MACMILLAN CANCER SUPPORT

PLANNING AHEAD FOR THE END OF LIFE

Scotland

> As a family, we know this was what Dennis wanted, and we all agreed to help his wife Joyce cope with his care.

Adrienne, who helped her father-in-law Dennis plan his care, before he died.

About this booklet

This booklet is about some of the ways you can plan ahead and make choices about your future care if you live in Scotland. It is for anyone who wants to plan ahead, whether they have a serious illness or not.

Planning for your future care is also called anticipatory care planning. It is important in case you ever become unable to make choices yourself. For example, this could be if your health changes and you became unconscious or lose capacity (the ability) to make decisions about treatment.

This booklet should help you to:

- think about what is important to you and the ways you can plan ahead
- talk about your plans with the people close to you, and with the health and social care professionals involved in your care
- start making plans so that the people involved in your care know what is important to you – for example by writing a will, or making a power of attorney or advance directive.

We hope it helps you deal with some of the questions or feelings you may have.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 5 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 90 to 96, there are details of other organisations that can help.

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

Quotes and cover

In this booklet we have included quotes from people who have been involved in anticipatory care planning. Some are from our Online Community (**macmillan.org.uk/community**). The others are from people who have chosen to share their story with us. This includes Adrienne, who is on the inside front cover of this booklet. In this booklet, Adrienne shares the story of her father-in-law Dennis and how his family helped plan his care before he died. The cover of this booklet shows Megan, Dennis's granddaughter and Joyce, his late wife. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Contents

PLANNING AHEAD

Why is it important to plan ahead?

Many people think they do not need to make decisions about their future care unless they are diagnosed with a serious illness or are very unwell. A serious illness might include advanced cancer, heart disease, chronic obstructive pulmonary disease (COPD), motor neurone disease (MND) or early dementia.

However, planning ahead is important whether you have a serious illness or not. None of us can know for sure that we will always be able to make our own decisions about our care. For example, if you suddenly became very ill, you may be unable to make decisions about your healthcare or finances.

Knowing your wishes can make it easier for your family, or anyone with a power of attorney for you. It will help them to make decisions about your care on your behalf, with your healthcare professionals. If you plan your care in advance, there is more chance that your care will be right for you. Planning ahead can also help you to feel more in control of your life. You will still be able to alter your plans if you change your mind later.

Your healthcare

Planning ahead is also important because healthcare professionals cannot always know how you would like to be cared for in certain situations. For example, they may be unsure of what your wishes would be if you became unwell and were unable to talk to them.

Only you know what is most important to you, and how and where you would like to be cared for. Even your close family and friends may not know this, if you have not told them in advance. This could mean you are not cared for in the place or way you would have chosen.

For example, if you had an illness that could not be cured and your condition suddenly got worse, you may want to be cared for at home. If your family or healthcare team did not know this, and you were too ill to tell them, you may be taken to hospital. You may also be offered treatments that you may not want to have.

> ‘When you are in your 20s making a will feels very far away. And it can be an emotional task, so people put it off. But if you don’t make a will your wishes won’t be heard. By writing a will you are more in charge of your life.’
>
> **Teresa**

Your finances

You may also want to plan how you will pay bills and access your money if you are unwell and unable to be at home. You may want to arrange for a family member or friend to do this for you.

It also can be helpful to think about how you will get help in an emergency, and how emergency services can access your home.

> ‘I’m a very practical person and while I never thought that I was going to die when I was diagnosed with cancer, I did feel that I needed to get my affairs in order. I’ve made a will and a list of other things I should get sorted if I die. For me, it’s about making the burden more manageable for my family.’
>
> **Samixa**

How you can plan ahead

There are several ways you can plan ahead. We have listed them here, but you do not have to do them all. Many people find it helpful to start with the ones that are most relevant or important to them.

Writing a will

Writing a will makes sure your wishes are followed after you die. It means that your loved ones are provided for in the way you want. It is easier to make a will when you are feeling well.

A will is a legal document that gives instructions about who you want to give your money and belongings to when you die. It may also include instructions about:

- who you would like to look after your children or anyone who is dependent on you (dependants)
- any specific funeral arrangements you want.

There is more information about writing a will in our booklet **Your step-by-step guide to writing a will** (see page 86).

Your wishes for your care

You can talk to people about your wishes and what matters to you, but it is usually better to write them down. These can include any specific wishes about how and where you would prefer to be cared for if you become unwell. This may be at home, or in a hospital, care home or hospice. You can use a document to help plan and write down your wishes for your care.

