

**Compassion
in Dying.**

Your end of life. Your way.

Planning Ahead

My treatment
and care



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We can help you prepare for the end of life.
How to talk about it, plan for it, and record
your wishes. Have any questions? Talk to us.

 **0800 999 2434**

 info@compassionindying.org.uk



What is this booklet for?

Most people have an opinion about the treatment and care they want to receive. This guide will support you to record your preferences to help ensure they are respected if you cannot make a decision for yourself, or tell people what you want.

It provides an introduction to the ways you can plan for your treatment and care.

It is best to make plans for your future while you are well and able to do so. Any adult can plan for their treatment and care – you do not need to be unwell or over a certain age.

This booklet explains your rights under the Mental Capacity Act 2005, which is a law in England and Wales. If you live in Scotland or Northern Ireland please contact Compassion in Dying for information on how to make your wishes known.

Introduction

Why should I plan for my treatment and care?



There may come a time when you are unwell and cannot tell the people around you what you do and do not want. By making plans now, you can record your preferences for treatment and care so that if you are ever in this situation, your wishes are known and can be followed.

Recording your wishes allows you to express who you are and what is important to you. This gives you control over your treatment and care, and reassurance that the right decisions will be made. It can also be a good way to start conversations with your friends and family about what you want in the future.

Here are some of the reasons why people have planned for their treatment and care:

“So that I’m surrounded by the people and the things that I love”

“So my family do not have to make difficult decisions”

“To ensure I am not in pain”

“I want my doctor to know my wishes”

“It is important to me that I continue treatment for my illness for as long as possible”

“To avoid family disputes”

“I want people to know who I am, and how best to care for me”

“To preserve my dignity”

“I don’t want my life to be prolonged when I have no quality of life”

“I am worried that people won’t know how to care for me”

“Now that I have things organised, I can get on with living life – knowing people will know my wishes when it counts.”



Who can make decisions about my treatment and care?

While you have capacity you have the right to make decisions about your treatment and care. You can decide if you want to consent to or refuse treatment, even if doing so may shorten your life.

If you lack capacity to make a decision for yourself, and you have not recorded your wishes, the healthcare professional in charge of your care will decide how to treat you. They must make decisions based on what they think would be in your best interests, but there is no guarantee that this would be what you would choose for yourself.

Many people think that their family or next of kin can make decisions about their treatment or care if they are unwell, but this is not always the case. Even though these people should be consulted when a decision is made, they will not have the final say.

By making plans now you can ensure the important people in your life, and your healthcare team, know your wishes.

If you plan ahead by making an Advance Statement, Advance Decision and/or Lasting Power of Attorney for Health and Welfare, they will only be used if you can no longer make decisions for yourself.

You can cancel or make changes to your Advance Statement, Advance Decision and Lasting Power of Attorney at any time – see page 40 for more information.



What is capacity?

Capacity is the ability to make a decision for yourself. Your capacity to make a decision depends on when the decision needs to be made, and what the decision is.

You might lack capacity to make a decision on one day but be able to make that decision at a later date. For instance, this might be because you have dementia and your ability to remember information differs from one day to the next.

You might also have capacity to make some decisions but not others. For example, you might have capacity to decide what you want to eat each day, but not to make a decision about life-sustaining treatment.

You lack capacity to make a decision if:

- You have an impairment or disturbance of the mind or brain. For example, because you are unconscious, have dementia, a mental health condition, a brain injury or a stroke

and because of that impairment, you cannot do one or more of these things:

- Understand information relating to the decision
- Remember that information for long enough to make the decision
- Take that information into account when making the decision
- Communicate the decision

The law says that people must be assumed to have capacity unless it is proven otherwise.

However, if a decision needs to be made and a healthcare professional thinks that you might lack capacity, then they will assess whether or not you have capacity to make that decision.

How does someone decide what is in my best interests?

If you lack capacity to make a decision then someone may have to make that decision for you. If this happens they have to act in your best interests.

A best interests decision is based on your values, beliefs and preferences. It should be the decision you would make for yourself if you could.

The Mental Capacity Act 2005 says the decision-maker must consider:

- All the relevant information, including the potential benefits or risks of a particular treatment, or any long-term consequences of giving or withholding the treatment such as the impact on your quality of life.
- Your past and present wishes and feelings, any wishes you have previously expressed, written down, or what you say you want now.
- Any values and beliefs you have that would be relevant to the decision.
- The views of your family members, carers and other relevant people.



How to plan for my treatment and care

Talking about my wishes

Talking about your health and your priorities for the future is important for you and the people around you. It can help you to make informed decisions, and give you peace of mind knowing that others understand what is important to you.

Having these conversations can also help to make the important people in your life feel involved, and ensure they are not left guessing if your healthcare team asks them for information about your wishes when making a decision in your best interests.

Talking about your wishes and feelings with your family, friends or a healthcare professional can be emotionally demanding, especially if they do not

agree with you, or have values which challenge your own. But these conversations can also bring you closer together, and many people find them rewarding.

To prepare for these conversations, you may want to take some time to think about what is important to you and your quality of life. Some people find writing their thoughts down helpful.

Need help?

Our booklet 'Starting the Conversation' can support you to have conversations about your treatment and care.

