

Living with a life-limiting condition:
planning for the future



palliative,
neurological
and bereavement
support

Contents

- 3 Introduction
- 4 Setting up a lasting power of attorney
- 7 What is an advance care plan?
- 10 Do I need a will?
- 11 When should I make a will?
- 12 What do I need to include in my will?
- 12 How do I make a will?
- 17 Can I change my will?
- 18 Making things easy to find

Introduction

When you're facing a life-changing diagnosis, it can save your family unnecessary distress at an already difficult time to have your wishes clearly set out.

This leaflet explains things you might need to think about when planning for the end of your life. As the law is different in Scotland, the advice only applies to people living in England and Wales.



Setting up a lasting power of attorney

As you become more unwell, you are likely to find it more difficult to manage your money and financial affairs, and you may become too unwell to make decisions about your health and care. If you are worried about what will happen if this occurs, you can give someone you trust power of attorney to make decisions and take care of things on your behalf.

What is a power of attorney?

In England and Wales there are two types of lasting power of attorney. You can set up one or both.

- **A property and financial affairs lasting power of attorney** lets someone manage all your financial affairs – for example, running your bank and savings accounts, paying your bills and collecting your benefits or a pension. It can be used as soon as it's registered, with your permission.
- **A health and welfare lasting power of attorney** lets someone make decisions about your health, care and welfare – for example your daily routine (e.g. washing, dressing, eating); your medical care; and life-sustaining treatment. It can only be used when you're unable to make your own decisions.

The person or people who will manage your finances or make decisions about your care on your behalf are called your 'attorneys', and they're usually friends or family members. The person giving power of attorney (you) is called the 'donor'.

Do I need to set up a power of attorney?

You may find it reassuring to know that someone you trust will be able to make decisions on your behalf if you become too unwell. This is particularly the case for illnesses such as dementia, which will increasingly affect your ability to understand things and make your own decisions. Even if you do not have an illness that will affect your thinking and reasoning, your speech and communication may well be affected as your illness progresses, making it tiring and more difficult to have detailed discussions about what you want.

You can set out some of your preferences to do with your health and care in an advance care plan but these only apply to the specific treatments and circumstances you write about in the document. There may still be some decisions to make which you didn't include when you wrote the advance care plan. The people involved in your care will try to make the decision they believe is in your best interests and in accordance with your wishes, but if someone has power of attorney for your health and welfare, that person can make the decision on your behalf.

When should I set up power of attorney?

In general, if you decide that you would like to set up a power of attorney, it is better to do it sooner rather than later. This is because you can only set up a power of attorney when you have the mental capacity to make your own decisions. 'Mental capacity' means that you are able to understand information and make and communicate your decision. At the point you need to receive end of life care, you are likely to be too unwell to set up a power of attorney.

Usually the power of attorney will only come into force once it has been registered. Registration with the Office of the Public Guardian takes 8–10 weeks so it might be a good idea to do this sooner rather than later too, in case your condition changes suddenly. Setting up a power of attorney doesn't mean you have to give up control, as it can ONLY come into force when you lose capacity. If you lack capacity and there is no welfare attorney appointed, doctors have a duty to act in your best interest taking into account your wishes as you may have expressed them to relatives or friends.

If you have already lost capacity and do not have a lasting power of attorney in place for your financial affairs, your partner or family members will not be able to access your money to pay for any care you need or to pay any bills. Emergency applications for people with lack of capacity can be made, for more information see www.gov.uk/court-of-protection

If you change your mind, you can always cancel the lasting power of attorney by notifying the attorneys and Office of the Public Guardian, even if it's been registered; as long as you still have mental capacity.

What do I need to do to set up a power of attorney?

There are three key steps in setting up a power of attorney:

1. Choosing your attorney(s). Your attorney can be anyone over the age of 18, but should always be someone you trust to understand and respect your wishes and make the best decisions for you. Most people choose someone like their husband, wife, partner, another family member or a close friend. You might want to choose more than one attorney. If you do, you can say whether they need to make decisions jointly or whether each can decide things without the other (this can be a good way for people to share the work).

Make sure that each person agrees to be your attorney before you name them in your lasting power of attorney.

2. Completing the form. In England and Wales, you can get the forms and guidance you need from the Office of the Public Guardian who can send the form to you, or you can download it from their website or complete it online.

Often a solicitor will be happy to visit you at home and help you to draw up your power of attorney. Once you have completed the forms you need to send these back to the Office of the Public Guardian. They'll check that the forms have been completed accurately and if there are errors or problems they'll return the forms to you.