Power of attorney

A power of attorney is a legal document that lets you choose (appoint) someone to make decisions for you. In Scotland, there are three types of long-term power of attorney.

Before any type of power of attorney can be used, it needs to be registered with the Office of the Public Guardian.

Continuing power of attorney

A continuing power of attorney is for financial decisions and legal decisions. It includes things like paying bills, managing your bank accounts or selling your home. A continuing power of attorney can be used when you are still able to make your own decisions but want help with managing your finances or home. Or, you can set it up so that it can only be used when you are unable to make decisions for yourself.

Welfare power of attorney

A welfare power of attorney is for health and care decisions. It includes things like treatment, care, medication and where you will live or be cared for. A welfare power of attorney can only be used if you become unable to make decisions yourself.

Combined power of attorney

A combined power of attorney is a combination of the first two types. It gives financial and welfare powers to the same person.

Advance directives

You can write down your wishes about any treatments you do not want to have in the future. This is in case you are not able to tell your doctors or family yourself at the time. These are called advance directives (see pages 51 to 61).

Organ and tissue donation

You might want to write down your wishes about organ and tissue donation (see pages 63 to 67). You may want to donate your body for medical research or teaching. If it is possible for you to do so, you might also want to write this down.

Funeral planning

You may want to be involved in planning your funeral. It is also possible to pay for your funeral in advance. There is more information about funeral planning on pages 69 to 75.

Who can help you with planning ahead?

You may not always be able to make decisions for yourself if you become unwell.

If you have cancer or another illness, you might find it hard to plan ahead. You may already be struggling with fears and uncertainties about the future. It is important that you do not feel alone when planning ahead. There are healthcare and other professionals who can help you, as well as your family and friends.

Professionals

If you want to start planning ahead, you can talk to your:

- GP
- district nurse
- specialist nurse
- social worker
- hospital doctors.

They will be able to tell you the best person to speak to. If you are thinking about making a will (see pages 23 to 29) or creating a power of attorney (see page 12), you can contact a solicitor to help you.

Starting a conversation about planning ahead may feel difficult. You could start with something like:

'I've been thinking about making plans for my future care, just in case something happens to me and I can't make decisions for myself. I wonder whether you could help me, or tell me who could help me find out my options and explain what I need to do?'

Family and friends

If you can, it is helpful to involve people who are close to you, such as your family and friends. They may be able to help you think through some of the issues, so you can plan ahead better. It will also help them know what your wishes are, so they can help make sure they are carried out.

Your plans may involve your family members or friends taking on more responsibility for your care or making decisions for you. For example, this might need to happen if you would like to die at home. It is important to discuss this with them. Talk with them about whether they think they will be able to help look after you, and what worries they might have.

You can also talk to the healthcare professionals looking after you. They can tell you more about the support that might be available and about other care options.

If they do not want to talk about it

Sometimes family and friends do not want to talk about planning ahead. They may not seem able to think about the future. They may not want to talk about your worries, or they may change the subject when you try to talk about them. If you find this difficult to cope with, try explaining why it is important for you to plan ahead.

You could also ask them to read this information so you can talk about it together when you feel ready. Perhaps start by reassuring them that this is something you want to do and that it would help if you could talk to them about it.

You could try saying something like:

‘I know it’s difficult, but I would really like to talk to you about how I would like to be cared for if I became very unwell.’

Coping with your emotions

Planning ahead can cause many different emotions, particularly if you are already coping with an illness. You may feel sad, anxious and scared. These are normal reactions when coping with uncertainty about the future. Even if you are well, thinking about how you would like to be cared for if you were to become seriously ill can cause lots of difficult feelings.

There are many people who can help you cope with your emotions. Talking to close family members or friends can help. Health and social care professionals can also give you support. This could be your GP, specialist nurse, social worker or hospital doctor. You may also find it helpful to join a support group, or talk things through with a support organisation (see pages 90 to 96).

If you feel you need more support, ask your GP, specialist nurse or hospital doctor about finding a counsellor. Counsellors can be very helpful, particularly if you do not feel like talking about your feelings with people close to you.

Planning ahead can be hard. But it may help you feel more in control of your life and your future.

How to plan ahead

You can plan ahead in simple steps. You do not need to follow all these steps in order. Do what feels right for you and take your time.