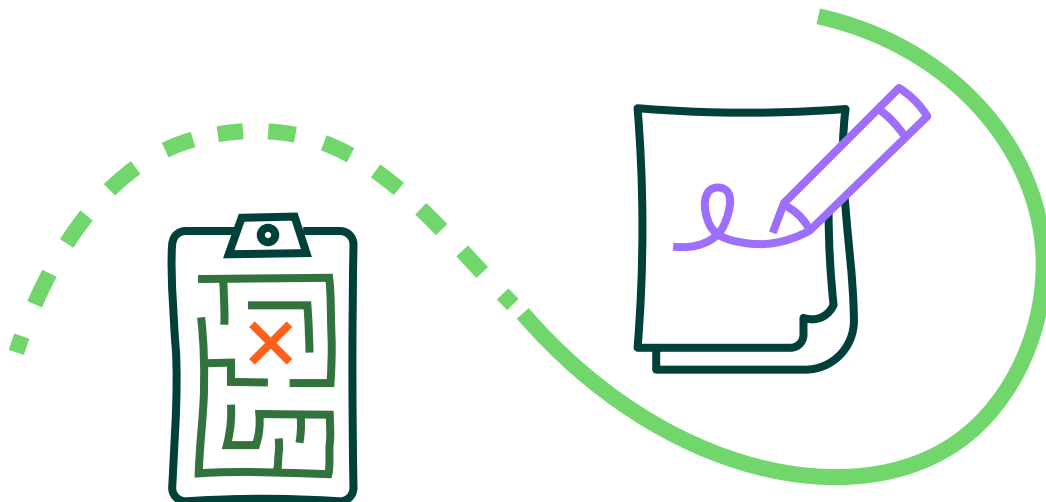
Should I talk to my doctor about my wishes?

If you are able to, it is a good idea to speak to your doctor about your wishes. Your doctor can help you to understand your treatment and care options, including any likely benefits and risks. This will help you decide what is right for you, based on your personal priorities, values and beliefs.

You can speak to any professional involved in your care including your GP, consultant, or nurse.

Even if you would prefer not to discuss your wishes with your doctor, it is still important to make sure your wishes are recorded on your medical notes. This helps to make sure they are known about and can be followed.

Our booklet **'What now? Questions to ask after a terminal diagnosis'** can support you to ask questions and find the information you need from health and care professionals, so that you can make informed decisions about your treatment and care.



Recording my wishes

Once you have thought about and discussed your preferences for your treatment and care, you can put these in writing. This is an important step because it will help to ensure that your wishes are clear, and that they can be followed by a healthcare professional.

There are three main ways that you can record your wishes. You can make all three, or you might feel that one is better for you than another. The following pages give more information about each option.

“I’ve planned ahead for peace of mind for everyone – do it for yourself, all those who know you, and everyone involved in your care. Once you have made plans for the future, you can truly live your life more fully.”

You can make an:

1

Advance Statement

Information about you, your lifestyle, and the care you would prefer to receive (free)

2

Advance Decision

Details of any treatments you do not want to receive (free)

3

Lasting Power of Attorney for Health and Welfare

Choosing someone you trust to make decisions for you (registration fee only)

Advance Statement

What is an Advance Statement?

An Advance Statement is a general statement of anything that is important to you in relation to your health or wellbeing.

It can contain information about your lifestyle, the care you would prefer to receive, and information about what is important to your quality of life.

• Your Advance Statement will only be used if you are unable to tell people how you wish to be cared for.

How can an Advance Statement help me?

- It will give the people caring for you an idea of who you are and how best to care for you, if you cannot tell them.
- It will help to make sure health and care professionals take your preferences into account - an Advance Statement should be considered by anyone making a decision in your best interests.



You might want to include:

- ✔ **The things that are important in your life**
Activities you enjoy, people you like spending time with, things you like to talk about and places you like to visit.
- ✔ **The things that are important to your identity**
What independence, privacy and dignity mean to you. The clothes you like to wear, what you like to be called, and how you like to present yourself.

- ✔ **Your values and religious or spiritual beliefs**
What your religious or spiritual beliefs mean to you. How your values and beliefs affect the decisions you make about your treatment and care.
- ✔ **Information about your lifestyle**
What time you like to get up and go to bed. What your preferred meal times are, or if there is a time of day when you feel particularly good or bad.
- ✔ **Your food preferences**
Anything you like or dislike, anything you are allergic to or intolerant of.
- ✔ **Living arrangements**
Where you would like to live and be cared for, and by who.
- ✔ **The important people in your life**
When you like to see them and at what time of day.
- ✔ **Information about your health**
Your current conditions or illnesses, any medication you are taking, anything that helps you to feel better, or anything you would prefer not to happen to you.



Things to think about

- An Advance Statement is not legally binding. This means that a health or care professional does not have to follow the exact instructions in it, but they should consider it when caring for you, and making a decision in your best interests.
- It does not cost anything to make an Advance Statement and you do not need a solicitor. Compassion in Dying can support you to write your Advance Statement.



How can I make one?

There is no set form for making an Advance Statement. Compassion in Dying provides free forms or you can make one online using our free website: www.mydecisions.org.uk

To make an Advance Statement you should:

- **Think** about what is important to you and what you feel is important to your quality of life – you can use the questions on the previous page or our free form to help you.
- **Talk** to the important people in your life and anyone involved with your care about your preferences for treatment and care.
- **Write** your Advance Statement – it is a good idea to include your name, date of birth and address. If you cannot make your Advance Statement in writing, you can make a voice recording or a video.
- **Share** photocopies of your Advance Statement with the important people in your life, your GP and anyone else involved in your care.

Ana's story

Advance Statement

When I was first diagnosed with terminal cancer, it was such a shock. I didn't know what to think or feel. As it sank in, I realised I needed to think about what was important to me for the time I had left. I knew that I wanted to spend my time doing the things that I care about most – being involved in my local church, watching tennis, and having a pub lunch on a Sunday after a walk on the beach.

I know that as my cancer progresses I'll be less able to go out and about, and I also may not be able to tell people what I want. I would prefer to stay at home for as long as possible and have carers to help me. I've written down all of the things I want them to know, like how I enjoy watching the garden from my window, and that I love to talk about sports.

