

# **PLANNING AHEAD:** MAKING CHOICES FOR THE END OF LIFE.

**COMPASSION  
IN DYING.**  
SUPPORTING YOUR CHOICES



## FOREWORD.

“Planning for the end of life is something that few of us want to think about when we’re healthy. Lots of us don’t consider how we might want to be cared for until we witness the death of a loved one, or

experience the first symptoms of an illness. Yet when we start to think about illness or our own deaths, most of us do have strong ideas about what we want for our future treatment and care.

Being at the centre of your end-of-life care and being empowered to make your own decisions is hugely important in achieving a good quality of both life and death. However, all too often people aren’t aware of their rights, and aren’t supported to take the steps needed to make sure their wishes are respected.

This booklet aims to inform and support people and their loved ones to understand their rights so that they can plan in advance. It also explains what happens if people can no longer make decisions for themselves.

Talking about the end of life can be difficult, and thinking about what you want can throw up all kinds of feelings and challenges. But I know from experience that understanding your rights and taking steps to plan ahead is vitally important to make sure you have the right experience for you at the end of life. Perhaps most importantly, the peace of mind gained from knowing that you have put your wishes in place can allow you to get on with living now.”

**ESTHER RANTZEN,**

Patron of Compassion in Dying



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If you would like to talk about any of the topics discussed in this guide you can contact Compassion in Dying's information line on:

**T 0800 999 2434**  
**E [info@compassionindying.org.uk](mailto:info@compassionindying.org.uk)**

## Scotland and Northern Ireland

This guide is written for people living in England and Wales. If you live in Scotland or Northern Ireland, contact Compassion in Dying for information on your rights.



# 1 WHAT ARE MY RIGHTS TO MAKE DECISIONS ABOUT MY TREATMENT AND CARE?

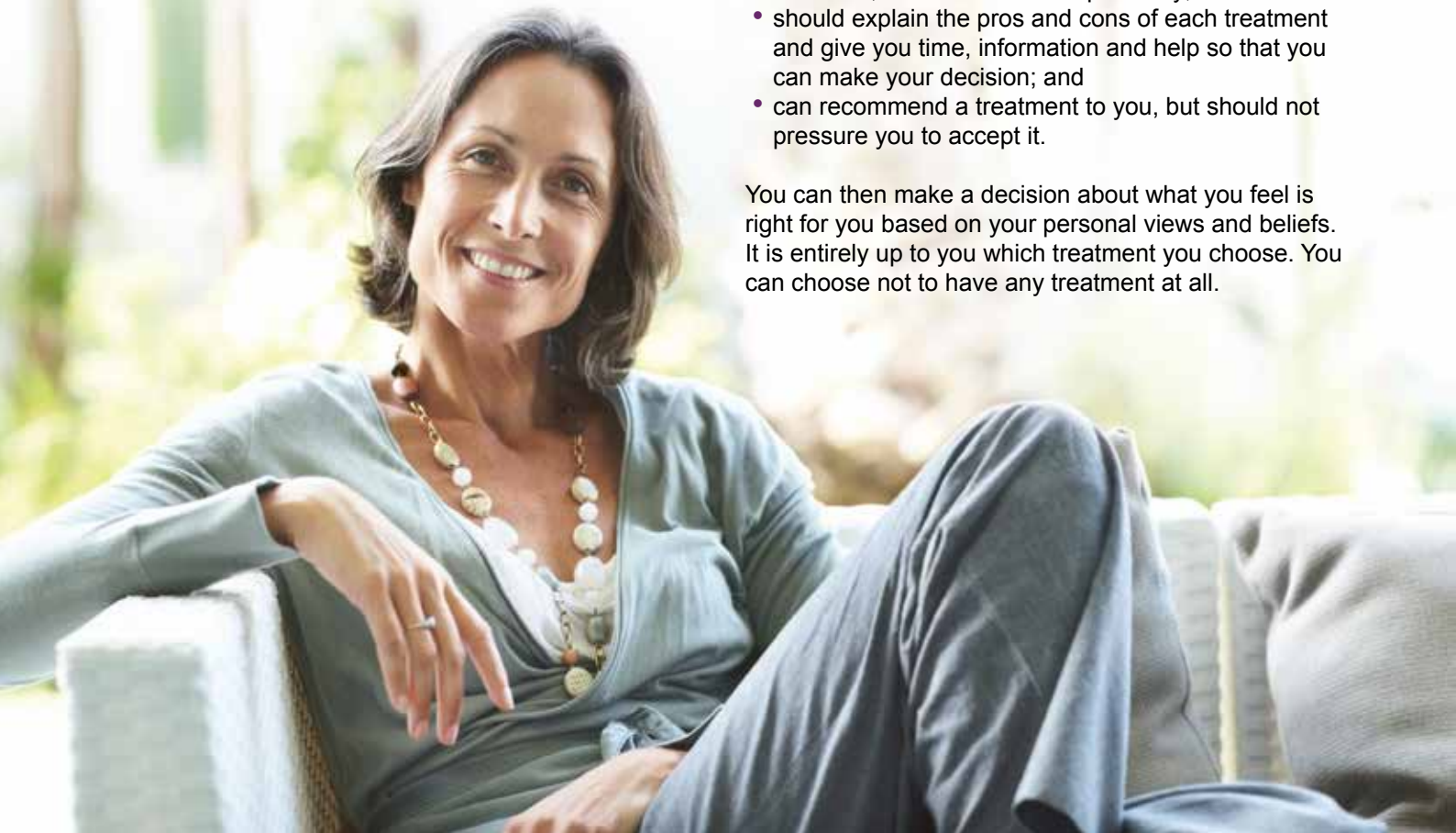
**This section explains the rights you have to make choices about treatment and care if you are able to make decisions for yourself.**

If you are over 18 you have the legal right to refuse any medical treatment, including life-sustaining treatment. You do not have to justify your decision, but you do have to show that you have the capacity to make it (see page 6 for more information on capacity).

If you are an adult with mental capacity, you can make the final decision about what treatment you want from the options offered to you by your doctor. To help you decide what treatment is right for you, your doctor:

- should explain to you in clear language what your diagnosis means and what your treatment options are;
- should answer any questions you have about your condition, treatment or life expectancy;
- should explain the pros and cons of each treatment and give you time, information and help so that you can make your decision; and
- can recommend a treatment to you, but should not pressure you to accept it.

You can then make a decision about what you feel is right for you based on your personal views and beliefs. It is entirely up to you which treatment you choose. You can choose not to have any treatment at all.



Sometimes information about your health can be hard to take in, so your doctor should repeat information or try to explain it in a different way if you do not understand something they have said. If you need support or help asking questions, you can have a friend or family member with you during any conversations with your healthcare team.

You may not want your doctor to give you all the information about your illness and life expectancy at once. It is important to let them know how much information you want, and to tell them if you want to go over the information again.

The NHS Constitution for England (2013) states that you have the right to be involved in discussions and decisions about your health and care, and to be given information to enable you to do this. However, if you find it difficult to talk to your doctor, you can speak to other professionals involved in your care, such as nurses, social workers or another doctor.

You can ask for a second opinion if you are not satisfied with your doctor's advice. You do not have the legal right to a second opinion, however a doctor will rarely refuse to refer you for one. Arranging a second opinion may take time and this could cause a delay to your treatment. Your doctor will be able to tell you if a delay in starting treatment could be harmful to you.

## Requesting a treatment

You are entitled to request a treatment, or to suggest to your doctor why you feel a certain treatment is right for you, but you do not have the right to demand a treatment. This is because doctors do not have to give you treatment just because you ask for it. Doctors decide whether treatment is medically appropriate for your condition and then you decide whether or not you want that treatment. If you do want that treatment you give your consent to having it.

## 2 WHAT HAPPENS IF I CANNOT MAKE DECISIONS FOR MYSELF?

**If you are unable to make a decision for yourself then your rights are protected by law. This section explains what the law says about how decisions must be made. It also explains who makes decisions about your treatment and care if you lack capacity and have not planned ahead by making an Advance Decision or Lasting Power of Attorney.**

**You can find contact details for any of the organisations mentioned at the back of this guide.**

### **What is 'capacity'?**

Capacity is the ability 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.

You might 'lack capacity' because, for example, you have:

- dementia
- a mental health problem
- a brain injury
- had a stroke
- been given end-of-life sedation

The Mental Capacity Act states that people must be assumed to have capacity unless it is proven otherwise. However, if a decision needs to be made about your health or care and your capacity is in question, then a doctor or other healthcare professional will need to assess whether you have the capacity to make that decision.

