

Compassion
in **Dying.**

Your treatment and care:

Planning ahead for the LGBT community



**OPENING DOORS
LONDON**

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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.

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What is this booklet for?

Most people have some form of opinion about how they would like to be treated at the end of their lives, regardless of their identity or background. For LGBT people in particular, your identity might have an impact on the treatment and care you would like to receive.

This guide is here to help you record your wishes to ensure they're respected if you can't make a decision for yourself or tell people what you want. It provides an introduction to the ways you can plan ahead for your future treatment and care, by making a:

- Lasting Power of Attorney for Health and Welfare
- Advance Decision
- Advance Statement

It 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.



Introduction

What is planning ahead?

There may come a time when you become unwell and can't tell the people around you what you do and don't want. Planning ahead is a way to record your wishes so that if you are ever in this situation, they are known about and can be followed.

Why should I plan ahead?

You have the right to make decisions about your medical treatment and care. You can decide if you want to consent to treatment and you can also decide to refuse treatment, even if doing that puts your life at risk. But, if you lack capacity to make a decision, the healthcare professional in charge of your care (such as a hospital doctor or GP) 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 the decisions you would want.

Many people think that those close to them can make decisions about their care or treatment if they are unwell but this isn't always the case. Even though these people must be consulted when a decision is made, they won't have the final say.

What is capacity?

Capacity is the ability to make a decision for yourself. It's time and decision-specific. This means that whether or not you have capacity depends on when the decision needs to be made and what the decision is. So, you might lack capacity to make a decision on one day but be able to make that decision at a later date. This might be because you have dementia and your ability to remember information differs from one day to the next.

You might have capacity to make some decisions but not others. For example, you might have capacity to decide what you want to eat every day but not to make a decision about refusing 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 of these things:

- Understand information relating to the decision
- Retain 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's proven otherwise.

Planning ahead is a way to express who you are and what's important to you now, in case you're later unable to make a decision for yourself. Recording your wishes gives you control over your future treatment and care and reassurance that the right decisions will be made. It can also be a good way to start conversations with those close to you about what you want in the future.

“It felt empowering, like I had taken control. It allowed me to get on with enjoying living now.”



Next of kin and significant other

The term next of kin is sometimes misunderstood. Your next of kin is someone you can name to be kept informed or be contacted in certain situations, for example if you are taken to hospital from your GP surgery or have an accident at work. It doesn't have to be a relative or partner – you can choose anybody, including a significant other. You don't have to choose anyone if you don't want to.

People in the LGBT community are sometimes worried that those traditionally seen as 'next of kin', such as family members, will automatically make decisions on their behalf. This isn't true. **Your next of kin doesn't have any legal power and won't be able to make decisions about your care or treatment if you lack capacity.** This is the same with a family member or a significant other – they don't have any legal rights to make decisions on your behalf either.

To give someone else legal power to make decisions about your health or care you must make a Lasting Power of Attorney. This is explained in more detail on page 7.

How can I plan ahead?

There are three main ways that you can plan ahead and record your wishes. You can make a Lasting Power of Attorney, an Advance Decision and an Advance Statement.

You can make all three or you might feel that one is better for you than another. The following pages give more information. The “how can it help me” sections explain when each one could be useful.

Lasting Power of Attorney for Health and Welfare

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 if you lack capacity to make those decisions. The person making the LPA (you) is called the ‘donor’ and **the person given the power to make decisions is called the ‘attorney’**.

There are two types of LPA:

- An LPA for Property and Financial Affairs covers decisions about your money and property. This could include paying your bills, selling your house or collecting benefits.
- 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 or your daily routine.

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 and registered but it will not apply to decisions about your health.

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 agree unanimously on every decision they make, or you might want them to be able to make decisions separately.

When making an LPA you can include instructions that your attorneys must follow or preferences that you would like them to take into account.

You must also choose if you want your attorneys to be able to make decisions about life-sustaining treatment.

How can it help me?

- It gives you the chance to say who you want to make decisions for you – you can choose the person you trust and who knows what you would want.
- It means the person you trust will have the legal power to make decisions on your behalf – decisions won't be left to healthcare professionals.
- As long as your attorney makes decisions in your best interests, they can't be overruled by anyone, including family members.