I prefer to have the TV on as background noise instead of music, and I don't like to eat a lot of dairy because it makes me feel unwell.

It's very important to me that I continue to go to church for as long as possible, and pray each day at home. The idea of being bathed by a male carer or nurse makes me feel anxious, and I'm worried that I'll be in pain.

Now that I've written these things down, people caring for me will understand what matters to me, and can make the right decisions for me.



Advance Decision (‘Living Will’)

What is an Advance Decision?

An Advance Decision allows you to record any medical treatments that you do not want to be given in the future, in case you later lack capacity and cannot make or communicate a decision for yourself.

The legal name is an Advance Decision to Refuse Treatment, and it is sometimes called a Living Will or an Advance Directive.

If an Advance Decision meets certain requirements it is legally binding and healthcare professionals must follow it.

..... Your Advance Decision will only be used if you lack capacity to make a decision.



How can an Advance Decision help me?

- An Advance Decision allows you to refuse treatment in advance, which helps to ensure you maintain a quality of life that is meaningful to you.
 - It is made by you, in your own words. This means you stay in control of your treatment, and decisions will not be left to healthcare professionals.
- Compassion in Dying provides free forms that take you through different scenarios in which you could lose capacity such as dementia, brain injury, diseases of the central nervous system, or terminal illness. The form allows you to record what treatment(s) you want to refuse in each scenario. There is also space for you to record a refusal of treatment in other situations.

Things to think about

- An Advance Decision can only be used to refuse medical treatment. You cannot use it to demand a particular treatment.
- Your Advance Decision will only apply to the treatments and circumstances that you include. It will not apply if you are in a situation that is not covered in your Advance Decision.
- You cannot use your Advance Decision to refuse basic care, such as food and drink by mouth.
- It does not cost anything to make an Advance Decision and you do not need a solicitor.



How can I make one?

There is no set form for making an Advance Decision. Compassion in Dying provides free forms or you can make one online using our free website: www.mydecisions.org.uk

To make an Advance Decision you should:

- **Think** about the quality of life that is acceptable to you. This will help you to decide if there are certain situations in which you would want to refuse treatment, or if there are any treatments you would want to refuse in every situation.
- **Talk** to the important people in your life and your healthcare team about your health, and your priorities for treatment and care.
- **Write** your Advance Decision.
- If you are refusing life-sustaining treatment, your Advance Decision must be in writing and include the words 'my refusal applies even if my life is at risk or shortened as a result'.
- If you are refusing life-sustaining treatment, you must sign and date your form in the presence of a witness. Your witness must also sign and date the form.
- **Share** photocopies of your Advance Decision with the important people in your life, your GP and anyone else involved in your care.

You should review your Advance Decision every two years, or sooner if your health changes. If you are satisfied that your Advance Decision still reflects your wishes, then you can re-sign and date your form – there is a review date section on the Compassion in Dying form.

If you want to make changes see page 40 for more information, or contact our free information line on 0800 999 2434.



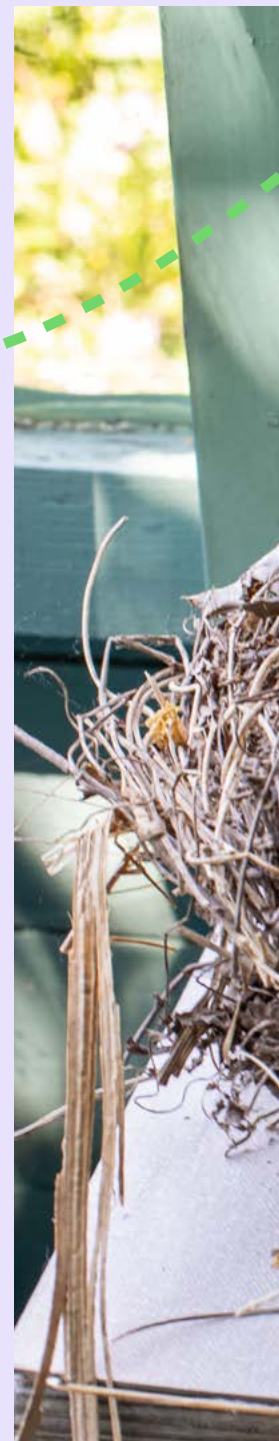
**Advance
Decision**

Elizabeth's Story

My wife had an on-going heart condition. She'd had several heart attacks and was tired of living with failing health. When she had her last heart attack, she explained to me that she didn't want any more treatment.

She told her healthcare team, and wrote her Advance Decision in case she lost the ability to tell people what she wanted. Her treatment plan changed immediately based on her wishes, and she was kept comfortable. She asked for all medication for her heart condition to be stopped, and she was given pain relief and whatever she wanted by way of food and drink.

As she became unable to swallow, she was given fluid through a drip. She drifted into a coma and her Advance Decision, which refused all further treatment for her heart condition, was followed. She died three weeks later surrounded by her family. I am so grateful that she had written her wishes down, and did not have to suffer any more pain.





Lasting Power of Attorney

What is a Lasting Power of Attorney?

A Lasting Power of Attorney (LPA) allows you to give someone you trust the legal power to make decisions for you if you lack capacity.

There are two types of LPA:

- An **LPA for Health and Welfare** covers decisions about your health and care. This could include decisions about medical treatment, where you are cared for, and your daily routine.
- An **LPA for Property and Financial Affairs** covers decisions about your money and property. This could include paying your bills, selling your house, or managing your benefits.

You can complete one or both types of LPA. If you make both, you must complete and register a separate form for each.

The person making the LPA is called the 'donor' and the person given the power to make decisions is called the 'attorney'. You can choose the same attorney for both types of LPA, or you can choose different people.

