


END OF LIFE CHOICES

Your guide to Advance Decisions
and Statements of End of Life
Wishes.

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A photograph of two hands, one slightly larger than the other, clasped together in a supportive grip. The hands are positioned at the top of the page, with the fingers interlaced. The background is a plain, light color.

This guidance and the Advance Decision form apply to England and Wales. The law is different for Northern Ireland and Scotland.



LEGALLY BINDING: ADVANCE DECISIONS

ADVANCE DECISIONS

An Advance Decision is a legally binding document that tells medical and healthcare professionals about any treatments that you don't want, when you are unable to communicate your wishes. An Advance Decision is also known as an Advance Decision to Refuse Treatment and they are sometimes called 'Living Wills'.

An Advance Decision comes into force if you're unconscious or incapacitated, or if you've lost the mental capacity to make decisions about what's best for you. In an Advance Decision, you set out the circumstances when you want medical professionals to understand that you refuse certain treatments and which treatments you want to refuse. You must include a statement to the effect that it is to apply to that treatment even if your life is at risk or shortened as a result. When you make an Advance Decision:

- You must be over 18
- You must have mental capacity – 'be of sound mind'
- It must be in writing and signed by you in the presence of a witness. The witness must also sign it in your presence and then you must date it.

You need to think carefully about the circumstances and situations when you do not want to be given treatments. You can change your mind at any time and revoke your Advance Decision, or make a new Advance Decision and get the latest one signed, dated and witnessed.

You can't refuse basic care like hygiene, or food and drink by mouth – but you can refuse to be fed artificially.

ADVANCE DECISIONS

You can't ask medical or health professionals or anyone else to help you to die – it's currently not legal. However, you can say that if medical assistance to die becomes legal, you'd want an assisted death, and set out the circumstances when you'd want assisted dying care.

You will need to tell your family, friends and medical and health professionals that you have an Advance Decision, and say where to find it. You don't need to get legal advice to make an Advance Decision, but we do recommend that you get it checked by an appropriate person to make sure it is properly completed, signed and witnessed.

You might also like to consider including in your Advance Decision an account of your Life Values. This could include information about your health, your ethical reasons for your choices and why you have made the decisions that you have. You can for example say you have carefully considered the decisions you've made about refusing treatments, and that you haven't been pressured or coerced in any way. Make sure you don't contradict your Advance Decision by anything you say in your account of your Life Values.

My Death, My Decision has a template Advance Decision form which includes space for you to set out your account of Life Values too. It also includes an optional Statement of End of Life Wishes – there is an explanation of that below.

If you feel confident that you can make your own Advance Decision then our form might be suitable for you – have a look:

<https://www.mydeath-mydecision.org.uk/wp-content/uploads/2021/04/Advance-Decision.pdf>

FURTHER RESOURCES

If you want personal assistance or advice in making your Advance Decision, these organisations have further useful guidance and provide individual support:

www.adassistance.org.uk/make-an-ad/

<https://compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/advance-decision-living-will/>

<https://www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment/>

LEGALLY BINDING: LASTING POWERS OF ATTORNEY



LASTING POWERS OF ATTORNEY

While you are considering such important matters as Advance Decisions, you are likely to want to think about Lasting Powers of Attorney (LPAs) too. There are two different types of LPA, one for Property and Financial Affairs, one for Health and Welfare. It is outside the scope of this note to address them in detail, but in the context of health matters, it is important to consider an LPA for Health and Welfare when you are also looking at Advance Decisions.

Like an Advance Decision, you can only make an LPA when you have mental capacity. There are greater formalities involved and it must be registered with the Office of the Public Guardian to be valid. That costs £82 (as at April 2021) and takes up to 12 weeks to process. There is more information about LPAs here: <https://www.gov.uk/power-of-attorney>

The key thing to bear in mind is that your attorneys (the people you nominate to make decisions on your behalf) can only use an LPA for Health and Welfare to make decisions for you if you no longer have mental capacity to do so yourself. The decisions your attorneys can make depend on what you specify – they can include far broader issues than an Advance Decision, like day-to-day care, where you live (e.g. at home or in a care home), as well as decisions about life-sustaining treatment.

Since an LPA gives your attorneys the ability to make critical health and welfare decisions on your behalf, it is important to select people you can trust completely.

INTER-RELATIONSHIP BETWEEN ADVANCE DECISIONS AND LPAS

The main difference between an Advance Decision and an LPA is that through an Advance Decision you make your own choice about the treatment you wish to refuse. With an LPA, you give the decision-making to your attorneys.