3. Registering your lasting power of attorney. You must register your lasting power of attorney or your attorney(s) won't be able to make decisions for you. There is a fee of £110 for registering it in England and Wales.

Each institution your attorney deals with, for example your bank, pension provider, mortgage company, GP or other care providers will need to see either the original relevant power of attorney or a copy that's been signed by a solicitor (this is called a 'certified' copy), so you may want to get several signed copies when it's drawn up. Bear in mind that getting different organisations to recognise the power of attorney may in itself take time.

What is an advance care plan?

An advance care plan or advance statement is a written statement that sets out your wishes, beliefs, values and preferences about your future care. It provides help for healthcare professionals, and anyone else who might have to make decisions about your care if you become too unwell, to make decisions or to communicate them.

Do I have to have an advance care plan?

You don't have to have an advance care plan, but you may find that it gives you reassurance to know that you will be cared for in the way you would prefer, if you become unable to make decisions or communicate your wishes.

Although health and social care professionals have a duty to consult friends and relatives, even those close to you may not know how you would want to be cared for and can't make decisions on your behalf unless they have power of attorney for your health and welfare. If you plan how you want to be cared for in advance, not only do you know that your care will be right for you, but people making decisions on your behalf will be reassured that they are following your wishes.

Once the plan is written, you can continue to make changes to it if you change your mind.

What does an advance care plan include?

An advance care plan can cover any aspect of your future health or social care and can include anything that's important to you

Examples of things you may like to include in your plan are:

- how you like to do things, for example if you prefer a shower instead of a bath, or like to sleep with the light on
- how you want any religious or spiritual beliefs you hold to be reflected in your care
- which people – such as close friends or family – you would like to be involved in your care
- who you would like to be consulted if there are decisions to be made about your care and treatment
- where you would like to be cared for when you are dying
- any practical issues you have concerns about, such as who will look after your dog if you become ill

Can I choose to stop treatments I don't want?

As part of your advance care planning, you may want to say if there are particular treatments you don't want to have. This is called an 'Advance Decision to Refuse Treatment' (known as an ADRT for short). It lets your family, carers and health professionals know whether you want to refuse specific treatments in the future, and is only used if you are unable to make or communicate your own decisions.

You can use an Advance Decision to set out specific circumstances in which you would not want a particular treatment to be given, or when a treatment should be stopped. This can include refusing treatments that could potentially be used to keep you alive. For example, you might decide to refuse ventilation if you can't breathe by yourself or to refuse antibiotics for life-threatening infection. An Advance Decision can't include a request to have your life ended.

If you are thinking about whether there may be some treatments that you would want to refuse in the future, it is worth talking it through with your health professional, who can help you understand what might happen and your different options. You may also want to talk about it with people who are important to you, and make them aware of any decisions you make.

Although you don't need a lawyer to write an Advance Decision to Refuse Treatment, Advance Decisions do have to contain certain wording to be legally binding, and therefore it is best to follow a template form.

If you have put a lasting power of attorney in place to make decisions about your healthcare if you are unable to, you should let them know if you create an Advance Decision to Refuse Treatment, so they can ensure that your wishes are followed.

What do I need to do to create an advance care plan?

You can fill in an advance care plan on your own, but you will probably find it more helpful to talk about it with your healthcare team. They know about your health and will be able to explain your likely treatment and care options, and what those options will mean for you and anyone caring for you. They can also talk to you about how realistic your preferences are and any alternatives if it isn't possible to meet your wishes. For example, you may feel that you would like to die at home, but if you don't have anyone who can support you at home, it may be more realistic for you to be cared for in a hospice.

It is also important to talk about your wishes and preferences with the people who are important to you. Although it may be difficult for you to talk together about the end of your life, and they may not agree with all the choices you want to make, involving them can help you to think through some of your options, and it can help them to understand what you want, so they can follow your wishes as far as possible.

Once you have created your advance care plan it will be added to your medical notes, so that anyone involved in your care is aware of your wishes.

Will I definitely be cared for the way I ask?

An Advance Decision to Refuse Treatment is legally binding (as long as it contains certain wording). An advance care plan is not legally binding, but anyone who is making decisions about your care must take it into account. In some cases, it may not be possible to follow your wishes. For example you may prefer to be cared for at home, but you develop a new symptom that can't be managed at home.

In these cases your healthcare team will always talk with you, or the person you have nominated to act on your behalf (see the section on setting up a lasting power of attorney), about the best way to care for you in the circumstances.

Can I change my mind?

The plan is not set in stone and you can change your mind about anything you put in your advance care plan as long as you still have mental capacity. In fact it is quite common for people to make changes to their advance care plan. If you do change your mind about something, simply let your healthcare professional know, and they will ensure that any changes are written down, so everyone involved in your care knows your preferences.