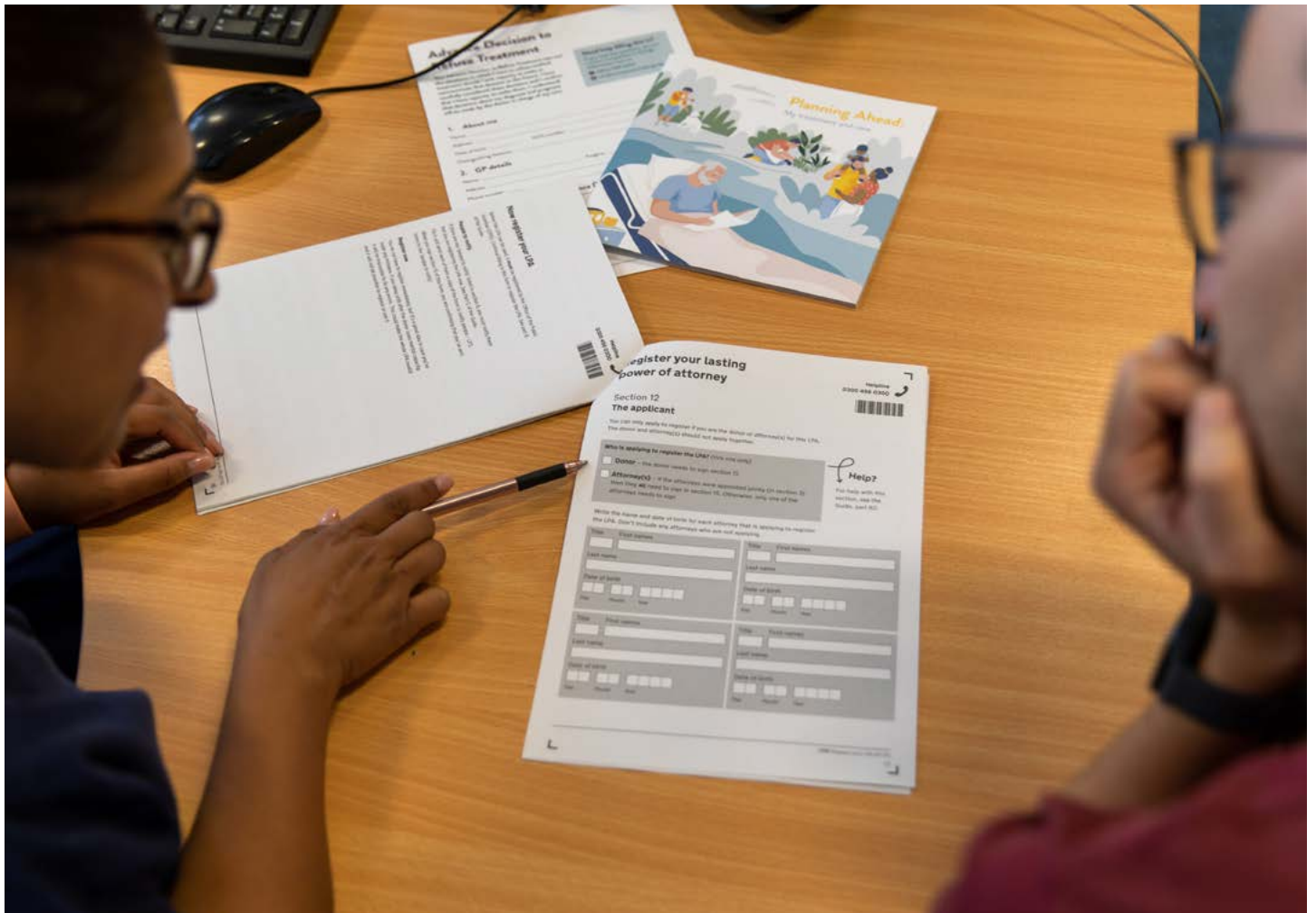
An LPA is not valid until it has been registered with the Office of the Public Guardian. The Office of the Public Guardian is a government body that manages the LPA process and has a register of all LPAs.

• The following pages refer to the LPA for Health and Welfare.

• To find out more about the LPA for Property and Financial Affairs visit: www.gov.uk/lasting-power-attorney-duties/property-financial-affairs

Enduring Power of Attorney

You might have heard of an Enduring Power of Attorney (EPA). This only covers decisions about money and property and has been replaced by the LPA for Property and Financial Affairs. If you already have an EPA, it can still be used but it will not apply to decisions about your health.



Lasting Power of Attorney for Health and Welfare

An LPA for Health and Welfare allows you to give someone you trust the legal power to make decisions about your treatment and care. The person given the power to make decisions is called the 'attorney'.

You can have as many attorneys as you like and you can choose how you want them to make decisions. For example, you might want them to have to agree on every decision they make, or you might want them to be able to make decisions individually.

When making an LPA you can include instructions that your attorneys must

follow and/or preferences that you would like them to take into account when making a decision on your behalf. For example, you can include that they must follow your Advance Statement and/or Advance Decision.

You must also choose if you want your attorneys to be able to make decisions about life-sustaining treatment. For information about how your LPA and Advance Decision work together, see page 39.

• Your attorneys will only be able to make decisions for you if you lack capacity to make decisions yourself.



How can an LPA for Health and Welfare help me?

- An LPA gives the person or people you trust the legal power to make decisions on your behalf.
- As long as your attorneys make decisions in your best interests, they cannot be overruled by anyone. Your attorneys can ask your healthcare team for advice on treatment options to help them make decisions.