Whether or not you have capacity is decided on a decision-by-decision basis. For example, you might have the capacity to decide what you want to eat every day, but not have the capacity to understand the consequences of refusing life sustaining treatment. You might lose capacity to make a decision for a short time (for instance, if you are knocked unconscious) or for the indefinite future (for instance, if you were in a persistent vegetative state).

## The Mental Capacity Act 2005

The Mental Capacity Act 2005 (MCA) was created to protect people who cannot make decisions for themselves. It sets out in law how decisions should be made on behalf of a person who lacks capacity. The Act is based on five key principles, which should underpin healthcare professionals' approach to decision-making:

1. Every adult has the right to make decisions for themselves. People must be assumed to have capacity until it is proven otherwise.
2. People should be given all possible help and support to make their own decisions before anyone concludes that they lack capacity. This includes supporting people to communicate in different ways, such as making noises or blinking if they cannot speak properly.
3. It is every adult's right to make a decision that seems unwise or strange to someone else. If a person makes such a decision it does not necessarily mean that they lack capacity.
4. Any decision that is made on behalf of a person that lacks capacity must be made in that person's 'best interests' (see page 8 for more information).
5. People who lack capacity should not have their basic rights and freedoms restricted unnecessarily. This means that whenever a decision is made on someone else's behalf the person making the decision must consider if a different decision or action would interfere less with the person's rights and freedoms.



## 8. 2. What happens if I cannot make decisions for myself?

**There are ways you can plan in advance to ensure that your wishes for treatment and care are followed if you lose capacity. You can do this by making an Advance Decision or a Lasting Power of Attorney for Health and Welfare (see section 3). If you cannot make a decision about your medical treatment and you have not made an Advance Decision or a Lasting Power of Attorney, then a doctor will decide what treatment to give you. They will make their decision according to what they believe is in your 'best interests'.**

### **How does someone decide what is in my best interests?**

The MCA states that anyone who makes a decision on your behalf must act in your 'best interests'. In order to decide what action is in your best interests the MCA provides a non-exhaustive list of things that must be considered when a decision is made. This list dictates that, amongst other things, the decision-maker must:

- consider all the relevant information;
- consider your wishes and feelings (this includes anything you have said to other people and things you have written down);
- consider any values and beliefs that would be likely to influence the decision;
- take into account the views of your family members, carers and other relevant people; and
- not be motivated to bring about death when making decisions about life-sustaining treatment.

If you do not have the capacity to make a decision about your medical treatment your doctor will decide what treatment to give you. They are legally and ethically obliged to base their decision on what they believe is in your best interests, but there is no guarantee that their decision will reflect what you would actually want.

Your doctor must speak to your family members and others close to you, but he/she does not legally have to follow what they say. This means that if you have not made an Advance Decision or Lasting Power of Attorney, the doctor has the final say about what treatments you receive. Your loved ones can challenge their decision in the **Court of Protection**, but this can be costly and time-consuming, and ultimately the final decision will then lie with a judge.

## **DID YOU KNOW?**

# 48%

**OF PEOPLE WRONGLY BELIEVE THEY HAVE THE LEGAL RIGHT TO MAKE DECISIONS FOR A LOVED ONE WHO IS SERIOUSLY ILL<sup>1</sup>.**

<sup>1</sup> YouGov, *Compassion in Dying*, 2013



### What is the Court of Protection?

The Court of Protection was set up to protect people who are unable to make decisions about their personal health, welfare or finance. The court has the power to make decisions about a person's personal welfare and can decide whether to provide, withdraw or withhold medical treatment from a person who lacks capacity. It can also appoint a Deputy to make decisions on behalf of another person.

### Court Appointed Deputies

If you lack capacity and there are ongoing decisions that need to be made about your health or welfare then someone close to you can apply to the Court of Protection to be appointed as your Deputy. This means that they will have the legal power to make decisions about certain aspects of your personal welfare. However the court will limit the power the Deputy has to specific decisions depending on your needs. This is because the Deputy is appointed after you lose capacity and you therefore have not chosen this person yourself.

See page 23 for more information on Court Appointed Deputies.

### What if I do not have anyone close to me?

If you do not have any family members or friends who can be consulted in the decision-making process and you have not made an Advance Decision or Lasting Power of Attorney then an Independent Mental Capacity Advocate (IMCA) may be appointed.

The role of an IMCA is to support and protect the rights of particularly vulnerable people who lack capacity and have nobody else to speak for them. An IMCA will not be the person that makes the final decision, but it is their job to gather and present any information that will help the decision-maker (your doctor) to take action that is in your 'best interests'.

They should ask questions on your behalf, ensure that your rights are upheld, and check that the decision-maker has acted appropriately. They will try to find out what your wishes and feelings are, take into account your values or beliefs and put your perspective across.

It is the responsibility of your local authority or NHS organisation to make sure that IMCAs are available to represent people who lack capacity. The person or team responsible for your care, such as your social worker or hospital doctor, has a legal duty to 'instruct' (refer you to) an IMCA if:

- a decision needs to be made about serious medical treatment provided by the NHS; or
- it is proposed that you have a long-term stay in a care home (for longer than eight weeks) or in hospital (for longer than 28 days); or
- it is proposed that you move to different accommodation on a long-term basis;

and

- you are over 16 years old and lack capacity; and
- there is nobody, apart from paid staff or professionals, who is willing and able to be consulted about the decision.

For more information you can contact your local **Patient Advice and Liaison Service (PALs)** or the **Office of the Public Guardian**.

## 3 HOW CAN I PLAN AHEAD TO ENSURE MY WISHES ARE FOLLOWED?

There are steps you can take to ensure that your wishes are followed if you cannot speak for yourself. This section sets out the different ways you can plan ahead to record your wishes so that your family and friends know about them and, crucially, so that healthcare professionals can act on them.

You can find contact details for any of the organisations mentioned at the back of this guide.

There are two ways you can plan ahead in a way that is legally binding. You can:

- make an Advance Decision to Refuse Treatment (ADRT); and/or
- make a Lasting Power of Attorney (LPA) for Health and Welfare

Your wishes can also be recorded and communicated through:

- an Advance Statement
- an Advance Care Plan
- a Do Not Attempt Resuscitation (DNAR) form

although these are not legally binding in the same way as an ADRT or an LPA (see page 21 for more information).

Planning ahead plays a crucial role in ensuring that your wishes are respected. It enables healthcare professionals to understand how you want to be cared for if you become too ill to make decisions or speak for yourself. It can also make things easier for your family and friends because it helps them to understand what you want when you are nearing the end of life.

### DID YOU KNOW?

82%

**OF PEOPLE SAY THEY HAVE STRONG WISHES ABOUT HOW THEY WOULD LIKE TO BE TREATED AT THE END OF LIFE, BUT ONLY 4% HAVE SET OUT THEIR WISHES IN A LEGALLY BINDING ADVANCE DECISION<sup>2</sup>.**

<sup>2</sup> *Divided in Dying. Compassion in Dying, 2013*

## ADVANCE DECISIONS TO REFUSE TREATMENT.

An Advance Decision to Refuse Treatment (commonly called an Advance Decision) is a document that allows you to make a legally binding refusal of treatment in advance of a time when you cannot communicate your wishes or do not have the capacity to make a decision for yourself. It is sometimes called a Living Will or an Advance Directive.

You can use an Advance Decision to set out the specific circumstances in which you would not want a treatment to be given, or in which you would want a treatment to be stopped (for example if you had reached a certain point in your illness, or if you were in a persistent vegetative state)

An Advance Decision enables healthcare professionals to know what your wishes are even if you cannot tell them yourself, for example if you have severe dementia or are in a coma. It only comes into effect if you lose capacity.

The Mental Capacity Act (2005) gave Advance Decisions legal force. As long as an Advance Decision is valid and applicable then any refusal of treatment within it is legally binding in England and Wales. This means that if a doctor knowingly ignores an Advance Decision they can face criminal prosecution or civil liability.

### Should I make an Advance Decision?

If you lose capacity then an Advance Decision is a direct communication between you and the doctors treating you. It allows you to speak for yourself and means that other people will not have the responsibility of making serious decisions about medical treatment on your behalf.

If you have ideas about what kind of treatment you would want to refuse or accept in specific circumstances then an Advance Decision will help to ensure your wishes are followed.

Preparing an Advance Decision can open a dialogue between you and your friends or family, enabling you to talk about what you want and make your wishes known.

“The Advance Decision will take the responsibility out of the hands of my loved ones. They and the doctors know what my wishes are, and will be spared having to make terribly difficult decisions.”