Do I need a will?

People often feel that because they are not leaving much they don't need to make a will. But making a will is important because:

- A will makes it much easier for your family or friends to sort everything out when you die – without a will the process can be more time consuming and stressful.
- If you don't have a will, everything you own will be shared out in a standard way defined by the law. People you would like to leave something to – such as a partner you are not married to or in a civil partnership with – may end up with nothing. Having a will is the only way to ensure that your money and possessions are shared between the people and causes you care about in the way that you want. You can even specify simple things, like people you would like to leave particular sentimental items to.

- Without a will, no one knows your wishes, and the people who are important to you may have to make some difficult decisions. And may even argue about how your estate should be divided up.
- If your estate is worth more than £325,000, a will can help to reduce the amount of inheritance tax that may be payable on the value of any property and money that you leave.
- Writing a will is especially important if you have children, a partner you are not married to or in a civil partnership with or other family who depend on you financially. Or if you want to leave something to people outside your immediate family.

When should I make a will?

People often put off making their will, thinking that it's something they can do at a later stage. In theory you can write your will at any time, but if you put it off, time often runs away with you, and you may find you are coping with other things and don't feel able to make a will. By the time you are receiving end of life care or are in a hospice, or if you leave it until you are very unwell, you may not be able to make a will, as you may be considered by the law to lack mental capacity.

It is better to do it when you are reasonably well and are feeling up to it. Knowing you have done it can also help to clear your mind of unnecessary worries, helping you to relax and make the most of the time you have.

“When I mention about making a will, people say to me ‘I’m not that bad yet, am I?’, but I always tell people it’s better to do it when you’re feeling well and up to it, than waiting until you feel awful or become too ill.”

– Pam, Sue Ryder specialist palliative care doctor.

What do I need to include in my will?

Your will should set out:

- whom you want to benefit from your will (your beneficiaries)
- who should look after your children if they are under 18
- who is going to sort out your estate and carry out your wishes after your death (your executor)
- what happens if the people you want to benefit die before you

Funeral wishes can also be included in a will.

How do I make a will?

Making a will is your opportunity to make sure that the people and charities that you choose will benefit from your estate, so it is worth taking the time to think through what you want and to ensure that your will is legal and valid.

The main things you need to do are to:

- plan what you are leaving and to whom
- work out whether you need professional advice
- choose an executor
- draw up your will
- make sure your will is legal
- keep your will safe

Plan what you are leaving and to whom

- Make a list of who you want to include in your will. You might want to include your partner, civil partner or spouse, children and other family members, friends and charities. These people (or charities) are called your beneficiaries.
- Write down your assets (things like your savings, any property you own and any valuable items) and a rough idea of what they're worth. You should also think about any sentimental items that you might want particular people to have.
- Think about how you want to split your assets between the people you've listed. You may find it helpful to think about what's important to you. For example it might be things like making sure that your partner is provided for, or ensuring that your grandchildren get the best education. Thinking about these things will make it easier to work out what to leave to whom.

Getting professional advice

One of the most common areas people need advice on is inheritance tax. The Inheritance Tax threshold is currently £325,000 for an individual or up to £650,000 for a married couple or a couple in a civil partnership. If your estate is worth more than this when you die, Inheritance Tax (currently 40%), will have to be paid on the excess. The rules aren't straightforward. If you think you're near the limit you need to get more information on how to legally avoid it or minimise the amount – which could save thousands of pounds. You'll probably want to get professional advice to help with this.

Choose your executors

The person who sorts out your property when you die and carries out the instructions in your will is called your executor. It can be a complicated job even if your instructions and your property are quite simple – it's not unusual for the process to take several months and the job of an executor is sometimes difficult. For example, they might have to decide when to sell your property so that the people who inherit the money from the sale of your property get the most money.

You can appoint up to four executors, but people normally appoint two, in case one is unwilling or unable to act for you when the time comes. An executor may also be a beneficiary in your will, so you can choose your partner or children (providing they are 18 years old). There may be advantages of using somebody who is familiar with your affairs, but a solicitor can also do this if you'd like to save the people close to you the job at what is likely to be a difficult time. It is always good to check with whoever you plan to name as your executor that they are happy to take on the job!

In case you were thinking of asking us, Sue Ryder declines any request to act as executor.

Draw up your will

The more complex your financial affairs, the more sensible it is to take advice from a solicitor. Using a solicitor may be cheaper than you might think, and it means that you have peace of mind of knowing it's been done properly. You should definitely consider using a solicitor if your family position is complicated.