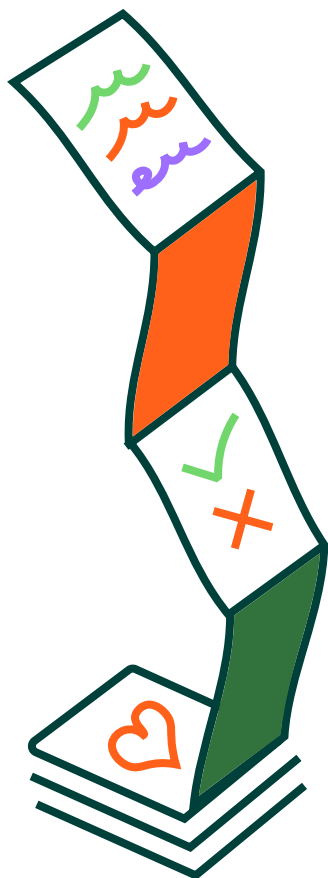
Things to think about

- You need to trust your attorneys to understand your wishes, respect your values and be able to make the best decisions for you.
- It is important that your attorneys understand their responsibilities. They must be available to support you, and be prepared to advocate for you - sometimes this may be difficult and they may need to push to ensure your wishes are followed by healthcare professionals, or other people involved in your care.
- There is a fee to register an LPA, in 2018 it was £82. It is possible to get a reduced fee if you have an income under a certain amount, or are receiving certain benefits. For more information visit:
www.gov.uk/government/publications/power-of-attorney-fees
- You do not need a solicitor. Compassion in Dying or the Office of the Public Guardian can support you to complete the forms.



How can I make one?

There are three steps to making an LPA:



1

Choose your attorneys

To make an LPA you need the following people:

- An attorney - you can choose one or more attorneys.
- A witness - someone must witness your and your attorneys' signatures and must also sign the form.
- A certificate provider - someone must check that you understand what you are doing and that nobody is putting pressure on you to make the LPA. They can either be a professional (like a GP or solicitor) or someone who has known you for at least two years (like a friend or neighbour). They must also sign the LPA form.
- People to notify - you can also include the details of anyone you would like to be told when the LPA is registered. This is optional, but it is a way to tell other people who you have appointed as your attorneys.

2

Complete the LPA form

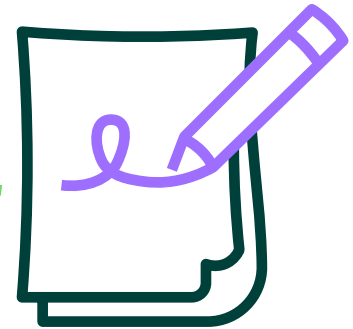
You can get an LPA form in three ways:

- Complete the form online using the Office of the Public Guardian's website:
www.lastingpowerofattorney.service.gov.uk/home
- Download the form from the Office of the Public Guardian's website:
www.gov.uk/government/publications/make-a-lasting-power-of-attorney
- Request a paper form by calling the Office of the Public Guardian on 0300 456 0300.

3

Register the form with the Office of the Public Guardian

- An LPA must be registered with the Office of the Public Guardian to be valid (this can take up to ten weeks). The way you register your LPA will depend on how you made it, for more information visit:
www.gov.uk/power-of-attorney/register



Lasting Power
of Attorney

Peter's Story

Dad had hidden his memory difficulties, and did not find talking about his health easy. But he was clear that he wanted me to support him and make decisions for him if needed, so he made me his attorney for health and welfare.

After mum died in 2009, dad was able to continue living at home despite his memory problems. He had daily support for shopping, cleaning and cooking from his carers and me.

Sadly, in 2016 we were told his kidneys had failed. He was offered dialysis, which might delay the effects by a few months, but he would have to travel to the hospital several times a week - which was a two hour drive away from his house. I was told that dad did not have capacity to make this decision, and as his attorney I would need to decide for him.

I had already spoken to dad about his priorities, and I knew that he would

like to live for as long as possible, but only if he could have the lifestyle he had at the time - living at home, spending days in the garden and watching the sea. At this point dad was 92, he did not travel easily and he found new places difficult.

Based on the limited benefits of the dialysis treatment, and dad's priorities, I believed it was best for him not to travel several days every week. I refused the dialysis treatment on his behalf, and continued to make his life comfortable and pain free. It was a very difficult decision to make. I had to explain why I was refusing the treatment to his doctors, but they understood that I was acting in dad's best interests and so they supported my decision.

He died a year later in September 2017. His last months were spent doing the things he enjoyed most, seeing his family and enjoying his garden.





Do Not Attempt Resuscitation (DNAR)

Another decision you may need to make is about resuscitation. The information below explains what a DNAR (Do Not Attempt Resuscitation) form is and how it works.

What is a DNAR form?

A DNAR form is a document issued and signed by a doctor, which tells your medical team not to attempt cardiopulmonary resuscitation (CPR) – a treatment used to try to restart a person’s heart and/or breathing.

There are many names used for a DNAR form including a DNAR order, a DNACPR order, and a ReSPECT form.

DNAR forms are designed to be easily recognised, allowing healthcare professionals to make decisions quickly about how to treat you.

A DNAR form only refuses CPR, so if you have a DNAR form you will still be given all other types of treatment for your condition as well as treatment to ensure you are comfortable and pain-free.

You can request a DNAR form from your doctor, or they can choose to discuss this with you.

A DNAR form is not a legally binding document. Instead, it is a tool used by healthcare professionals to communicate to other healthcare professionals that CPR should not be attempted. If you would like to record your wish to refuse CPR in a legally binding way, then you can make an Advance Decision. See page 18 for more information about how to make an Advance Decision.

What is CPR?

CPR stands for cardiopulmonary resuscitation (CPR). It is an emergency attempt to restart a person's heart and/or breathing if they have a cardiac arrest. CPR is used to keep the person alive while the cause of the cardiac arrest is found and treated if possible.