**SARAH, CAMBRIDGE**

### How do I make an Advance Decision?

Anyone can write an Advance Decision but **Compassion in Dying** provides free forms that meet all the criteria needed to be legally binding. For your Advance Decision to be legally binding you must:

- be 18 or over and have the capacity to make your Advance Decision;
- not have been forced by others to complete it;
- say what treatment you wish to refuse (this can be in everyday non-medical language);
- say the circumstances in which you want to refuse treatment;
- if you want to refuse life-saving treatment, include a sentence that states ‘My Advance Decision still applies even if my life is at risk or shortened as a result’ (Compassion in Dying’s Advance Decision form includes this wording);
- have signed and dated your Advance Decision in the presence of at least one witness, who must also have signed and dated the Advance Decision in your presence.

## 12. 3. How can I plan ahead to ensure my wishes are followed?

### Reviewing and updating your Advance Decision

If your health changes or if you are going into hospital for treatment or surgery you should review and update your Advance Decision. We also strongly recommend you review your Advance Decision every two years even if your health is stable.

If you lose mental capacity and your Advance Decision was updated in the last two years, the doctor treating you can be more confident that what you have said in your Advance Decision is still what you want.

If your Advance Decision includes a refusal of life-saving treatment then the doctor treating you has to be sure that it is both valid and applicable. An Advance Decision made a long time ago is not automatically invalid or inapplicable, but it may raise doubts as to whether or not it still reflects what you want, which may in turn cause a doctor to choose not to follow it.

### What can an Advance Decision not do?

You cannot use an Advance Decision to:

- ask for your life to be ended, because helping someone to die is against the law;
- refuse food and drink by mouth or basic care that attends to your comfort and/or personal hygiene. This is because these things are a basic human right that no one can decline in advance;
- nominate someone else to make decisions about treatment on your behalf. Nominating another person to make decisions about your health and care is done by making a Lasting Power of Attorney for Health and Welfare;
- demand certain treatments. This is because doctors do not have to give you treatment just because you ask for it. Doctors decide whether treatment is medically appropriate for your condition and then you decide whether or not you want that treatment.

Mrs Bell has been diagnosed with cancer and knows that she does not have many months left to live. She wants to enjoy the last months of her life and spend time with friends and family, so she has decided she does not want to undergo any surgery. She speaks to her doctor about the kinds of surgery that would be likely in her situation and writes them down in a legally binding Advance Decision. She gives a copy of her Advance Decision to her son, her doctor and her local hospital so that they are all aware of her wishes.



“My GP was very supportive and after we discussed why I wished to have an Advance Decision, he told me my medical files would be amended accordingly”

**ROGER, LANCASHIRE**

## Doctors

You should always speak to your doctor about your Advance Decision and any wishes you have for your future treatment. They can explain your likely treatment options so you can decide what you want to refuse. Your doctor can give you information to help you consider the consequences of any decision carefully.

If your doctor is unwilling to speak to you about your Advance Decision for any reason, they should refer you to someone else at the practice. Let **Compassion in Dying** know if you have any problems speaking to your doctor about your Advance Decision.

## Which treatments can I refuse in advance?

You can use an Advance Decision to refuse any treatment, including life-sustaining treatment. If you have refused life-sustaining treatment your healthcare team will still do everything they can to keep you comfortable and pain free.

Here are some examples of the kinds of treatment you can refuse with an Advance Decision. This is not a complete list so please make sure you speak to your doctor about your likely treatment options. Also any refusal you make would only apply in the situations that you had specified. So, for example, if you had stated in your Advance Decision that you only wanted to refuse life-sustaining treatment if you were in a persistent vegetative state, you may still be given such treatment under other circumstances.

## Examples of things you can refuse within an Advance Decision:

### Cardiopulmonary resuscitation (CPR)

CPR is an emergency treatment used to restart a person's heart and breathing if they stop (called a cardiopulmonary arrest). The aim is to keep the person alive while a correctable cause of the cardiopulmonary arrest is identified and treated. CPR includes chest compressions (repeatedly pushing firmly on the chest), inflating the lungs (by inserting a tube into the windpipe or by placing a mask over the mouth and nose) and defibrillation (using electric shocks to restart and correct the heart's rhythm).

### Mechanical or artificial ventilation

This is a machine that helps you to breathe if you cannot do it on your own. Ventilators are also known as respirators or life-support machines.

### Artificial nutrition and hydration

If you cannot eat and drink, your doctor might provide you with a liquid that contains the nutrition or hydration that you need. The liquid can be given though an intravenous drip, a tube through the nose or through a tube directly into the stomach (known as a PEG feed).

### Antibiotics

Antibiotics are a life-sustaining treatment in the event of a life threatening infection. Such infections (for example, pneumonia or a bladder infection) are more common when someone is very ill, for example the person has advanced cancer or has suffered a stroke. Antibiotics can be given through an intravenous drip or by mouth as a tablet or liquid.



## 14. 3. How can I plan ahead to ensure my wishes are followed?

### HEALTH AND WELFARE LASTING POWERS OF ATTORNEY.

A Health and Welfare Lasting Power of Attorney (LPA) is a document that gives one or more trusted persons the legal power to make decisions about your health and welfare if you lose the capacity to do so yourself. The person who grants power is known as the 'Donor' and the person(s) appointed to make decisions is the 'Attorney'.

Your Attorney can make decisions about anything to do with your health and welfare such as refusing medical treatment, where you are cared for and the type of care you receive, as well as day-to-day things like your diet, dress and daily routine.

When making an LPA you must choose whether or not you want your Attorney to be able to make decisions about life-sustaining treatment. If you choose no, then all decisions about life-sustaining treatment would be made by your healthcare team (unless you have made an Advance Decision).

You can also list any restrictions that your Attorney must follow, or any guidance that you would like them to take into account when making decisions on your behalf.

Attorneys only begin to act for you if you lack the capacity to make or communicate the decision(s) in question. Your Attorney could not make decisions for you if you were able to do so yourself.

In October 2007 the Mental Capacity Act (2005) came into force and created two types of LPA – the Health and Welfare LPA and the Finance and Property LPA.

A Health and Welfare LPA only covers decisions about your health, personal care and welfare. If you also want your Attorney to make decisions about your money or property then you have to make a Finance and Property LPA as well.

Before October 2007 the finance and property LPA was called an Enduring Power of Attorney. If you made an Enduring Power of Attorney before October 2007 it is still valid, but it does not cover decisions about health and welfare.

For more information about Enduring Powers of Attorney or Lasting Powers of Attorney for property and finance, contact the **Office of the Public Guardian**.

“ My family responded well and understandingly about my wishes. They will take joint responsibility to ensure that I am given pain relief and comfort in my care. I feel a deep relief at having made a Lasting Power of Attorney, I now have no concerns about my end-of-life care ”

**ALYSON DORSET**



### Who should I choose as my Attorney?

You need to trust your Attorney to understand your wishes, respect your values and make the best decisions for you. Your Attorney must also feel confident and comfortable making potentially life-changing decisions on your behalf. You should discuss your wishes at length with your prospective Attorney and consider writing them down in an Advance Statement (see page 20 for more information).

Your Attorney can be anyone over the age of 18 such as a partner or family member or trusted friend. If you wish you can appoint more than one Attorney. If you do so then you can choose whether they can make decisions individually, which is called acting 'jointly and severally', or whether they must all agree on every decision, which is called acting 'jointly'.

Attorneys are bound by law to make decisions that are in your 'best interests'. The **Office of the Public Guardian** can step in and take action if someone feels that an Attorney is not acting in this way (see page 8 for more information on best interests).

### What is the Office of the Public Guardian?

The **Office of the Public Guardian** is part of the government's Ministry of Justice department. They manage the LPA registration process and maintain a register of all LPAs. They also deal with any complaints if, for example, someone feels that an Attorney is acting wrongly.

16. 3. How can I plan ahead to ensure my wishes are followed?



## How do I make a Lasting Power of Attorney?

There are three key steps to the process:

1. Choose your Attorney(s)
2. Complete the form
3. Register your LPA with the Office of the Public Guardian

Mr Cox has motor neurone disease. He is very clear that he does not want to receive life-sustaining treatment of any sort once he gets to the stage where he cannot communicate. He is very close to his daughter and they have talked about what he wants, but he is worried that she may not be asked for her views if he is taken into hospital.

Mr Cox appoints his daughter to be his Lasting Power of Attorney for Health and Welfare. This gives him the peace of mind of knowing that she has the legal power to make decisions about his treatment if he cannot communicate.

An LPA is not legally binding until it is registered with the **Office of the Public Guardian**.