Find out about the different ways you can plan ahead

We have information about the different ways you can plan ahead (see pages 11 to 13). You may find it helpful to contact another organisation for more information and support. For example, you could contact Good Life, Good Death, Good Grief or the Law Society of Scotland (see pages 90 to 91). It is your decision whether you use just one way or many ways to plan ahead.

Talk to your family and friends

They may be able to help you decide on your plans, and it may also help them feel involved.

Talk to a health or social care professional

It may take some time to discuss your plans. The professionals helping you will not expect you to rush into making any plans, unless you are sure about them. It might take several months before you feel ready to make plans for your future care or treatment.

Write your plans down

Ask a healthcare professional if they have a specific document for writing down your wishes for your care or making an advance directive. These are also called living wills.

Key Information Summary

Your healthcare professionals may record some of your wishes for your care on a Key Information Summary (KIS). This is a care summary that has information about what is important to you, including your wishes. A KIS document makes sure that this key information is available for professionals involved in your care to refer to when your GP surgery is closed. This includes out-of-hours GPs or paramedics. Your healthcare team can tell you more about the KIS document.

Keep your documents safe

Make sure important documents can be found easily and quickly by your family, friends, and health or social care professionals. Tell your family and GP where they are kept. Wills can be recorded at **nationalwillregister.co.uk**

Review your documents regularly

Reviewing your documents is important, as it makes sure they still reflect your most recent wishes. Your wishes might change over time, especially if your situation changes. You can review your documents with your health and social care professionals. They will help you write down any changes you want to make to your plans, and make sure everything is up to date. It is also important to regularly talk to the people close to you about any changes in your wishes.

Make changes to your plans if you need to

You can make changes to your plans at any time. If you do change any of your plans, you may want to talk to your family and friends first. You will need to make sure that everyone involved in your care knows. This includes your GP and other healthcare professionals.

You should also write down your new wishes, even if this is not a legal requirement for the plan you want to change. Writing down your wishes and sharing them makes sure that everyone involved in your care knows what they are. Updating your KIS document will ensure this happens.

It is a good idea to speak to a solicitor if you want to:

- make a will (see pages 23 to 29)
- create a power of attorney (see pages 43 to 49).

This is because these are important legal documents. You can also talk to a solicitor about making an advance directive.

You may find it helpful to use our planning ahead checklist at the back of this booklet. You can use it to keep a record of:

- the ways you have planned ahead
- important contacts
- where you keep certain documents.

Make sure someone close to you knows where you keep this checklist.

MAKING A WILL

Why is making a will important?

A will is a legal document. It gives instructions about who you want to give your money and belongings to when you die. Writing a will makes sure everything you leave when you die goes to the people you want it to.

What you leave when you die is called your estate. This is made up of:

- everything you own, including money, property and belongings
- your share of anything you own jointly with someone else.

Anything you owe is taken off the value of your estate. For example, the value of a mortgage would be taken off.

As well as instructions about money and belongings, your will can also include instructions about:

- who you want to look after your children – this person is called a legal guardian
- funeral instructions
- who you want to sort out your estate – this person is called an executor.

If you die without making a will, this is called dying intestate. There are laws about how your property will be passed on. These are called the rules of intestacy. They say:

- who should sort out your estate
- who your estate should be passed on to.

If you die without a will, it can take much longer to deal with your estate. It may also mean your money and belongings will not go to the people you would have chosen.

Involving a solicitor

Making a will is not as expensive or difficult as you might think. But it is a legal document and must be prepared properly. So it is best to use a solicitor. They will make sure your wishes are clear and are carried out exactly as you want.

If you need help finding a local solicitor, you can contact the Law Society of Scotland. It is a good idea to look around or ask for a few quotes to find the right solicitor for you.

Macmillan has a list of organisations that can offer a discounted will-writing service. You do not have to leave a gift to Macmillan in your will to get a discount.

The organisations offer a range of online, telephone and face-to-face services. Visit **macmillan.org.uk/willwriting** to find out more.

Things to think about when making your will

It will help to think about the following things before you meet with a solicitor.

The value of your estate

Make a list of everything you own, and how much each thing is worth. These are your assets. They might include your:

- house
- car
- jewellery
- bank and building society accounts
- savings accounts
- life insurance policies.

Then, make a list of everything you owe and how much this adds up to. These are your liabilities. They may include how much is left on your mortgage and any overdrafts, credit card debts and bank loans. An overdraft is any money you take out of your bank account after your balance reaches zero.