Dave's Story

Dave is a 68 year old gay man. He lives alone and his partner of 18 years died in 2002. He has a small and close group of friends who he has known for a long time.

He has a brother and sister but hasn't spoken to either of them other than at events such as their mother's funeral, in the last thirty or so years. Whilst his brother has never expressed a real problem with him being gay, Dave's sister refuses to acknowledge or accept that he is gay which led to them falling out and not speaking.

Dave is worried that should something happen to him, people who he barely knows may be consulted by doctors about his treatment. He adamantly doesn't want his sister involved in decisions about his care as he doesn't trust that she has his best interests at heart. He is less anxious about his brother being involved, but still feels uncomfortable with someone he barely knows anymore having a say about how he is treated.

He would much prefer for his close friend Chris to be able to make decisions about his medical treatment. Dave has known Chris for a long time and trusts him to make the decisions that he would want.

Dave decides to make a Lasting Power of Attorney for Health and Welfare and appoints Chris as his attorney.



Things to think about

- Your attorney will only be able to make decisions for you if you lack capacity to make those decisions yourself.
- You need to trust your attorney to understand your wishes, respect your values and be able to make the best decisions for you.
- To make an LPA you need the following people:
 - At least one person to be your attorney
 - Certificate provider – someone who signs the form to check that you understand what you are doing and that nobody is putting pressure on you. 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)
 - Witness – someone must witness your and your attorneys' signatures and must also sign the 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 is a way to make sure people are kept informed of what's happening with your care
- Registering an LPA can take up to three months.
- You do not need a solicitor to make an LPA.

How can I make one?

There are three key steps to making an LPA:

1. Choose your attorney and the other people involved
2. Complete the LPA form
3. Register the form with the Office of the Public Guardian (OPG)

An LPA must be registered with the OPG before it can be used. The OPG is a government body that manages the LPA process and has a register of all LPAs.

It costs £82 to register an LPA but it's possible to get reduced fees if you have an income under £12,000 or are receiving certain benefits.

You can get an LPA form in one of three ways:

- Ask the OPG to send the form to you: 0300 456 0300
- Download it from their website:
<https://www.gov.uk/government/publications/make-a-lasting-power-of-attorney>
- Complete it online using their digital tool:
www.lastingpowerofattorney.service.gov.uk/home

Advance Decision

What is it?

An Advance Decision allows you to record any medical treatments that you don't 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 used to be known as a Living Will.

It will only be used if you lack capacity to make a decision for yourself.

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

How can it help me?

- If you don't feel you have anyone else you trust to make decisions for you, an Advance Decision is a way to make sure your wishes are respected.
- It's in your own words – it means that you stay in control of your treatment and decisions won't be left to healthcare professionals.
- It helps to make sure that you maintain a quality of life that is meaningful to you.

"I felt it was better not to think about things in case it made them happen but when I did, I felt relieved."

"Don't allow someone else's issues or barriers prevent you from expressing your wishes."



Jane's Story

Jane is 46 and has been with her wife Esther for 8 years. They have a 3 year old daughter called Alice.

Esther is in remission from breast cancer. After watching Esther go through treatment Jane started to think about what she would want for herself if she was ever in that situation. She has also seen her dad have a stroke and be unable to communicate for two weeks before he died and is really concerned about what would happen if the same thing happened to her.

Watching Esther go through treatment for breast cancer also made Jane realise that she and her wife have very different views about how they'd like to be treated. Esther was clear she would fight to the end if needed but Jane really wouldn't want to put herself, Esther or Alice through that if she lacked capacity. She is also worried that Esther may push doctors to continue to treat her until the end and she isn't sure she wants that. She wants a record somewhere of what treatment she doesn't want and in what circumstances.

Jane decides to make an Advance Decision refusing life-sustaining treatment if she has a stroke or a terminal illness. She talks to Esther about her wishes and also her GP, who puts a copy with her medical records.