The completed LPA form can be registered by you (while you still have capacity) or by your Attorney (at any time, even after you have lost capacity). There is no requirement to register an LPA straight away but the **Office of the Public Guardian** strongly recommends that you do so. If you register your LPA immediately, any errors in the forms can be identified while you still have the capacity to correct them. If your LPA is not registered until you lose capacity and it contains errors that result in your form being rejected, you will not be able to correct these errors and your LPA will therefore be invalid.

Registration costs £110 although those on a low income or certain benefits are exempt from fees.

You can obtain the form in one of the following ways:

- Ask the **Office of the Public Guardian** to send the form to you by telephoning 0300 456 0300;
- Download it from the website [www.gov.uk/government/publications/make-a-lasting-power-of-attorney](http://www.gov.uk/government/publications/make-a-lasting-power-of-attorney); or
- Complete it online using their digital tool. The digital tool offers step by step guidance as you fill it in and it automatically chooses and fills in the parts of the form you need using the information you provide. Once completed you still need to print the form for all involved to sign but the online tool is designed to make the process quicker and easier. You can find the online tool here [www.gov.uk/lasting-power-of-attorney](http://www.gov.uk/lasting-power-of-attorney).

For more information or if you need help filling in the form you can contact **Compassion in Dying**.



**18.** 3. How can I plan ahead to ensure my wishes are followed?



**My family know my wishes. Do I need to plan in advance by making an Advance Decision or a Lasting Power of Attorney?**

If you lose capacity and you have not made an Advance Decision or an LPA, then your doctor will decide what treatment to give you. They will base their decision on what they believe is in your best interests but this may not be what you would have wanted.

Your doctor should speak to your family or next of kin but does not legally have to follow what they say. This means that if you have no Advance Decision or LPA, the doctor has the final say about what treatments you receive. Your family can challenge their decision in the **Court of Protection**, but this can be costly and time consuming, and ultimately the final decision will then lie with the judge.

**Which should I make - a Lasting Power of Attorney or an Advance Decision?**

There are some important differences between an Advance Decision and an LPA which you may wish to take into account when deciding what is best for you:

- 1. Timescale:** An Advance Decision comes into effect as soon as it has been signed and witnessed correctly. An LPA is only valid once it has been registered with the Office of the Public Guardian, which can take up to eight weeks.
- 2. Flexibility:** An Advance Decision is only applicable to the specific treatments and circumstances you detail within it. It will not apply if you find yourself in circumstances you did not envisage at the time of writing.

An LPA can apply to a wider range of healthcare situations, whether or not you specifically considered them at the time of appointing your Attorney. Your Attorney will be able to make any health and welfare decision on your behalf, this could mean deciding



where you live and how you are cared for, your diet and what you wear, as well as making decisions about life-sustaining treatment if you give them that power.

3. **People involved:** In order to complete your Advance Decision you need one person to witness it (although we recommend having two witnesses, and also getting your GP to sign to witness your capacity).  
To appoint an LPA you need one or more people to act as your attorney, as well as a witness, an independent person or relevant professional to 'certify' your application, and up to five persons to be notified of the application.
4. **Cost:** An Advance Decision is free. An LPA currently costs £110 to register, although those on a low income or certain benefits are exempt from fees.
5. **Accessibility:** Both an Advance Decision and an LPA are legally binding. In practical terms, however, you need healthcare professionals involved in your care to know that you have made an Advance Decision or an LPA. This happens in different ways:
  - An LPA is approved for registration by the Office of the Public Guardian and then entered on a register which is searchable by healthcare professionals caring for you. It would also be advisable to let your GP know that you have an LPA.
  - Advance Decisions are not centrally registered but you should give a copy to your GP or local hospital. Some Ambulance Trusts are happy to record that you have one, or you can carry a Notice of Advance Decision card, obtainable from **Compassion in Dying**, or wear a **MedicAlert** bracelet.

### Should I make both?

There are some issues to consider when deciding whether to have both a Health and Welfare LPA and an Advance Decision. It is important to remember that the one you made most recently will always take priority for dealing with the decision in question. See Miss Hart's story below, or contact **Compassion in Dying** for more information.

Miss Hart appointed her brother, George, to be her Attorney for health and welfare. A few weeks later she also made an Advance Decision to refuse resuscitation if she had a heart attack, as she was worried that George would not be able to go through with making this decision for her. If she becomes ill in the future, the doctor will follow George's decisions in almost all circumstances because he is her Attorney. However, if she has a heart attack, they will follow her Advance Decision because this was made more recently. George cannot tell the doctor not to follow his sister's Advance Decision.

If Miss Hart had appointed George to be her Attorney AFTER making her Advance Decision, and she had given him the power to make decisions about life-sustaining treatment, he would have the power to tell the doctor not to follow her Advance Decision.

If you have an Advance Decision and an LPA you should let your Attorney know and discuss the content of your Advance Decision with them.

## WHAT OTHER WAYS CAN I PLAN IN ADVANCE?

**There are other ways you can set out and document your wishes for your future care:**

### Advance Statements

An Advance Statement (also called a Statement of Wishes) is a general statement of what you want and what is important to you. It is written down and can contain any information you feel is important for others to know, such as your food preferences, religious beliefs or daily routine.

It helps people involved in your care to understand what you want and what is important to you if you cannot speak or make decisions for yourself. It is not legally binding like an Advance Decision. However anything you say in an Advance Statement must be taken into account by healthcare professionals when any decision is made in your best interests (see page 8 for more information on best interests). Often, statements in writing have more weight than oral statements or comments you may have made to family or friends.

**Compassion in Dying's** free Advance Decision form contains a section that allows you to express your wishes in this way.

### Advance Care Plans

Advance Care Plans will normally be made in partnership with your healthcare team when you near the end of life, unlike Advance Decisions, Advance Statements and Lasting Powers of Attorney which can be made at any time. Advance Care Plans are used to record your care and treatment wishes. They should be attached to your medical notes and be easily accessible to those involved in your care. If you have made an Advance Decision, Advance Statement or Lasting Power of Attorney, this should be noted in your Advance Care Plan.

The most commonly used type of Advance Care Plan is called the Preferred Priorities for Care (PPC) document. Although you can decide what you want to include in an Advance Care Plan, the PPC contains a number of questions to prompt you.

An Advance Care Plan is not legally binding. However, if you are near the end of life it is a good idea to make one so that people involved in your care know what is important to you. Doctors will try to follow your wishes and the document will be taken into account when deciding what is in your best interests.

You should include anything that is important to you in relation to your future health and care. The kind of wishes you can set out include:

- where you want to receive care
- where you want to be cared for when you are dying, and where you want to die
- who you want to be with you
- values, such as religious beliefs
- any dietary requirements you have

You should always talk to your doctor or nurse about your preferences. They will be able to explain your likely treatment and care options and help you to understand how any decisions or choices you make will affect you. They can also discuss whether or not your wishes are realistic. For example, if you would prefer to die at home but do not have anyone close who can support you at home, it may be more realistic for you to be cared for in a hospice.

It can be difficult to talk to your loved ones about your wishes and preferences for the end of life. Sometimes they may not want to acknowledge that you are dying or they may disagree with you. However, if you feel able to, it is important to involve your family and friends when you fill in the document because it can help them to understand what you want, what is likely to happen to you, and to be realistic about what is possible.

Many people feel they need help from their nurse or doctor to fill in an Advance Care Plan. You can also complete one yourself.

Everyone who is approaching the end of their life should be given the opportunity to make an Advance Care Plan. Speak to your doctor or contact **Compassion in Dying** if you have any questions.

### DNAR forms

A DNAR (Do Not Attempt Resuscitation) form is a document issued and signed by a doctor, which tells your medical team not to attempt cardiopulmonary resuscitation (CPR). The form is designed to be easily recognised and verifiable, allowing healthcare professionals to make decisions quickly about how to treat you. It is also called a DNR or DNACPR order.

CPR is an emergency treatment used to restart a person's heart and breathing if they stop (called a cardiopulmonary arrest). The aim is to keep the person alive while a correctable cause of the cardiopulmonary arrest is identified and treated. CPR includes:

- chest compressions (repeatedly pushing firmly on the chest)
- inflating the lungs (by inserting a tube into the windpipe or by placing a mask over the mouth and nose)
- defibrillation (using electric shocks to restart and correct the heart's rhythm)

A DNAR form is not a legally binding document. Instead it acts as a tool to communicate to the healthcare professionals involved in your care that CPR should not be attempted. It only relates to CPR so if you have a DNAR form you will still be given other types of treatment for your condition (unless you have specifically refused them in an Advance Decision) as well as treatment to ensure you are comfortable and pain-free.