You might need a solicitor if:

- your estate may have to pay inheritance tax (currently, you'll have to pay if your estate's value is more than £325,000)
- you've got a complex family situation, like former partners or estranged children, and you want to be sure how your estate can be divided
- you want to protect someone's interests after you've gone, like a disabled family member, or
- you want to talk through the options with an expert or you need some support you can trust
- you plan to leave out anyone who would expect to inherit, for example, a son or daughter

If you already have a solicitor they will often come out to you at home or in a hospice to help you write your will. Otherwise you might ask a friend for a recommendation, or you can search the Law Society database for a solicitor near you: solicitors.lawsociety.org.uk

The riskiest way to write a will is to do it yourself, and we do not recommend this as an option. Possible consequences of getting it wrong include that the will might be invalid or not have the effect intended. The only time you might choose to do this is if your affairs are very simple – for example if you're married or in a civil partnership, you have no children, and you want to leave everything to your spouse or civil partner when you die. But you should remember that the law about inheritances and how they're taxed can be complex, and things might change between you writing your will and when you die. That makes it risky to write your own will without any advice at all.

If you are getting support from a family support team and/or social worker they can normally help you think through what support you might need to draw up your will but will not be able to recommend an individual solicitor or firm.

Make sure your will is legal

Particularly if you are doing your will yourself, you need to make sure that your will is legal. For it to be legally valid, you must:

- be 18 or over
- make it voluntarily
- be of sound mind
- make it in writing
- sign it in the presence of two witnesses who are both over 18
- have it signed by your two witnesses, in your presence – although you need to be aware that if someone acts as your witness, neither they nor the person they are married to or have entered into a civil partnership with, can inherit anything in your will.

Keep your will safe

You can keep your will at your home or you may well be able to store it with your solicitor or bank. There are also companies that store wills – you can search for these online.

If you decide to keep your will at home, make sure you tell your executor (the person you've chosen to carry out your will), close friend or relative where your will is.

If you have updated an existing will (other than by creating a codicil - see page 17) or replaced one, you should destroy all the copies of the old will, to avoid any confusion or problems.

Can I change my will?

If you already have a will, you may well need to review it, particularly if there have been any major changes in your life such as:

- getting separated or divorced
- getting married or entering into a civil partnership (this cancels any will you made before)
- having a child
- moving house
- if an executor named in the will dies and you need to replace them
- you move abroad or acquire property in another country

If you already have a will and want to make some small changes – such as making a specific gift to a person or organisation – it may not be necessary to change the whole document. It is wise to consult your solicitor, but you may be able to record any changes by creating a codicil, which is a legally binding document that alters or adds to your existing will. A codicil must be signed and witnessed in the same way as a full will to make it legal.

If you want to make substantial changes, it is better to create a new will. A new will normally includes wording that cancels all previous wills with words such as 'I hereby revoke all previous wills, codicils and testamentary provisions made by me at any time and declare this to be my last will.'

Making things easy to find

Although you probably know where you keep everything, it will make it easier for your friends and family to sort things out when they need to if you have put the things they are likely to need together in a safe place. And don't forget to let your executor and your family know where all these things are!

The kinds of things it is helpful to put in one place:

- bank statements
- credit card statements
- mortgage information
- details of savings and investments – things like share certificates, Premium Bonds and pension plan statements
- tax certificates such as your P60
- birth and marriage certificates
- divorce papers
- passport
- driving licence
- your will
- deeds of the house
- insurance policies (e.g. life, home and car insurance)
- funeral wishes

If you deal with things like your bills and bank accounts online then printing out some copies will help.

Digital legacy

You might like to leave instructions for what you would like to happen to your social media accounts and online presence after you die. Anything in your will is subject to the terms and conditions of the online account provider, so you might want to check with your provider what would happen.

“It’s comforting to know that you’re not alone”

When someone you care about is dying or has died, it’s comforting to know that help is never far away. Sue Ryder’s Online Community is a safe place to go for free, 24/7 practical and emotional support when you’re coping with the loss of a loved one.

Available from your computer, tablet or mobile and moderated by Sue Ryder, our community is there to support you whenever and wherever you need it.

Join our community at www.sueryder.org/support



Contact us

Sue Ryder Supports people through the most difficult times of their lives. Whether that's a terminal illness, the loss of a loved one or a neurological condition – we're there when it matters.

For over 65 years our doctors, nurses and carers have given people the compassion and expert care they need to help them live the best life they possibly can. We take the time to understand what's important to people and give them choice and control over their care. For some this may mean specialist care in one of our centres, whilst others might need support in their own home.

For more information about Sue Ryder

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