There is also an important timing issue that needs to be borne in mind if making an Advance Decision and an LPA. If you make an Advance Decision followed by an LPA, your attorneys under the LPA could override the decisions in your Advance Decision. On the other hand, if you make an Advance Decision after your LPA, if you lose mental capacity your attorneys would not be able to consent to any treatment which you specifically stated should be refused in your Advance Decision.

A close-up photograph of two hands clasped together. The hand on the left is wearing a grey and white patterned sweater, while the hand on the right is wearing a brown sweater. The background is a soft, out-of-focus field of dry grass under a clear sky.

NOT LEGALLY BINDING: **STATEMENT OF END OF LIFE WISHES**

STATEMENT OF END OF LIFE WISHES

The Advance Decision form ([link above](#)) includes a section called ‘Statement of End of Life Wishes’, which is not legally binding. It is optional whether you complete this section.

A Statement of End of Life Wishes sets out what a person wants when they are nearing the end of their life and just after their death. It has no legal status, but it’s much more likely that medical and care providers and those close to you will follow your wishes if you’ve written them down and, even better, also talked to people about what your wishes are.

Your Statement is a very personal record of all the things you want the people caring for you at the end of your life to know – about how you want to be treated and looked after, what’s important for others to know about you as you approach your death and what happens after your death.

The My Death, My Decision Statement of End of Life Wishes template can be used as it is, with you filling in sections that are relevant to you, or deleting sections that don’t apply. Or you may prefer just to use the MDMD template as a guide and write your own, personal version.

Medical assistance to die is not legal in the UK. You can’t ask for assistance to die, nor can you refuse basic care, although you can ask to be sedated to relieve any suffering if you have chosen to refuse treatments, and you can refuse food and drink and ask for any care, such as washing, that causes you distress, to be stopped, and pain relief given, even if it shortens your life.

STATEMENT OF END OF LIFE WISHES

My Death, My Decision is working hard to change the law to allow the choice of medical assistance to die for adults of sound mind who are terminally ill or intolerably suffering. Having a Statement of End of Life Wishes mentioning your attitude to assisted dying and also setting out your views and wishes will contribute to evidence that your refusal of treatments and medical interventions is well-considered, of long-standing, and made freely without pressure or coercion.

My Death, My Decision is working with GPs and other health professionals to encourage the government to set up a register of Advance Decisions, similar to registers for Lasting Powers of Attorney for Health and Welfare and Financial Powers of Attorney.

PUTTING YOUR AFFAIRS IN ORDER?



PUTTING YOUR AFFAIRS IN ORDER

As you're someone who is making an Advance Decision and Statement of End of Life Wishes and thinking about personal responsibility for your own health decisions, it's likely you'll have made a Will and possibly also a Lasting Power of Attorney for Health and Welfare. My Death, My Decision recommends that you use a solicitor or professional will-writing service to ensure your Will is valid and that all your wishes are followed.

It's not necessary to get a solicitor's advice to make a legally binding Advance Decision, but you should check carefully that your Advance Decision is correctly completed and witnessed.

A gift in your Will, or an instruction in a Letter of Wishes with your Will or codicil, could help change the law on assisted dying. My Death, My Decision campaigns for an assisted dying law that would give adults of sound mind who are either terminally ill, or suffering from an incurable condition they consider intolerable, the choice of an assisted death. My Death, My Decision will press for any such law to include robust safeguards to satisfy independent medical assessors that the person is fully informed, has made a well-considered and consistent request and has not been coerced.

As a not-for profit grassroots movement almost entirely run by unpaid volunteers, My Death, My Decision relies on gifts and donations from supporters who believe the law must change - whatever the amount donated or left to us in a Will, all gifts will help to make the law on assisted dying more just and compassionate.

PUTTING YOUR AFFAIRS IN ORDER

Any information you share with us will be treated with respect and in confidence, and you can change your gift any time.

Your gift could bring about a lasting legacy – a change in the law on assisted dying to benefit generations to come. Thank you so much for supporting our campaign and for considering making a donation or a legacy.

PUTTING YOUR AFFAIRS IN ORDER

Title

Name

Email Address

Address

Postcode

Contactable Number

Tick as applicable:

- ☐ I have already included a donation to My Death, My Decision in my Will
- ☐ I intend to leave a donation to My Death, My Decision in my Will
- ☐ I have instructed my executor in a Letter of Wishes to make a donation to My Death, My Decision
- ☐ I would like to talk to the Chair of My Death, My Decision about leaving a gift in my Will to My Death, My Decision
- ☐ I don't want to leave a gift in my Will but I will make a donation to the cause now

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