Normally a DNAR form will only be added to your medical records after a discussion between you and your healthcare team and if they believe that CPR is unlikely to be successful. You should be told if this is the case.

It is different to an Advance Decision because it can only be issued by a doctor, you cannot write one yourself. Also it usually applies in all situations, unlike an Advance Decision in which you can specify the circumstances in which you want the refusal of treatment to apply (for example if you have been unconscious for a certain length of time).

# 4 CAN I MAKE DECISIONS ON BEHALF OF SOMEONE ELSE WHO LACKS CAPACITY?

This section explains the rights and choices you have as the carer, family member or friend of someone who cannot make decisions for themselves.

Contact details for all of the organisations in this section can be found at the back of this guide.

## Will I be given information about my loved one's illness?

Doctors should try to make sure that carers and family members are involved in decisions about a loved one's care and treatment. You should be given information about their illness and told which services are available. The NHS Constitution for England states that patients have the right to be involved in discussions and decisions about their care, including end-of-life care, and to be given information to enable them to do this. It also states that where appropriate this right includes the patient's family and carers.

## Can I represent a family member or friend who lacks capacity?

You can make decisions for someone who lacks capacity if they have previously appointed you as their Lasting Power of Attorney (LPA) for Health and Welfare. See page 14 for more information.

Even if you are not an Attorney, doctors must speak to the relatives, partner or next of kin of the patient in order to make decisions in their 'best interests' (see page 8 for more information on best interests decisions). They should listen to your views, although legally they do not have to follow them.

## Court Appointed Deputies

If your loved one has not appointed an LPA for Health and Welfare and now lacks capacity, and there are ongoing decisions that need to be made on their behalf, you can apply to the Court of Protection to be appointed as a Deputy. This means that you will have the legal power to make decisions about certain aspects of their health and care.

If your application to become a Deputy is successful the court will issue a court order that gives you authority to act on behalf of your loved one and explains which decisions you are legally allowed to make. The court will limit your decision-making power to specific issues, depending on the circumstances of the case. This is because the person has not chosen you to make decisions for them, as they would have done if they had appointed you as an Attorney before they lost capacity.

In order to be a Deputy you must be over 18. Deputies are usually a family member or friend of the person who lacks capacity.

As a Deputy you must always make decisions in the person's 'best interests' (see page 8 for more information on best interests decisions).

To apply to become a Court Appointed Deputy there is an initial fee of £400. The application is the first part of a longer process. Once the court order is issued there are continuing tasks and responsibilities that the Deputy has to complete.

The Office of the Public Guardian will support and supervise decisions that the you make, and you will have to submit reports to them on any action or decision that is taken on your loved one's behalf. Further fees have to be paid to cover the cost of this supervision. They are as follows:

- £100 for the Deputy Assessment fee. This is paid once to the Office of the Public Guardian to determine the level of supervision needed;
- An annual supervision fee of either £35 or £320. The amount will depend on how closely the Deputy needs to be supervised.

It is always better to be appointed as an LPA before your loved one loses capacity. This is because the process of applying to be a Deputy can be lengthy and costly. You will have to report on all decisions you make, which you do not have to do as an Attorney. Your decision-making is also limited to specific decisions, and Deputies can never have the right to make decisions about life-sustaining treatment.

For information on how to become a Court Appointed Deputy contact **Compassion in Dying**, or **The Court of Protection**.



## 24. 4. Can I make decisions on behalf of someone else who lacks capacity?

### **My loved one has made an Advance Decision, but the doctor does not want to follow their wishes.**

Doctors have to respect a wish to refuse treatment if it is set out in a legally binding Advance Decision. Giving unwanted medical treatment that has been refused in a valid and applicable Advance Decision is classed as assault.

However, problems can arise if a doctor believes that your loved one's Advance Decision is not valid or applicable to the situation they are in. In this situation the doctor can decide not to follow the Advance Decision.

If you believe that your loved one's Advance Decision is valid and applicable, but doctors have not followed it, ask for a meeting with the doctor in charge of their treatment. Explain why your loved one wanted to refuse treatment and discuss the doctor's reasons for disagreeing.

See page 11 for more information on what makes an Advance Decision valid.

If this does not work you can make a formal complaint to the hospital about the doctor. See page 29 for information on how to make a complaint about an NHS service. You can also speak to a solicitor.

The **Court of Protection** can decide whether your loved one's Advance Decision is valid and applicable. There are emergency procedures in place to ensure that urgent cases can be dealt with quickly.

Contact **Compassion in Dying** if you and your loved one are in this situation. We may be able to help by putting you in touch with a legal expert.



### **My loved one appointed me as their Attorney for Health and Welfare. What do I do if the doctor does not follow my decisions?**

An LPA for Health and Welfare gives you the legal authority to make decisions on behalf of a loved one. This can include decisions about life-sustaining treatment if they have given you that power.

You must always make decisions in the 'best interests' of the person who appointed you, based on what they have told you about what they want.

If they also have an Advance Decision and this was made after you were appointed as their Attorney, you cannot override the decisions made in their Advance Decision (see page 19 for more information on Advance Decisions).

If your loved one's doctor does not follow your decisions, ask for a meeting with the doctor in charge. At this meeting you should explain your decisions and discuss their reasons for disagreeing.

Ask for a second opinion if you and the doctor disagree about which treatment would be in your loved one's best interests.

If this does not work you can make a formal complaint to the service provider about the doctor (see page 29 for more information on how to make a complaint). You can also speak to a solicitor.

If you are still unable to settle the disagreement you can apply to the **Court of Protection** to make a decision. There are emergency procedures in place to ensure that urgent cases can be dealt with quickly.

Contact **Compassion in Dying** if you are in this situation. We may be able to help by putting you in touch with a legal expert.

### **Can I complain on behalf of a family member or friend?**

If you feel the person you care for is not getting the standard of care they need, you are entitled to make a complaint (see page 29 for more information on how to make a complaint).

### **What support is available to carers?**

A carer is someone who provides unpaid care to an ill, frail, disabled or dying person who could not cope without this support. You may provide care for a relative, partner, neighbour or friend, and without ever considering yourself a 'carer'. However, if you provide support to another person you are entitled to support.

For information on local respite care services, and services specifically for carers, contact the **Carers Trust** or **Carers UK**. Your doctor should also be able to provide information on local services that provide respite care to give carers a break. For those caring for loved ones with dementia, **Dementia UK** provides a specialist nursing service to support people with dementia and their carers.

You may also be entitled to financial support (see page 31 for information on benefits).

## 5 WHERE CAN I BE CARED FOR AT THE END OF LIFE?

**There are several places in which you can receive care at the end of life. This section sets out the main options available to you.**

**You can find contact details for any of the organisations mentioned at the back of this guide.**

If you feel strongly about where you want to die, make sure that your loved ones and the people who provide your care know what your wishes are. A good way to do this is to make an Advance Care Plan, such as the Preferred Priorities for Care document (see page 20 for more information on ways to plan in advance).

### Care at home

Many people want to stay in their own home for as long as possible and often this can be arranged with help from a combination of palliative care nurses, district nurses, your GP and social services.

Your GP can usually arrange for district nurses and palliative care nurses (such as Macmillan nurses, or nurses from your local hospice) to come to your home. They can help with things like controlling your pain and symptoms, providing hands-on nursing care and giving emotional support. In some cases, a specialist nurse or an outreach worker from your local hospice can care for you at home. This type of nursing care is usually free.

Social services can organise for carers to come to your home and help with things like washing, going to the toilet, shopping and other domestic tasks. If you feel you would benefit from homecare such as this then you or another person can contact social services and ask for a community care assessment. If you are found to have an eligible need then your local authority has a duty to provide it. You may have to contribute towards the cost of your care or social services may pay for all of it. How much you pay will depend on the amount of savings you have and any income you earn. Each local authority can decide what to charge for support at home, but their rates must meet government guidelines of fairness.

### DID YOU KNOW?

# WHEREVER

**YOU CHOOSE TO BE, YOU HAVE THE RIGHT TO COMPLAIN IF YOU DO NOT FEEL YOU ARE GETTING THE STANDARD OF CARE YOU FEEL YOU NEED. SEE PAGE 29 FOR MORE INFORMATION.**

If you have complex ongoing healthcare needs, then you may be eligible for NHS Continuing Healthcare funding (CHC). CHC care packages are solely funded by the NHS and are for people who are not in hospital. To find out if you are eligible your care needs first have to be assessed by a health or social care professional. This will either be done in hospital before you return home (by a doctor or nurse), or in your own home (usually by a social worker). After this initial screening you will be told whether or not you will then be referred for a full assessment.

