning (ACP): A term for the process of planning in advance for your future care and treatment. This can involve conversations with your loved ones and healthcare team as well as a written explanation of your wishes, such as an Advance Statement or Advance Decision.

Advance Decision: An Advance Decision is a document that allows you to make a legally binding refusal of treatment in advance of a time when you can't communicate your wishes or don't have the capacity to make a decision. It is commonly known as a Living Will and is also sometimes called an Advance Directive.

Advance Statement/Statement of Wishes: An Advance Statement (sometimes called a Statement of Wishes) is a general statement about anything that is important to you in relation to your future treatment and wellbeing. You can use it to express your preferences for care or to detail any values or beliefs that inform the decisions you make.

Allow Natural Death order (AND): A document similar in principle to the DNAR form but which covers more than just CPR and would therefore indicate that all life-prolonging treatment to be withheld. It is issued by clinicians and is only used in certain parts of the country.

Capacity: Mental capacity is the ability of a person to make decisions for yourself about a particular matter. Having 'capacity' means having the ability to understand and retain information relating to the decision, understanding the consequences of any choice you make, taking that information into account and being able to communicate your wishes.

Cardiopulmonary resuscitation (CPR): An emergency procedure which may be used if your heart or breathing stops (a cardiopulmonary arrest). This includes chest compressions, inflation of the lungs (including intubation) and defibrillation.

Care Quality Commission: The independent regulator of all health and social care services in England. Their job is to check whether hospitals, care homes and care providers are meeting national standards.

Care and Social Services Inspectorate Wales (CSSIW)/Healthcare Inspectorate Wales (HIW): The Welsh health and social care services regulators.

Clinical Commissioning Groups (CCGs): CCGs are responsible for commissioning most hospital and community NHS services in their local area. They replace what used to be called Primary Care Trusts.

Coma: A deep state of unconsciousness that means you cannot react to your environment or respond to people.

Comfort care: Treatment designed to keep you comfortable – for example, pain relief.

Court Appointed Deputy: Someone who is given the power to make decisions for you by the Court of Protection after you have lost mental capacity.

Court of Protection: A specialist court that makes decisions and appoints people to make decisions for people once they have lost mental capacity.

Defibrillation: A process in which an electronic device sends an electric shock to the heart to stop an extremely rapid, irregular heartbeat, and restore the normal heart rhythm.

Do Not Attempt Cardiopulmonary Resuscitation form (DNAR): A DNAR form (also called a DNR or DNACPR order) is a document issued and signed by a doctor, which tells your medical team not to attempt cardiopulmonary resuscitation (CPR).

End-of-life care: This is the common name for care in the last stages of life.

Enduring Power of Attorney: The old name for a Lasting Power of Attorney for property and financial affairs.

General Medical Council (GMC): The independent regulator of doctors in the UK

Intravenous feeding: A method of artificial feeding where nutrients are given directly into the blood.

Lasting Power of Attorney for Health and Welfare (LPA): A legal document that lets you appoint someone to make decisions about your health and welfare if you lose mental capacity. LPAs can only be made through the Office of the Public Guardian.

Lasting Power of Attorney for Property and Financial Affairs: A legal document that lets you appoint someone to make decisions about your property and financial affairs if you lose mental capacity.

Life-sustaining treatment: Treatment that replaces or supports a body function that you could not survive without, for example, artificial ventilation if you could not breathe by yourself.

Living will: The old name for an Advance Decision.

Mental Capacity Act (2005): An Act applicable in England and Wales. It's primary purpose is to provide a legal framework for acting and making decisions on behalf of adults who lack the capacity to make particular decisions for themselves.

Mental Capacity/Competence: See 'Capacity'.

National Institute for Health and Clinical Excellence (NICE): The independent body that guides the NHS on promoting good health and treating illness. This includes recommending which medicines and procedures should be available on the NHS.

NHS England: NHS England is a public body and is part of the Department of Health. It is responsible for budgeting, planning and delivering services within the NHS in England

Office of the Public Guardian: The OPG is part of the Ministry of Justice and has responsibilities for England and Wales. It supports the Public Guardian in the registration of Enduring Powers of Attorney (EPA) and Lasting Powers of Attorney (LPA), and the supervision of deputies appointed by the Court of Protection. It also helps Attorneys and deputies to carry out their duties, and protects people who lack the mental capacity to make decisions for themselves.

Palliative care: End-of-life care that includes pain control as well as psychological, emotional and spiritual support for patients and their loved ones.

Palliative sedation: This is very heavy sedation, meaning you are unconscious until death.

Parliamentary and Health Service Ombudsman: The independent body that investigates complaints about the NHS.

Percutaneous endoscopic gastrostomy (PEG) feeding: A method of artificial feeding where nutrients are given directly through a tube in the stomach.

Persistent vegetative state: A state of unconsciousness where there is no response from the brain but responses that do not rely on awareness may still work. A person in this state may still be able to breathe and move spontaneously.

Preferred Priorities for Care (PPC): A document that is used to record what is important to you during the last days, weeks or months of life. It is not meant for recording your treatment decisions and unlike Advance Decisions or Lasting Powers of Attorney, it is not legally binding.

Summary Care Record: An electronic record of important information about your health that is accessible to any health or care professional 24 hours a day.

Ventilator: A machine which supplies air to your lungs if you are unable to breathe naturally.

How can we help?

- Compassion in Dying can send you a free Advance Decision form
- We provide a free and comprehensive guide to *Your Rights at the End of Life*

- The following Compassion in Dying factsheets may be helpful:
 - *Understanding Advance Decisions – England and Wales*
 - *Understanding Advance Directives - Scotland*
 - *Understanding Lasting Powers of Attorney for Health and Welfare – England and Wales*
 - *Understanding Welfare Powers of Attorney – Scotland*
 - *Understanding the General Medical Council’s Guidance ‘Treatment and Care Towards the End of Life’*

If you would like any of the factsheets mentioned here or want information about end-of-life rights more generally please call our free **Information Line** on **0800 999 2434** or visit our website www.compassionindying.org.uk.