Things to think about

- An Advance Decision covers refusals of medical treatment, you cannot use it to demand a particular treatment.
- Your Advance Decision will only apply to the treatments and circumstances that you write about. It will not apply if you are in a situation that is not covered in your form.
- It does not cost anything to make an Advance Decision and you do not need a solicitor.



How can I make one?

Compassion in Dying provides free forms or you can make one online using our free website:



There is no set form for making an Advance Decision, so you can write one yourself as long as it meets the requirements needed to be ‘valid’ and ‘applicable’.

To make an Advance Decision you should:

- **think** about what you want and the situations you would want to refuse treatment in
- **talk** to those close to you about your wishes
- **write** your Advance Decision
- **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
- **sign** and date your Advance Decision form in the presence of a witness. Your witness must also sign and date the form
- **share** a copy of your signed and witnessed Advance Decision with the people close to you, your GP and anyone else involved in your care

Advance Statement

What is it?

An Advance Statement is a general statement of anything that is important to you in relation to your future health or wellbeing. It can contain your preferences for care or treatment, information about your views on quality of life or any religious or spiritual beliefs that inform the choices you make. It should be taken into account by anyone making a decision on your behalf if you lack capacity.

Things you might want to cover include:

Anything important to your identity

- Is there a name different to your given name that you would like to be called?
- What are your preferred pronouns?
- Do you prefer wearing certain clothes?
- Is there anything you would not want to wear?
- Do you practice a particular religion?

Place of care

- Would you like to be cared for at home?
- Would you like to go into a hospice if you are at the end of life?
- Would you prefer a private room if you were in hospital?

Treatment preferences

- Do you prefer tablets or liquids?
- Do you take any particular painkillers?
- Do you have any allergies?

Food and drink

- What foods do you like or dislike?
- Are you vegetarian?
- Do you drink tea or coffee?

Quality of life

- Do you value your independence?
- Do you like to go outside?
- Do you enjoy listening to music?

Wishes for after death

- What type of funeral would you like?
- What would you like to happen to your body after you die?

How can it help me?

- It's a way to explain to others who you are if you can't communicate for yourself - it helps the staff treating you know how to care for you.
- It helps to make sure your preferences will be taken into account by healthcare professionals – an Advance Statement must be considered by anyone making a decision in your best interests.
- If you don't have anyone to explain what's important to you and your quality of life, an Advance Statement helps to make sure that your wishes and what's important to your identity will be known about.

Phil's Story

Phil is a 42 year old trans man. He transitioned in his mid-thirties with the support of his GP, who knows him very well.

Every time Phil has been into hospital there has been some confusion or problem because of his trans status. He finds that people still refer to him by his previous name in conversations and finds it tiring and stressful to constantly 'out' himself with every new doctor or nurse that consults his records. He has spoken about this with his GP and they have worked out a process where he tells any healthcare professionals to contact her if they have any questions about his medical records. She can then answer the repetitive and basic questions about how he should be treated so Phil doesn't have to.

Phil is concerned that if he loses capacity he won't be able to tell healthcare professionals how he likes to be known and to contact his GP if there are any questions. Phil is also a Buddhist and wants to make sure that some of his possessions are around him if he gets ill. He wants a place where he can record all of this information if he is ever unable to communicate himself and decides to make an Advance Statement.







Things to think about

- A healthcare professional doesn't have to follow the exact instructions in your Advance Statement but they must consider it when making a decision in your best interests.
- An Advance Statement can include any information you would like someone else to know about you.

How can I make one?

Compassion in Dying provides free forms or you can make one online using our free website:



To make an Advance Statement you should:

- **think** about what you want to include, you can use the questions on the previous page to help you
- **talk** to those close to you about your wishes
- **write** your wishes down. It is also a good idea to include your name, date of birth and address and to sign and date the document
- **share** a copy of your Advance Statement with the people close to you, your GP and anyone else involved in your care



Other questions

Can I have both an Advance Decision and an LPA for Health and Welfare?

Yes, you can have both an Advance Decision and an LPA. 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.

For example, **if you have made an Advance Decision before registering an LPA**, your attorney(s) will be able to override what is written in your Advance Decision, as long as you have given them the power to make the decision in question. However your attorney(s) 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 attorney(s) 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 attorney will still be able to act on your behalf.