To find out about being cared for at home, speak to your doctor or social worker. You can also speak to **Independent Age**, **Age UK**, or **Macmillan Cancer Support**.

### Care in a hospice

Hospices support your emotional, social and spiritual needs, as well as your physical symptoms. They aim to promote dignity and respect and look after all of a person's needs, not just the medical ones.

Hospice services include pain control, nursing, complementary therapies, counselling.

The amount of time you spend in a hospice will depend on your needs and the availability of hospice spaces in your area. You can receive day care at a hospice and go home at night, stay in a hospice for a short time to help control symptoms or to provide respite for those caring for you, or move into a hospice for the last phase of your life. Hospice care is usually free.

If you would like to receive care in a hospice, speak to your doctor or contact **Hospice UK**.

### Care in a care home

You can receive end-of-life care in a care home.

There are two main types of home:

- Residential care homes – these types of home offer care and support in the day and night and, if needed, their staff will help with things like washing, dressing and going to the toilet as well as providing support at meal times;
- Nursing homes – these offer the same services as a residential home but also provide 24 hour care from a qualified nurse.

Care homes can be owned and run by private companies, voluntary organisations or a local authority.

The costs of these homes can vary and most people have to pay something towards their fees. Once you have been assessed as needing to move into a care home your council will calculate what you need to contribute based on your income and any savings that you have. If your assessment showed that you need to live in a nursing home then the NHS may fund the nursing part of the costs.

For more information about care homes in your area you can contact **FirstStop** or search the directory on the **Care Quality Commission** website. For information on how to find a care home, who pays for it and what to look for you can contact **Independent Age**.



### Care in hospital

Many people stay in hospital at the end of their life. Hospitals can vary greatly in size and in the services they provide, but all should be able to give palliative care that provides pain and symptom control. Some hospitals have their own specialist palliative care teams who can support you emotionally as well as physically, and who can also provide support to your family and loved ones. If you would like to know more about end-of-life care in hospital you can ask to speak to a palliative care specialist, or speak to your GP.



# 6 HOW CAN I COMPLAIN ABOUT TREATMENT OR CARE I HAVE RECEIVED?

If you are not happy with a health or social care service you have received you have the right to complain. This section explains how to complain about different types of service.

You can find contact details for any of the organisations mentioned at the back of this guide.

Every NHS service, social care service and care home must have an accessible, fair and responsive procedure for dealing with complaints. You should ask your service provider to let you see a copy of their complaints procedure. This will tell you who to contact, how your complaint will be dealt with and how they will learn from it. Your complaint has to be investigated and you have the right to be given a full and prompt reply. You can make a complaint by email, letter, in person, or by phone. It is a good idea to keep a record of anything you say, who you speak to and what they say in response.

## How do I complain about a care home or social care service?

**Stage 1** Contact the care home or social care service and tell them the details of your complaint. They should act quickly to resolve the issue and take action to stop it happening again.

**Stage 2** If you are not happy with the action taken to resolve your complaint you can then complain directly to your local council.

They will have a complaints procedure that you will need to follow. Your social worker, someone from your care provider, or someone from your council will explain what you need to do.

**Stage 3** If you are unhappy with the outcomes of Stages 1 and 2, you can complain to the **Local Government Ombudsman**. You can do this regardless of who pays for your care.

## How do I complain about a health or social care service that is paid for privately?

**Stage 1** Contact your private healthcare provider and tell them the details of your complaint. They should act quickly to resolve the issue and take action to stop it happening again.

**Stage 2** If you are not happy with the response you get check if your healthcare provider is a member of the **Independent Healthcare Advisory Service** in England or the **Welsh Independent Healthcare Association**. If it is, you can contact them for more information about how to complain.

If it is not a member, the **Patients Association** may be able to help. **Action Against Medical Accidents** may be able to refer you to specialist lawyers or other sources of support.

**30.** 6. How can I complain about treatment or care I have received?



### How do I complain about the NHS?

**Stage 1** First you should contact the service that provides your care, for example a hospital or GP practice. You can do this by speaking to a member of staff – for example, a doctor or nurse in hospital, or the Practice Manager of a GP surgery.

If you do not want to contact the service directly you can complain to the NHS organisation that pays for the service instead. Services like GPs and dentists tend to be paid for, or ‘commissioned’, by **NHS England**. Services like hospital care and community nursing are usually commissioned by your local **Clinical Commissioning Group**.

They should act quickly to resolve the issue and take action to stop it happening again.

**Stage 2** If you are not happy with the response you receive, you can take your complaint to the **Parliamentary Health Service Ombudsman**.

Making a complaint can be difficult. For help and support contact **The Patient Advice and Liaison Service (PALS)**, **The Patients Association**, or **Citizens Advice Bureau**.

The **Care Quality Commission** provides a leaflet on how to complain about a health or social care service.

# 7 WHAT FINANCIAL SUPPORT IS AVAILABLE?

There are a range of welfare benefits that you may be entitled to, some of which are dependent on the savings and income that you have (means-tested) and some of which are not (non means-tested). Some are for people of working age and some are earnings-replacement benefits.

It is important to remember that:

- benefits need to be claimed and, if you are eligible, you are entitled to receive them – always seek advice if you think you may be eligible;
- some benefits are inter-related, so new claims may have an impact on any existing benefits you receive;
- the benefits system can be complicated and frequently changes but this should not deter you from claiming.

For up-to-date information about what you are entitled to, visit **www.gov.uk** or get in touch with a local or national organisation that knows about welfare benefits (see page 36 for useful organisations to contact).

The following is basic information about some of the main benefits.

## Pension Credit

Pension Credit is a means-tested benefit for people over retirement age (see **www.gov.uk/calculate-state-pension**). It is designed to top up your weekly income to meet a minimum level set by the government. It is made up of two parts – Guarantee Credit and Savings Credit. You can receive either or both of these depending on your age, savings and income.

Contact **Independent Age** on 0800 319 6789 (10am to 4pm, Monday to Friday) or at [advice@independentage.org](mailto:advice@independentage.org) to find out more or visit their website at: **www.independentage.org**

## Attendance Allowance (AA)

This is a tax-free benefit for people aged 65 or over, which may be claimed regardless of your income and savings. You may be eligible if you have difficulty with personal care tasks, like washing, dressing or taking medication, or if you need supervision for some reason, such as if you are prone to falls or you are forgetful, for example. You must have had these problems for at least six months to qualify.

Contact **Independent Age** for information about Attendance Allowance.

## 32. 7. What financial support is available?

Ron is retired and has had health problems for a few years, including arthritis and gout. He already receives Attendance Allowance at the lower rate of £53.00\* per week but, following a stroke which leaves him needing help at night as well as during the day, he has become entitled to the higher rate of £79.15 per week. He also receives an extra Pension Credit premium called the Severe Disability Premium, which gives him an extra £59.50 per week. He uses these benefits to pay for taxis, a cleaner and his heating bills.

*\*all benefits rates quoted refer to the 2013/2014 financial year*

### **Personal Independence Payment (PIP), Disability Living Allowance (DLA)**

If you are aged between 16 and 64 and need regular help with personal care or supervision or you have difficulty walking or need someone with you to walk outside in unfamiliar places, you may be able to claim a Personal Independence Payment. This is a tax-free benefit replacing the Disability Living Allowance. As with Attendance Allowance, it may be claimed regardless of your income and savings.

If you currently receive DLA and you are under 65, you will be reassessed at some stage before March 2016 to see whether you are entitled to PIP instead.

### **Employment and Support Allowance (ESA)**

If you have an illness or disability that affects your ability to work, but are not receiving Statutory Sick Pay, then you may be able to claim ESA.

There are two types of ESA:

- Income-related ESA is means-tested and is tax-free;
- Contributory ESA (based on your National Insurance contributions) is non means-tested and is taxable.

If you claim ESA, you will need to undertake a medical test called a Work Capability Assessment.

Contact **Turn2us** for information about PIP or ESA

### **Special rules for claiming benefits if you are terminally ill**

If your doctor does not expect you to live for more than six months, there are special rules for claiming Attendance Allowance, Personal Independence Payment and Employment and Support Allowance. These rules are intended to help you get the benefit more quickly and easily.

### **Other financial assistance**

Depending on your circumstances, you may also want to know about Council Tax Support, Housing Benefit, Universal Credit, local welfare assistance schemes or other benefits and support available. (See page 36 for useful organisations to contact).

## What financial support is available for carers?

Many people find that at some stage of their life they become a carer for a family member, a friend or a neighbour. There is support available for carers and your local council has a duty to provide you with information about support services available for carers in your area. You may also be entitled to claim financial help in the form of Carer's Allowance.