Add up the value of everything you own and take away the total amount you owe. This will give you the value of your estate.

Who to include in your will

Make a list of all the people, pets or charities and organisations you would like to include in your will. Consider the types of gifts you want to leave them. For example, this may be a specific amount of money, or an item with financial or sentimental value.

Other important information

Other things you will need to think about include:

- who you want to follow the instructions in your will – this person is called an executor, and should be someone you trust
- who you want to be the legal guardians of any children you have who are under the age of 16
- who you want to look after any relatives who are dependent on you
- what, if any, funeral instructions you have
- who you would like to look after your pets, if you have any.

If you need help or more information, talk to your solicitor. They can also tell you about the role of your executors.

We have more information about making a will in our booklet **Sorting out your financial affairs** (see page 86).

You can also find more information about making a will from organisations (see pages 90 to 96) such as:

- Age Scotland
- Citizens Advice Scotland
- the Law Society of Scotland.

Meeting with a solicitor

You can make a will face-to-face with a solicitor or over the phone.

When you talk to your solicitor it will help to have your completed lists of:

- the things you want to leave in your will
- names of people you want to include in your will
- names of your executors – the people you want to carry out the instructions in your will
- names of people you want to be guardians for your young children
- names of people you want to look after relatives who are dependent on you.

After your meeting or phone call with a solicitor, they should arrange a follow-up appointment with you. This is to check that they have written your will the way you want it. It will then need to be witnessed and signed.

It is a good idea to update your will if your situation changes. For example, you should update it if you get married or divorced, or have more children or grandchildren. Or you may need to update it if your financial situation changes.

Leave your original will in a place where it will be safe and easily found. For example, you can leave it with your solicitor. Keep a copy yourself and make sure your executors know where to find it.

YOUR WISHES FOR YOUR CARE

Your wishes

When planning ahead, you may want to think about how and where you would like to be cared for. This is in case your health changes and you become too unwell to tell other people your wishes.

It is better to write down your wishes and what is important to you. You might want to use our What's important to me document at the back of this booklet. This will help your family, friends and health care professionals know how you would like to be cared for.

These statements about your preferences and wishes are not legally binding. This means they cannot be enforced by law. But healthcare professionals will use them to help guide decisions they make about your care.

Your written wishes and preferences for your care might be called an anticipatory care plan. There are different documents that can be used to record your wishes. They include a booklet and an app called My ACP. Visit **ihub.scot/project-toolkits/anticipatory-care-planning-toolkit/anticipatory-care-planning-toolkit/** for more information. You can ask your healthcare professional which documents are used in your area.

It can be reassuring for family and friends to know that you have recorded your wishes. Make sure they know where you keep your documents.

Talking about your plan

Try to talk about your plans with your family or a close friend before you write down your wishes. This can be helpful if you want them to:

- be involved in your care
- help you make the best decisions about your treatment and care.

It is also important to talk about your plans with the healthcare professionals looking after you. This includes your GP or specialist nurse. You may want to talk with them about how serious your illness is and what might happen in the future.

Knowing what support is available in your area can help you get back some control in your life.

You can talk to a healthcare professional about whether your wishes are realistic. For example, you may hope you can stay at home when you are dying. They can talk to you about whether this might be possible. If your wishes are not realistic, try to think of some other options.

It is also helpful to think about who will look after:

- anyone you are caring for (your dependents)
- any pets you have.

If it is not possible to follow your wishes

It may not always be possible to follow your wishes when you become more unwell. For example, you may want to be cared for at home by a family member. But if they become ill or too tired, they may not be able to do this.

You may not have any family members or close friends who can support you. Sometimes healthcare professionals can arrange care for you, so you can stay at home. If this is not possible, they will plan for you to have the best possible care somewhere else. This may be in a care home, hospital or hospice.

> ‘Mum and I discussed her wishes, so that as her next of kin, I knew what she wanted. I do wish we’d talked to medical professionals about options for end of life care though. It would have been good to know what the options are.’
>
> **Marlene, who cared for her mum**

What to include in your wishes for your care

Try to include what is most important to you. If you are worried about a particular part of your care, you can write a plan of what you would want.