CPR can include:

- Chest compressions (repeatedly pushing very firmly on the chest in an attempt to pump blood around the body).
- Defibrillation (using electric shocks to correct irregularities in the heart's rhythm).
- Artificially inflating the lungs (by inserting a tube into the windpipe or by placing an oxygen mask over the mouth and nose, to push air into the lungs).
- Intravenous medication (administering medications such as adrenaline into a vein to improve heart muscle contraction and blood pressure).

The type of CPR used will depend on where the person is when their heart and/or breathing stop, and who is treating them.

How often does CPR work?

CPR success rates vary depending on how well you are in the moments before your heart and/or breathing stop, and how quickly you receive medical treatment.

Following CPR a few people make a full recovery, some will still be very unwell and need more treatment, some will never get back to the level of health they had before, and most will not survive.

No one has the right to demand a treatment, including CPR. You can record your preference to be resuscitated, but like all medical treatments, you cannot demand that it is offered to you. If someone is in cardiac arrest, only their healthcare team can decide if resuscitation is a suitable option. This means that they will take into account the person's wishes and values, and those of their family, but CPR cannot be insisted on. You can choose to refuse CPR by asking for a DNAR form and also recording this in your Advance Decision, see page 16 for more information.



Dr Khan's story

Kate was a 56 year old woman with Motor Neurone Disease (MND) who was admitted to our respite unit. Kate was feeling very anxious about the recent advances in her progressive disease, as her ability to speak and swallow was now deteriorating. She was keen to talk about her future plans and, as part of that conversation we discussed resuscitation (CPR). I explained that her disease had begun to affect her muscles, and that there was an increased risk that her lungs could stop working and her breathing would stop.

Kate had always been a fiercely independent woman who owned her own business. Her diagnosis had been a huge shock and despite trying to continue as normal, the consequences of her disease meant she had to sell her business and

reconsider her life plan. Her main concern was her quality of life. She felt sad and frustrated about not being able to communicate with her young grandchildren whom she adored.

I explained that if her breathing did stop, an attempt to resuscitate her would be very unlikely to work. At best, it might result in her needing to use a ventilator which would breathe for her. Kate was adamant that she did not want this to happen, or for her family to witness this. As a result of this conversation Kate and I agreed that CPR would not be appropriate for her. A DNAR form was added to her medical records, and the decision not to attempt resuscitation was communicated to the relevant health care professionals and Kate's family.





DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION
Adults aged 16 years and over. THIS FORM IS TO BE SIGNED BY YOU YOURSELF

DATE OF ONSET OF ILLNESS
DO NOT PHOTOCOPY
This form is to be signed by you yourself. It is not to be signed by a doctor or other healthcare professional. It is not to be signed by a family member or friend.

Advance Decision to Refuse Treatment

This Advance Decision to Refuse Treatment sets out the situations in which I want to refuse medical treatment should I lack capacity to make or communicate that decision in the future. I have carefully considered these decisions and I confirm that I have capacity to make them. I understand and confirm that decisions about my diagnosis and prognosis will be made by the doctor in charge of my care.

Need help filling this in?
If you have any questions, you can contact Compassion in Dying
Information Line on:
0 8000 999 2824
info@compassionindying.org.uk

1. About me

Name: _____ NHS number: _____
Address: _____
Date of birth: _____
Distinguishing features: _____
Surgeon: _____

2. GP details

Name: _____
Address: _____
Phone number: _____

3. I have discussed this Advance Decision with

Large empty box for providing details of discussions with healthcare professionals or others.

How to make sure people know my wishes

If you make an Advance Statement, Advance Decision or Lasting Power of Attorney, it is important that the people involved in your care know about it. There are things that you can do to make people aware of your wishes:

- ✓ **Ask your GP to keep photocopies with your medical records.**
- ✓ **Give photocopies to anyone who is regularly involved in your care.** This could be a consultant, social worker, your local hospital, and local ambulance service.
- ✓ **Give photocopies to people you know and trust.** It is important that anyone who might be contacted if you are admitted to hospital knows how your wishes are recorded.
- ✓ **Keep a copy with you, preferably the original so that you can review it regularly.**
- ✓ If you make an Advance Decision, you can contact Compassion in Dying to request a Notice of Advance Decision card to keep in your bag or wallet.
- ✓ If you make an LPA, the Office of the Public Guardian has a register of all LPAs. However, searching the register can take a long time, so it is important to show anyone involved in your care your registered LPA form.
- ✓ MedicAlert provides jewellery for people who need to convey important information in an emergency. There is an annual fee and an additional charge for jewellery. For more information visit: www.medicalert.org.uk
- ✓ Order a free 'bottle' from Lions Club International to keep a copy of your Advance Statement or Advance Decision in the fridge. Paramedics should know to look for the Lions symbol when entering someone's house. To order call 0845 833 9502.



Frequently asked questions

How will it feel to plan ahead?

Some people find it challenging to think about their current health and their priorities for the future. This may be because they have had a recent diagnosis, or they know someone who has had a bad experience at the end of life. Thinking about your values and how they affect your preferences for treatment and care is a deeply personal experience and it can bring up unexpected and perhaps unwanted emotions.

Although it can be emotionally challenging, people also find that it can be incredibly worthwhile and a relief to have things organised. After making plans for their treatment and care people say that they feel more in control, and that they have peace of mind knowing that their wishes are recorded, which allows them to get on with living life now.

“It makes living easier. It’s liberating. It is good to have discussed these important things with loved ones. It can bring you closer together. Having all these decisions made saves a lot of worry.”

Even if this does not feel easy, if it is important to you it is worthwhile doing.