### Carer's Allowance

If you care for someone else (day or night) for at least 35 hours a week, you may be entitled to Carer's Allowance. It is important to ask a benefits expert first to do a benefits check for you and the person you are caring for, as getting Carer's Allowance could reduce the benefits they receive and, if you are awarded Carer's Allowance, it may mean that you become entitled to other benefits as well.

The person you are caring for needs to be claiming Attendance Allowance, Disability Living Allowance (at the middle or highest care rate) or Personal Independence Payment (the daily living component) at the time you make your claim for Carer's Allowance.

For up-to-date information about what you are entitled to as a carer, contact **Carers UK** or **The Carers Trust** or visit **[www.gov.uk](http://www.gov.uk)** to find out more about the Carer's Allowance.

Brenda and Harold are retired. Brenda has been diagnosed with cancer and needs extra help so her husband is now her carer too. She is eligible for Attendance Allowance of £79.15 per week and because Harold has applied for Carer's Allowance, they also receive an additional top up in their Pension Credit of £33.30 per week through the 'Carer's Premium', giving them an extra £100 a week.

*\*all benefits rates quoted refer to the 2013/2014 financial year*

## What financial support is available for bereaved people?

You may be eligible for a Bereavement Payment or Bereavement Allowance. For more information, contact the **Citizens Advice Bureau** or visit **[www.gov.uk](http://www.gov.uk)**.



# 8 INFORMATION IF SOMEONE CLOSE TO ME HAS DIED.

This section gives information and support if someone close to you has died.

Contact details for all of the organisations in this section can be found at the back of this guide.

## Care after death

In April 2011 the NHS published guidelines for staff who are responsible for patients after they have died. These guidelines do not give you legal rights, but they do set out what doctors and hospital staff should do.

Staff should:

- respect your loved one's spiritual, religious or cultural wishes;
- ensure that all legal obligations are met;
- prepare them to be transferred to the mortuary or funeral director. You should have the opportunity to be involved if you want to be;
- honour your loved one's wishes for organ and tissue donation; and
- return your loved one's possessions to you.

## Grief

The time after a loved one has died can be very painful. You may experience strong or unexpected emotions or find it difficult to express how you feel.

If you are finding it difficult to come to terms with the death of a loved one, contact **Cruse Bereavement Care** or the **Samaritans**.

## Registering a death

In England and Wales, you normally need to register a death within five days. The easiest way to do this is to go to the register office in the area in which the person died. You can find your local register office by looking in the phone book, contacting your local authority or visiting **www.gov.uk**.

Most deaths are registered by a relative and the registrar will normally only allow another person to do it if no relatives are available. More information on how to register a death is available from **www.gov.uk**.

**Tell Us Once** is a service for bereaved people offered by local authorities. It can notify other government departments about a death on your behalf, so that you do not have to contact them yourself.

If it is available in your area it should be offered to you when you go to register the death at the register office.

## Arranging a funeral

The **National Association of Funeral Directors** and the **Natural Death Centre** provide information on how to arrange a funeral and important things to consider.

## What other support is available?

A checklist of what to do when someone dies is available from **www.gov.uk**.

Most banks, utility companies and pension companies have a bereavement department that you can ask to be put in touch with.

You can ask for practical support from a wide range of people after the death of a loved one. This includes:

- health professionals;
- funeral directors;
- solicitors;
- social services; and
- **Citizens Advice Bureau**.

There may be a charge for some of these services.

## The Coroner's Service

In certain circumstances the cause of death has to be investigated. The doctor or lawyer responsible for investigating a death is called a coroner. A legal enquiry into a cause of death is called an inquest.

Not all deaths go through the Coroner's Service. The doctor will only report a death to the Coroner's Service in certain circumstances, such as:

- if the person dies during a surgical operation;
- if the person dies before recovery from an anesthetic;
- if the cause of death is unknown;
- if the death was violent or unnatural – for example, suicide, accident or drug or alcohol overdose;
- if the person who died wasn't seen by a doctor during their final illness; and
- if the cause of death appears to be a disease related to the person's workplace.

## Charter for the Coroner's Service

The Ministry of Justice has published a guide to coroner services, which gives an overview of what happens and details the standards you can expect during a coroner's investigation. For more information visit **www.gov.uk**.

# 9 SOURCES OF HELP AND SUPPORT.

## Action against Medical Accidents (AvMA)

Provides free specialist advice concerning NHS or private healthcare complaints.

**T:** 0845 123 2352

**W:** [www.avma.org.uk](http://www.avma.org.uk)

## Age UK

Campaigns on behalf of older people and provides information and services. There are over 160 local Age UKs. You can use the contact number below to find your nearest branch.

**T:** 0800 169 6565

**W:** [www.ageuk.org.uk](http://www.ageuk.org.uk)

## Alzheimer's Society

Membership organisation supporting people with dementia. They also have local branches which provide services such as befriending and day centres.

**T:** 0300 222 1122

**W:** [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

## Care and Social Services Inspectorate Wales

Independent regulator of care and social services in Wales.

**T:** 0300 062 8888

**W:** [www.cssiw.org.uk](http://www.cssiw.org.uk)

## Care Quality Commission

The independent regulator of health and social care services in England.

**T:** 03000 616161

**W:** [www.cqc.org.uk](http://www.cqc.org.uk)

## Carers Direct

Information for carers - part of NHS Choices.

**T:** 0300 123 1053

## Carers Trust

A charity working to improve support services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

**E:** [info@carers.org](mailto:info@carers.org)

**W:** [www.carers.org](http://www.carers.org)

## Carers UK

Provides information and support for carers.

**T:** 0808 808 7777

**W:** [www.carersuk.org](http://www.carersuk.org)

## Citizens Advice Bureau (CAB)

Provides free, independent, confidential and impartial advice to everyone on their rights and responsibilities.

**T:** 03444 111 444 (England)

**T:** 03444 772 020 (Wales)

**W:** [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

## Clinical Commissioning Groups (CCG)

To find your local Clinical Commissioning Group:

**W:** [www.nhs.uk/service-search/clinical-commissioning-group/locationsearch/1](http://www.nhs.uk/service-search/clinical-commissioning-group/locationsearch/1)

## Court of Protection

Makes decisions and appoints people to make decisions for people who have lost mental capacity.

**T:** 0300 456 4600

**W:** [www.gov.uk/court-of-protection](http://www.gov.uk/court-of-protection)

## Cruse Bereavement Care

Free, confidential support for bereaved people.

**T:** 0844 477 9400

**W:** [www.cruse.org.uk](http://www.cruse.org.uk)

**Dementia UK**

A national charity working to improve the quality of life for all people affected by dementia.

**T:** 020 7697 4160

**W:** [www.dementiauk.org](http://www.dementiauk.org)

**Dying Matters**

Coalition promoting awareness of death, dying and bereavement.

**T:** 08000 214 466

**W:** [www.dyingmatters.org](http://www.dyingmatters.org)

**Elderly Accommodation Counsel**

A national charity that aims to help older people make informed choices about meeting their housing and care needs.

**T:** 0800 377 7070

**W:** [www.eac.org.uk](http://www.eac.org.uk)

**FirstStop**

A helpline ran by the Elderly Accommodation Counsel. FirstStop aims to equip older people, their families and carers to understand their rights and options, and make informed decisions about care, housing and finance.

**T:** 0800 377 7070

**W:** [www.firststopcareadvice.org.uk](http://www.firststopcareadvice.org.uk)

**GOV.UK**

Government information and advice about public services.

**W:** [www.gov.uk](http://www.gov.uk)

**Healthcare Inspectorate Wales**

Independent regulator of healthcare services in Wales.

**T:** 0300 062 8163

**W:** [www.hiw.org.uk](http://www.hiw.org.uk)

**Healthtalkonline**

Shares experiences of health and illness.

**W:** [www.healthtalkonline.org](http://www.healthtalkonline.org)

**Hospice UK**

Supports organisations to provide the best quality hospice care. You can use their website to find hospice services in your area.

**T:** 020 7520 8200

**W:** [www.hospiceuk.org](http://www.hospiceuk.org)

**National Association for Hospice at Home**

A membership organisation for providers of hospice care at home.

**W:** [www.nahh.org.uk](http://www.nahh.org.uk)

**Huntington's Disease Association**

Support for people with Huntington's Disease.

**T:** 0151 331 5444

**W:** [www.hda.org.uk](http://www.hda.org.uk)

**Independent Age**

Provides free, independent and confidential advice and information for older people, their families and carers. Services include a helpline and befriending.