The plan might include the following:

- Where you would most like to be cared for when you cannot look after yourself. For example, you might want to be cared for at home, or in a hospital, care home or hospice.
- Where you would prefer to be cared for when you are dying. Again, this could be at home, or in a hospital, care home or hospice.
- What kind of care and treatments you would like. But remember, you cannot demand specific treatments.
- Any spiritual, religious or cultural practices that you would like to be included in your care.

- Who you would like to be part of your care. For example, you might want family members or close friends to be involved.
- Who you would like to make decisions about your care if you become unable to make the decisions yourself. You may want to set up a power of attorney so that others can act on your behalf (see page 44). You can find more information about power of attorney in Scotland by looking at The Office of Public Guardian **publicguardian-scotland.gov.uk** and My Power of Attorney **mypowerofattorney.org.uk**
- Whether you want to choose more than one attorney or a replacement attorney, in case your original attorney is unable to act on your behalf.
- Who you would like to look after any pets. We have more information about this on our website (see page 86).

Writing down your wishes for your care

Ask your health care professionals if they have a document where you can write down your wishes and preferences.

There may be a specific document that is used where you live. Or you can use our What's important to me document which you can find at the back of this booklet.

Once you have completed the document, share it with anyone who is, or is likely to be, involved in your care.

This may include:

- a family member
- a close friend
- your nurse
- your GP or hospital doctor.

The healthcare team looking after you will keep a copy of some of the information for their records. You also need to keep a copy in a safe place at home. Tell people involved in your care where it is. You might have a fridge sticker with information on. If you need to call an emergency doctor or paramedic, the sticker can tell them where you keep your documents. This is so they can follow your wishes. Your family or carers can also help make sure your wishes are followed.

It is important to regularly review your wishes and keep them up to date. You can change your mind at any time. But remember you need to make sure you record your changes. You also need to tell certain people and give them an updated copy of the document. You should tell the following people if you make any changes to your plan:

- your family or next of kin
- your community nurse
- your GP
- your hospital doctor.

Having a Key Information Summary (KIS) ensures everyone knows what your wishes are.

If you are admitted or transferred to a hospital, care home or hospice, take your written plan with you. Show it to the staff looking after you, so they know what your wishes and preferences are for your care.

On the next page is an example of some of the information included on a What's important to me document.

Your preferences and priorities
In relation to your health, what has been happening to you?
My doctors have told me that I am now only receiving care to control my symptoms. It is no longer possible to cure my illness.
What are your preferences and priorities for your future care?
If I were to become more unwell, I would like my wife to be involved in making decisions about my care. I would also like to be kept fully informed about what is happening to me.
Where would you like to be cared for in the future?
I do not mind where I am cared for, as long as my family are close by.

Date	18/01/20

An example of writing down your wishes for your care

Below and on the opposite page, Adrienne talks about how her father-in-law Dennis wrote down his wes for his care.

‘In February, my father-in-law Dennis was diagnosed with small cell lung cancer. Unfortunately, the treatment did not work and in August the doctors told him that he would not benefit from any further treatment. Although disappointed, Dennis was relieved to stop, as it was exhausting him.

During the next few months, Dennis was referred to the community Macmillan nurse. They helped him and my mother-in-law, Joyce, talk to each other about the fact that he was dying.

As an ex-district nurse myself, I was keen for the district nurses to discuss with Dennis and Joyce his preferred priorities for care and write them down. The district nurses were reluctant at first. But when I spoke to them again they said Dennis had expressed a wish to die in a hospice. I knew this was not the case as he was petrified of hospices and had previously refused to attend the day hospice centre. I asked the district nurses to go back and speak to Dennis about his wishes, and help him write them down using the Preferred Priorities for Care document. One of the district nurses phoned me back to say Dennis had stated, and written down, that he wanted to die at home (and not in a hospice as the district nurses had suggested) as long as Joyce could cope. As a family, we knew this was what he wanted and all agreed to help Joyce.

Over the next few weeks Dennis became weaker. GPs suggested transferring him to the hospital or hospice, but each time we were able to show them his written Preferred Priorities for Care document and insist he stayed at home.

We had nurses overnight some nights and the family took it in turns the other nights. In October, Dennis died at home, in his own bed, with his dog Murphy lying beside him and his granddaughter Lauren holding his hand. It was a great comfort to Joyce and the rest of the family to know that Dennis's wish to die at home had been fulfilled.'

POWER OF ATTORNEY

What is a power of attorney?