Take your time.

Ask for help or support if you need it.

You don't have to do it all in one go. Some people find it easier to think about, or have conversations about their health, values and priorities in stages.



Is it difficult to plan ahead?

Some people find completing an Advance Statement, Advance Decision or Lasting Power of Attorney for Health and Welfare straightforward and can complete it on their own, and other people need more support. If you need support to complete a form or have any questions we can help.

Do I need a solicitor?

You **do not** need a solicitor to make an Advance Statement, Advance Decision or Lasting Power of Attorney for Health and Welfare. Compassion in Dying provides free support to complete these forms over the phone or by email.

If you have questions about planning ahead, we can help. Contact our free information line on:

 **0800 999 2434**

 **info@compassionindying.org.uk**

Is it expensive?

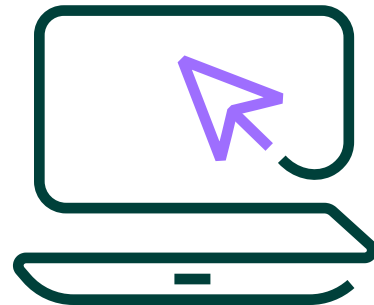
It is **free** to make an Advance Statement and/or Advance Decision. Compassion in Dying provides free forms or you can complete them online at: www.mydecisions.org.uk

There is a one-off fee when you register an LPA, in 2018 it was £82. It is possible to get a reduced fee if you have an income under a certain amount, or are receiving certain benefits. For more information see page 25.

If you would like to talk to someone about the information in this booklet contact our free information line:

 **0800 999 2434**

 info@compassionindying.org.uk



Can I have both an Advance Decision and a Lasting Power of Attorney?

You can have both an Advance Decision and a Lasting Power of Attorney (LPA) for Health and Welfare. If you do, the one that you made more recently will take priority when a decision needs to be made about your treatment or care.

If you have made an Advance Decision before registering an LPA your attorneys will be able to override what is written in your Advance Decision, if you have given them the power to make the decision in question. However your attorneys must always make decisions that are in your best interests. This includes taking into account anything that you have said or written down, including an Advance Statement or Advance Decision.

If you have made an Advance Decision after registering an LPA your attorneys will not be able to override what is written in your Advance Decision. In this situation, if a decision needs to be made about something that you have not included in your Advance Decision, then your attorneys will still be able to act on your behalf.

If you have both an Advance Decision and an LPA you should discuss your Advance Decision with your attorneys and give them a photocopy.

People often say that it is helpful to have someone's preferences for care written down when making decisions on their behalf, especially about life-sustaining treatment. Even though you should have spoken to your attorneys about your wishes, having something in writing is a great sense of support for your attorneys when making difficult decisions.

What if I change my mind?

While you have capacity you can cancel or make changes to your Advance Statement, Advance Decision, and Lasting Power of Attorney at any time.

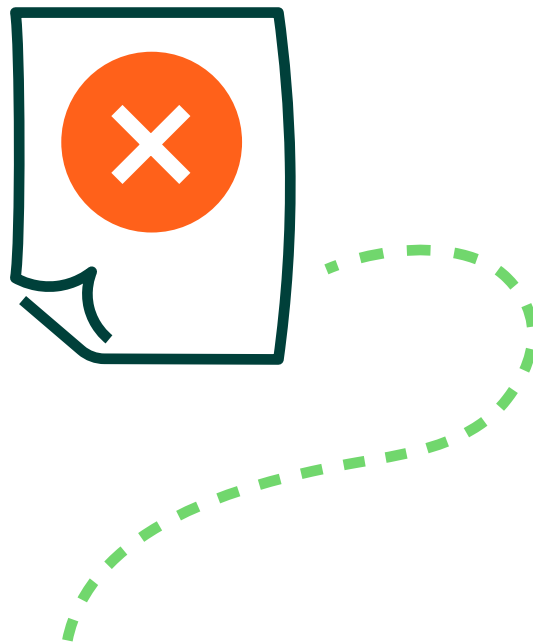
Advance Statement and Advance Decision

- You can cancel your Advance Statement or Advance Decision by destroying it (and any other photocopies you have given to other people).
- If you update your contact details or the details of your GP you can cross out the old information and write in the new details. You will need to sign and date next to the change, but you do not need to fill out a new form.
- If you would like to make other changes to your Advance Statement or Advance Decision then it is a good idea to make a new one. If you make changes to the existing form, it could make it hard for people to read. Filling out a new form will ensure that your wishes are clear and easy to follow.

Lasting Power of Attorney for Health and Welfare

- To cancel or make changes to your Lasting Power of Attorney you will need to contact the Office of the Public Guardian on 0300 456 0300.

Your Advance Statement, Advance Decision, and Lasting Power of Attorney for Health and Welfare will only be used if you lack capacity to make decisions for yourself.



Can anyone override my wishes?

While you have capacity you have the right to make decisions about your treatment and care. You can decide if you want to consent to or refuse treatment, and no one can override your wishes.

If you lack capacity and you have:

Made an Advance Statement

It is not legally binding, which means people can override it. But an Advance Statement must be taken into account when someone is making a decision on your behalf.

Made an Advance Decision

If it meets certain requirements and applies to the situation you are in, it is legally binding and must be followed. This means no one can override it.

Made an Advance Decision and an LPA for Health and Welfare

If you have made an Advance Decision before registering an LPA for Health and Welfare your attorneys can override your Advance Decision. However your attorneys must always make decisions that are in your best interests. This includes taking into account anything that you have said or written down.

If you have made an Advance Decision after registering an LPA for Health and Welfare, and your Advance Decision meets certain requirements and applies to the situation you are in, then no one can override it.