If you have both an Advance Decision and an LPA you should make sure that you tell your attorney about your Advance Decision and give them a copy.

Do I have to talk to my doctor about what I want?

If you are able to, it's a good idea to speak to your doctor about your wishes. Your doctor can:

- help you to understand your treatment options so you can decide what's right for you
- help you to think through any decisions about medical treatment, making sure you understand how any decisions or choices will affect you

However, you don't have to discuss things with your doctor, but even if you don't it's still important to make sure your wishes are recorded on your medical notes. If they're not then they might not be known about and followed.

Will my doctor talk to other people about my health and care?

Your doctor won't share any information about you with other people unless you give them your permission to do so.

You can choose who you'd like to be given information about your health and care. You should talk to your GP or other healthcare professionals about who you'd like your details to be shared with. You should also tell them if there is anyone you specifically don't want to be given information. You can include this information in an Advance Statement.

If you have a Gender Recognition Certificate, this shouldn't be disclosed by anyone in an official capacity unless you give your permission. Examples of people in an 'official capacity' include doctors, care home staff and social workers.

How will people know what my wishes are?

If you make an Advance Decision, Advance Statement or LPA, it's very important that the people involved in your care know about it. **There are a few things that you can do to make people aware of your wishes:**

- Ask your GP to keep copies with your medical records.
- Give copies to anyone else who is regularly involved in your care. This could be, for example, a consultant, social worker or your local hospital.
- Give copies to your friends, family members and other people close to you. It's important that anyone who would be contacted in the event of you being involved in an emergency knows where your wishes are recorded.
- Keep copies on your person.
- If you make an Advance Decision, you can contact Compassion in Dying to request a Notice of Advance Decision card. This is a card that you can keep in your wallet to alert people to the fact that you have an Advance Decision. There is space on the card for you to write the name and contact details of someone who has a copy of your Advance Decision.
- If you make an LPA, the OPG has a register of all LPAs which can be searched. However, it can take a long time for the register to be searched. So, it's important to let anyone involved in your care know who your attorneys are.

Can the law override my wishes?

If you make an Advance Decision then, as long as it meets the requirements to be valid and applicable, it must be followed by healthcare professionals and can't be overruled by anyone, even a family member.

If you make an LPA, the person you choose to act as your attorney has the legal authority to make decisions about your health and welfare on your behalf. As long as they make decisions in your best interests, they can't be overruled.

A healthcare professional doesn't have to follow the exact instructions that you write in an Advance Statement but it must be considered as evidence of your expressed wishes when anyone is making a decision in your best interests.

Remember that while you have capacity, you will still make decisions about your medical care and treatment.

What happens if I am discriminated against?

The law that says you must not be discriminated against is the Equality Act 2010. This states that you have a right not to suffer discrimination in NHS services and should be treated as an individual with respect and dignity.

If you feel that you have been discriminated against because of your gender identity or sexual orientation there are a few things that you can do. This includes making a complaint or, if necessary, taking legal action.

For more information about discrimination, contact Stonewall.

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.

T 0800 999 2434

E info@compassionindying.org.uk



Further sources of help and support

Stonewall

Stonewall is here to let all lesbian, gay, bi and trans people, here and abroad, know they're not alone. We believe we're stronger united, so we partner with organisations that help us create real change for the better.

Stonewall's Information Service can answer your questions on issues affecting lesbian, gay, bi or trans people. Contact us for more information about our work, details on LGBT rights and contacts for local groups and LGBT friendly services.

Phone; 08000 50 20 20

Email; info@stonewall.org.uk

Web; www.stonewall.org.uk/help-advice

Opening Doors London

Opening Doors London is the biggest project providing information and support services with and for older Lesbian, Gay, Bisexual and Trans* people in the UK.

If you would like to join us, need support, or think you can help, get in touch. Visit www.openingdoorslondon.org.uk or call 020 7239 0400

*The asterisk following the word trans and the LGBT acronym has been introduced by the community to indicate the most inclusive method of including the full spectrum of non-binary and gender nonconforming individuals who identify under the very diverse umbrella term of trans.

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.

Contact us

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