A power of attorney is a legal document. It lets you choose (appoint) someone to make decisions for you if you become unable to make decisions yourself. The person you appoint is called your attorney. The power you give them can be long or short term.

Setting up a power of attorney usually gives the person you have chosen the power to make the following decisions for you:

- legal decisions
- financial decisions
- healthcare decisions.

In Scotland, there are three main types of power of attorney:

- Continuing power of attorney – this is for financial decisions, including things like paying bills and selling your home.
- Welfare power of attorney – this is for health and care decisions, including things like treatment, care, medication and where you live.
- Combined power of attorney – this is a combination of the first two types. It gives your attorney financial and welfare powers.

Most people choose to make a combined power of attorney. But you can just make one of the others if you prefer.

All of these types of power of attorney can only be used when they have been registered with The Office of the Public Guardian (see page 92).

You can find out more about making a power of attorney at **publicguardian-scotland.gov.uk/power-of-attorney**

How a welfare power of attorney can help

A welfare power of attorney can give you reassurance that someone you trust will make decisions for you if you become seriously ill.

For example, you may decide to give welfare power of attorney to your adult children. You can then discuss your thoughts about any future care decisions with them. So you can be sure that your instructions for your care will be followed if you are unable to make your own decisions. Setting up a welfare power of attorney also means your loved ones do not have to apply for power of attorney through the courts at a later stage. This can be a long and expensive process.

If you do appoint someone to be your attorney, choose someone who:

- shares similar opinions and ideas to you
- has a good idea of your wishes.

They are more likely to make the decisions you would want. The law says that your attorney must make decisions that will benefit you, and are in line with your wishes.

Making a power of attorney

You must be aged over 16 to set up a power of attorney. You must also be able to make your own decisions. This is called having mental capacity. This means you can:

- understand the decision you are making
- understand what may happen as a result of the decision
- remember and process any information you need to make the decision
- make the decision
- communicate the decision to your doctor or others caring for you – this does not have to be by talking.

You can find out more about mental capacity at **gov.uk/make-decisions-for-someone/assessing-mental-capacity**

You can make a power of attorney online at **publicguardian-scotland.gov.uk/power-of-attorney/epoar/submitting-a-power-of-attorney** Or you can get a form through your solicitor or your local stationery shop.

Although you can make your own power of attorney, it is a legal document and must be prepared properly. So you may want to get help from a solicitor. They will make sure your wishes are clear and are carried out exactly as you want.

If you do not have a solicitor, you can find one by contacting the Law Society of Scotland (see page 91). You may be able to have legal assistance to help with legal fees. This means you may not have to pay the solicitor's fees for helping you make a power of attorney, or you may only have to pay part of them.

To find out more about legal aid, speak to your solicitor or contact the Scottish Legal Aid Board on **0131 240 2082** (Monday to Friday, 8.30am to 5pm).

A power of attorney must include a certificate signed by a solicitor or medical doctor to say that you are capable of making the power of attorney. The power of attorney must be registered with The Office of the Public Guardian before it can be used (see page 92). This can take up to 30 working days.

There is usually a fee to register a power of attorney. If you are on certain benefits, you may not have to pay the fee or you may only have to pay part of the fee. To find out more visit **publicguardian-scotland.gov.uk/power-of-attorney/fees**

It is a good idea to tell your GP if you have made a power of attorney. This is so they can add this to your Key Information Summary (a document that includes important information about your wishes).

Welfare power of attorney and advance directives

If you make an advance directive, your welfare attorney will need to follow your decisions in the directive. This is only if your advance directive is up to date, relevant to your situation and known to still reflect your views.

Other things to think about

If you have a financial power of attorney, your attorney cannot manage your property or finances after you have died. This means that your property and finances will be looked after according to the instructions in your will.

ADVANCE DIRECTIVES

What is an advance directive?

An advance directive is sometimes called a living will. It is a written statement of your wishes to refuse a certain treatment. It may also include the specific situation in which you wish to refuse the treatment. It is a way of making sure that everyone knows what treatment you do not want to have, if you become unable to make your own decisions in the future.

For example, you may decide one of the following things:

- If your illness cannot be cured and you become very unwell after having all possible treatment, you do not want to be kept alive by being fed through a feeding tube or drip.
- If your condition and quality of life is not improving and is getting worse while you are being fed via a feeding tube or drip, you do not want these treatments to continue.
- If you are very ill and only expected to live for a few days, you do not want to be given antibiotics for an infection.