**T:** 0800 319 6789

**E:** [advice@independentage.org](mailto:advice@independentage.org)

**W:** [www.independentage.org](http://www.independentage.org)

**Independent Healthcare Advisory Service / Welsh Independent Healthcare Association**

The trade body for independent healthcare services in England and Wales.

**T:** 020 7379 8598

**W:** [www.independenthealthcare.org.uk](http://www.independenthealthcare.org.uk)

**Local Government Ombudsman**

Looks at complaints about councils and other local authorities.

**T:** 0300 061 0614

**W:** [www.lgo.org.uk](http://www.lgo.org.uk)

**Macmillan Cancer Support**

Cancer information and support.

**T:** 0808 808 0000

**W:** [www.macmillan.org.uk](http://www.macmillan.org.uk)

### Marie Curie

Nursing care for people with terminal illnesses.

**T:** 0800 716 146

**W:** [www.mariecurie.org.uk](http://www.mariecurie.org.uk)

### MedicAlert

Provides jewellery that alerts healthcare professionals to key medical information.

**T:** 01908 951 045

**W:** [www.medicalert.org.uk](http://www.medicalert.org.uk)

### Mind

Information and support for people with mental distress.

**T:** 0300 123 3393

**W:** [www.mind.org.uk](http://www.mind.org.uk)

### Motor Neurone Disease Association (MND)

Information and support for people with Motor Neurone Disease.

**T:** 0845 762 6262

**W:** [www.mndassociation.org](http://www.mndassociation.org)

### MS Society

Information and support for people with multiple sclerosis.

**T:** 0808 800 8000

**W:** [www.mssociety.org.uk](http://www.mssociety.org.uk)

### MS Trust

Information and support for people with multiple sclerosis.

**T:** 0800 032 3839

**W:** [www.msstrust.org.uk](http://www.msstrust.org.uk)

### National Association of Funeral Directors (NAFD)

Trade Association of funeral directors.

**T:** 0845 230 1343

**E:** [info@nafd.org.uk](mailto:info@nafd.org.uk)

**W:** [www.nafd.org.uk](http://www.nafd.org.uk)

### The National Society of Allied & Independent Funeral Directors (SAIF)

Trade Association of independent funeral directors. Members are policed regularly and must adhere to a strict Code of Practice.

**T:** 0845 230 6777

**E:** [info@saif.org.uk](mailto:info@saif.org.uk)

**W:** [www.saif.org.uk](http://www.saif.org.uk)

### The Natural Death Centre (NDC)

A social, entrepreneurial, educational charity that gives free, impartial advice on all aspects of dying, funeral planning, bereavement and consumer rights.

**T:** 01962 712 690

**W:** [www.naturaldeath.org.uk/](http://www.naturaldeath.org.uk/)

### NICE (National Institute for Health and Care Excellence)

An independent organisation set up by the government to make sure that people have the same access to treatment and care wherever they live. They give independent advice about which treatments should be available on the NHS in England and Wales and provide guidance and advice to improve health and social care.

**T:** 0845 003 7780

**W:** [www.nice.org.uk/](http://www.nice.org.uk/)

### Office of the Public Guardian

Government body that registers Lasting Powers of Attorney (LPAs) and deals with mental capacity issues.

**T:** 0300 456 0300

**W:** [www.gov.uk/office-of-the-public-guardian](http://www.gov.uk/office-of-the-public-guardian)

### Patient Advice and Liaison Services (PALS)

Offer confidential advice, support and information on health related matters. A point of contact for patients, families and carers. You can find PALS in your local hospital or search for your nearest office here

**W:** [www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-\(PALS\)/LocationSearch/363](http://www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-(PALS)/LocationSearch/363)



### **Parkinson's UK**

Information and support for people with Parkinson's disease.

**T:** 0808 800 0303

**W:** [www.parkinsons.org.uk](http://www.parkinsons.org.uk)

### **Parliamentary and Health Services Ombudsman**

Undertakes independent investigations into complaints about government departments.

**T:** 0345 015 4033

**W:** [www.ombudsman.org.uk](http://www.ombudsman.org.uk)

### **Patients Association**

Advocacy service for patients.

**T:** 0845 608 4455

**W:** [www.patients-association.com](http://www.patients-association.com)

### **Prostate Cancer UK**

Fights to help more men survive prostate cancer and enjoy a better quality of life by supporting men and providing information, funding research and raising awareness and improving care.

**T:** 0800 074 8383

**E:** [supportercare@prostatecanceruk.org](mailto:supportercare@prostatecanceruk.org)

**W:** [www.prostatecanceruk.org](http://www.prostatecanceruk.org)

### **Relatives and Residents Association**

Representing older people in residential care settings.

**T:** 020 7359 8136

**W:** [www.relres.org](http://www.relres.org)

### **Samaritans**

Emotional support for people in distress.

**T:** 08457 90 90 90

**E:** [jo@samaritans.org](mailto:jo@samaritans.org)

**W:** [www.samaritans.org](http://www.samaritans.org)

### **The Silverline**

Free confidential helpline providing information, friendship and advice to older people.

**T:** 0800 470 80 90

**E:** [info@thesilverline.org.uk](mailto:info@thesilverline.org.uk)

**W:** [www.thesilverline.org.uk](http://www.thesilverline.org.uk)

### **The Stroke Association**

Information and support for people affected by stroke.

**T:** 0303 3033 100

**W:** [www.stroke.org.uk](http://www.stroke.org.uk)

### **Sue Ryder**

Provides care for people with long-term or terminal conditions.

**T:** 0845 050 1953

**W:** [www.sueryder.org](http://www.sueryder.org)

### **Tell Us Once**

Informs other government departments about a death on your behalf. Speak to the registrar when you go to register the death to see if this service is available in your area.

**W:** [www.gov.uk/tell-us-once](http://www.gov.uk/tell-us-once)

### **Terrence Higgins Trust**

Information and support for people with HIV.

**T:** 0808 802 1221

**W:** [www.tht.org.uk](http://www.tht.org.uk)

### **Turn2Us**

A charity that helps people in financial need to access welfare benefits.

**T:** 0808 802 2000

**W:** [www.turn2us.org.uk](http://www.turn2us.org.uk)

COMPASSION IN DYING.

- T 0800 999 2434
- E info@compassionindying.org.uk
- W www.compassionindying.org.uk

We are the only UK charity working to inform and empower people to exercise their rights and choices around end-of-life care. Our vision is of a world in which individuals are placed at the centre of their end-of-life care. We believe everyone should be given the information and support needed to make decisions about their treatment and be helped to plan ahead to ensure that their wishes are known and followed.

Compassion in Dying supports all people, whatever their faith or belief, to make their wishes clear at the end of life. Our services equally support people who wish to have all available treatment at the end of life, as well as those who wish to refuse it. We are the only charity which provides dedicated telephone and advocacy support on Advance Decisions and Lasting Powers of Attorney, to the benefit of over 10,000 people annually.

DIGNITY IN DYING.

- T 020 7479 7730
- E info@dignityindying.org.uk
- W www.dignityindying.org.uk

Dignity in Dying is a national campaign and membership organisation. Dignity in Dying campaigns to legalise assisted dying within upfront safeguards for terminally ill, mentally competent adults.



Compassion in Dying was founded by the membership and campaigning organisation Dignity in Dying in 2007. The two are sister organisations, and share a desire to see individual choice at the heart of end-of-life decision making. At Compassion in Dying, we support the uptake of existing legal rights and are not involved in Dignity in Dying's campaign for assisted dying for terminally ill, mentally competent adults, within the last six months of life.





# 10 COMMON WORDS AND PHRASES.

**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 cannot 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 be withheld. It is issued by clinicians and is only used in certain parts of the country.

**Capacity:** Mental capacity is the ability 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 stop (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 the former 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 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.

**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.

**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.

**Independent Mental Capacity Advocate (IMCA):** The role of an IMCA is to support and protect the rights of particularly vulnerable people who lack capacity and have nobody else to speak for them. The Mental Capacity Act (2005) gives some people who lack capacity the right to advocacy from an IMCA.

**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. Its 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:** Care that aims to improve the quality of life of people with serious illnesses through the relief of pain, symptoms and stress.

**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.



# PLANNING AHEAD:

**MAKING CHOICES FOR  
THE END OF LIFE.**

## CONTACT US.

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**f** [www.facebook.com/compassionindying](http://www.facebook.com/compassionindying)

**t** @agooddeath

Compassion in Dying is a registered charity in  
England and Wales (1120203) and a company  
limited by guarantee no. 05856324.

Published November 2014,  
Review date November 2017  
Written by Usha Grieve



**COMPASSION  
IN DYING.**  
SUPPORTING YOUR CHOICES