If there is a disagreement over how someone is being treated or cared for, you can talk to us:

 **0800 999 2434**

 **info@compassionindying.org.uk**

About Compassion in Dying

We can help you prepare for the end of life. How to talk about it, plan for it, and record your wishes.

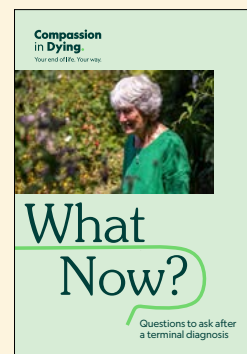
We help people through our free information line, publications and resources, and through our work with diverse communities. We specialise in supporting people to make Advance Decisions ('Living Wills') and to talk about their goals and priorities when living with a life-changing illness. Our free MyDecisions website helps people to record their wishes for care in a legally binding way.

Have any questions? Talk to us.

 **0800 999 2434**

 **info@compassionindying.org.uk**

Our publications include:



Other sources of information and support

General services

Citizens Advice Bureau (CAB)

A charity that provides independent, confidential and impartial advice to everyone on their rights and responsibilities, including work, benefits, housing, immigration and health.

T 03444 111 444 (England)

T 03444 772 020 (Wales)

W www.citizensadvice.org.uk

Samaritans

A charity that provides confidential, emotional support for people to discuss anything that they are worried or concerned about.

T 116 123

T 0808 164 0123 (Welsh Language Line)

W www.samaritans.org

Office of the Public Guardian

A Government body that protects people who do not have capacity to make certain decisions for themselves. They are responsible for registering Lasting Powers of Attorney.

T 0300 456 0300

W www.gov.uk/government/organisations/office-of-the-public-guardian

Services for older people

Age UK

A charity that provides support and information on money, care and health for people in later life.

T 0800 055 6112

W www.ageuk.org.uk

FirstStop

An independent and impartial service offering advice and information to older people, their families and carers about housing and care options for later life.

T 0800 377 7070

W www.firststopcareadvice.org.uk

Independent Age

A charity that specialises in providing independent and confidential information on care and support, money and benefits, and health and mobility for older people, their families and carers.

T 0800 319 6789

W www.independentage.org

Lions Club International

A membership organisation which empowers volunteers to serve their communities, meet humanitarian needs, encourage peace and promote international understanding.

T 0845 833 9502

W www.lionsclubs.org

The Silver Line

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

T 0800 470 8090

W www.thesilverline.org.uk

Healthcare services and end of life care

Dying Matters

A coalition which aims to help people talk more openly about dying, death and bereavement.

W www.dyingmatters.org

Hospice UK

A charity that supports hospices to provide the highest quality of care to people with life-limiting or terminal conditions and their families. You can use their website to find hospice services in your area.

T 020 7520 8200

W www.hospiceuk.org

Marie Curie

A charity that provides information about hospice services and nursing care for people with a terminal illness.

T 0800 090 2309

W www.mariecurie.org.uk

MedicAlert

A non-profit membership organisation providing jewellery that alerts healthcare professionals to key medical information.

T 01908 951 045

W www.medicalert.org.uk

Patients Association

An advocacy service for patients, providing specialist information and advice about health and social care services, including how to make formal complaints.

T 020 8423 8999

W www.patients-association.com

Sue Ryder

A charity that provides person-centred hospice and neurological care for people facing a life-changing diagnosis.

T 0808 1644 572

W www.sueryder.org

Services for carers

Carers Trust

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

T 0300 772 9600

W www.carers.org

Carers UK

A charity that provides information and support for carers.

T 0808 808 7777

W www.carersuk.org

Benefits and financial information

Turn2Us

A charity that helps people in financial need to access welfare benefits, charitable grants and other financial help.

T 0808 802 2000

W www.turn2us.org.uk

Services for specific conditions and illnesses

Alzheimer's Society

T 0300 222 1122

W www.alzheimers.org.uk

British Heart Foundation

T 0300 330 3322

W www.bhf.org.uk

Cystic Fibrosis Trust

T 0300 373 1000

W www.cysticfibrosis.org.uk

Dementia UK

T 0800 888 6678
W www.dementiauk.org

Huntington's Disease Association

T 0151 331 5444
W www.hda.org.uk

Macmillan Cancer Support

T 0808 808 0000
W www.macmillan.org.uk

Mind (mental health charity)

T 0300 123 3393
W www.mind.org.uk

Motor Neurone Disease Association

T 0808 802 6262
W www.mndassociation.org

MS Society

T 0808 800 8000
W www.mssociety.org.uk

MS Trust

T 0800 032 3839
W www.mstrust.org.uk

Muscular Dystrophy UK

T 0800 652 6352
W www.muscular dystrophyuk.org

Parkinson's UK

T 0808 800 0303
W www.parkinsons.org.uk

Prostate Cancer UK

T 0800 074 8383
W www.prostatecanceruk.org

Rethink Mental Illness

T 0300 5000 927
W www.rethink.org

The Stroke Association

T 0303 3033 100
W www.stroke.org.uk

Terrence Higgins Trust (HIV charity)

T 0808 802 1221
W www.tht.org.uk

Compassion in Dying.

At Compassion in Dying, we want people to be in control of their end-of-life decisions because there is no-one better to make them.

**We champion everyone's right to make informed decisions.
Free of cost and free of judgement.**

Contact us

181 Oxford Street, London, W1D 2JT

T 0800 999 2434

E info@compassionindying.org.uk

W www.compassionindying.org.uk

f www.facebook.com/compassionindying

@ [@agooddeath](https://twitter.com/agooddeath)

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Compassion in Dying is committed to ensuring the independence and integrity of our products and services. No conflicts of interest were identified during the development of this booklet.



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