It is important to be as clear as possible about:

- the treatment you would like to refuse
- the circumstances when you would like your advance directive to apply.

Your advance directive cannot include a request to be given specific treatments, or to have your life ended.

Who can make an advance directive and who should be involved?

You can make an advance directive if you are aged 16 or over, and are able to understand what it is and what it means for you. This is called having mental capacity (see pages 81 to 83).

Before making an advance directive, it is important to talk with a member of your healthcare team about the decisions you would like to make. This may be your GP, a specialist doctor or specialist nurse. They will be able to tell you what the likely effects of stopping a treatment will be. They will also make sure your advance directive meets legal requirements. It is also a good idea to discuss your decisions with your family, so they understand your wishes.

You may also want to contact a solicitor. They can help you to put together an advance directive. They will make sure your choices are accurately recorded and meet the legal requirements. Sometimes, you may be able to get help with the legal cost of making an advance directive. This means you may not have to pay the solicitor’s fees, or you may only have to pay part of them. To find out more about legal aid, speak to your solicitor or contact the Scottish Legal Aid Board on **0131 240 2082** (Monday to Friday, 8.30am to 5pm).

Advance directives and the law

In Scotland, adults with capacity to make decisions may choose to refuse a medical treatment. Making an advance directive means you will still have the right to refuse treatment if you lose capacity and can no longer tell others what you want.

Although not tested by the Scottish courts, an advance directive is likely to be treated as legally binding if it meets certain criteria. This means your healthcare team will almost certainly follow it, if they know about it.

These are examples of criteria that the advance directive must meet:

- You must be able to make the decision in the first place (legal capacity).
- The treatment you have chosen to refuse in your advance directive applies to your specific circumstances.

Your healthcare team or solicitor can tell you more about this.

What should be included in an advance directive?

Although you can make most advance directives verbally (spoken), it is better to write them down. This helps avoid confusion later. Your healthcare team or a solicitor will be able to tell you exactly what your written advance directive should include.

Once you have written your advance directive, it will need to be signed by you and witnessed by someone else. A solicitor can be there while you do this. The solicitor will usually want to make sure you understand the document and have not been influenced by another person when writing it.

In some cases, it may be better for you to have a welfare power of attorney instead of, or as well as, an advance directive (see pages 43 to 49). You could ask your healthcare team or your solicitor to help you decide which option is best for you.

Who should know about my advance directive?

When you have made your advance directive, it is important to tell the people caring for you about it. This can help to avoid any confusion if your condition changes. You should usually tell your:

- healthcare professionals
- next of kin – this is usually your closest living family member or family members
- family and friends
- welfare attorney, if you have one.

You may choose to keep a copy of your advance directive at home. You can also give copies to:

- your welfare attorney, if you have one
- your GP
- your specialist nurse at the hospital.

You can ask your healthcare team about who else should know about it.

It is helpful if your GP creates a Key Information Summary (see page 19). This is a care summary that includes key information about what is important to you and what your wishes are. It will say that you have an advance directive. It will also list the main decisions in it. This means that if you need urgent medical help when your GP practice is closed, other health professionals can find out about your wishes.

Reviewing your advance directive

You can change your mind and rewrite your advance directive at any time. But this must be clearly recorded.

Review your advance directive regularly so you can be sure it is up to date and reflects your current wishes. This is important as your wishes may change if your condition changes.

If you decide to cancel your advance directive, tell your healthcare professionals and the people close to you.

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

What is cardiopulmonary resuscitation (CPR)?

Cardiopulmonary resuscitation is a way of trying to restart the heart and breathing if they have stopped suddenly. It is more commonly called CPR.

When the heart stops beating suddenly, this is called a cardiac arrest. If breathing stops, this is called a respiratory arrest. Usually, both happen at the same time. This is called a cardiopulmonary arrest. If a person is having a cardiopulmonary arrest and their heart and breathing are not restarted quickly, they will die.

CPR involves different treatments to help restart a person's heart or breathing. It can work well in some situations but not in others. For example, if someone's cancer is very advanced, giving CPR is very unlikely to restart the heart.

What is a DNACPR decision?

You may hear doctors or nurses talk about a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision or form. This is a written document stating the decision not to give cardiopulmonary resuscitation (CPR) if someone's heart or breathing stops.

A CPR decision may be made and recorded on a Scottish DNACPR form if:

- you ask for a DNACPR form because you do not want CPR in certain circumstances
- your health is getting worse and your doctors and healthcare team do not think that CPR would work.

Making a decision about CPR

You may have already made a decision about not wanting to be resuscitated in a specific situation and included this your advance directive. If you have not made a decision about CPR but you want to, talk to your GP, medical team or specialist nurse. You may also want to talk to your family, a close friend, or a spiritual or religious leader.

Your GP or medical team can tell you how successful CPR is likely to be in different situations. They will consider any other health problems you have.

If a senior health professional thinks you may have a cardiac arrest and that resuscitation could be successful, they may ask if you want CPR to be given. For example, this may be if you have cancer that cannot be cured but you are expected to live with it for a long time. In this situation, you may want to know how successful CPR might be. Your doctor will make sure that you have all the information you need to make an informed decision.

Your doctor or nurse can explain to you:

- what is likely to happen if you have CPR
- how CPR might extend and affect your life
- what your quality of life might be after CPR
- the benefits and risks of CPR in your situation.

If your healthcare team are sure that CPR will not work or will have a poor outcome, they can decide in advance not to try it. They will write this down on a DNACPR form.

If your doctor feels that CPR will not be successful but you do not agree, you can ask another senior doctor for a second opinion. It is important to be aware that another doctor may have the same opinion as your own doctor.

Your healthcare team will take your wishes about CPR into account. However, you cannot insist on CPR being given if they think it will not work. Your healthcare team will use their clinical knowledge to decide about CPR. The final decision will be made by a senior doctor. They will consider the benefits and risks of CPR for you. Your doctor should also talk to your family, unless you have specifically asked them not to.

You may not want to be involved in making decisions about CPR. You do not have to talk about CPR with anyone or make a decision about it if you would prefer not to. Your healthcare team will ask you how much information you want. Together, you can make the decision that is right for you.

After a decision has been made

Your healthcare team will discuss the DNACPR decision with you and those close to you. After a decision has been made, a senior doctor or nurse who is responsible for your care signs the DNACPR form. The form is kept in your records if you are in hospital, at home with you, or by care home staff. The Key Information Summary will also have a record of any CPR decisions. If your healthcare team decide not to give CPR treatment, this will not affect any other care or treatment you have.

If you are at home, your doctor or nurse will ask you to keep your DNACPR form where it can easily be found. This is so emergency services can easily know your wishes if your Key Information Summary is not available or up to date. If you to go to hospital, take your DNACPR form with you.

NHS Scotland has an information leaflet called **Decisions about cardiopulmonary resuscitation**. There is also an information leaflet called **MyACP** that you might find helpful. You can download this leaflet from the **ihub.scot** website or ask your healthcare team for a copy.

We have more information about cardiopulmonary resuscitation for people with cancer on our website (see page 86).

ORGAN AND TISSUE DONATION

Thinking about organ and tissue donation

You may think that having a medical condition such as cancer means you cannot donate your organs or tissue to another person when you die. It is possible to donate if you have had cancer, but it may affect what you can donate.

An example of an organ is a kidney and an example of body tissue is the corneas of the eye.

If you decide to be an organ donor and you have a medical condition such as cancer, a healthcare professional will review your medical history after you have died. They will then decide whether one or more of your organs or tissues are suitable for donation. This means that while you are alive, you will not know whether your organs or tissues will be suitable. Only your next of kin will know this after you have died. Only a few people will die in a situation where they can donate their organs.

It is important to discuss organ or tissue donation with people close to you, such as family and friends. This means that when the time comes, they will find it easier to follow your wishes. It also means they will be prepared if donation is not possible.

Corneal transplants

The cornea is one type of tissue that is usually suitable for donation if a person dies with cancer.

The cornea is the clear tissue at the front of each eye. It lets light into the eye and focuses it on the retina so we can see. If someone's cornea becomes damaged, it can mean they are no longer able to see. Corneal transplants can replace the damaged tissue with a disc of healthy tissue from a donor's eye (or eyes). This can allow the person to see again.

Finding out more about organ and tissue donation

In Scotland, the law on consent for organ donation is changing. But no changes are expected before 2020. You can read more about the changes on the Scottish Government website. Visit **gov.scot/Topics/Health/Services/OrganDonation**

You can find out more about donation on the Organ Donation Scotland website (see page 92). They keep a register of people who wish to donate their organs or tissue after their death. You can join the register online, by phone or by text.

Donating your body for medical research

You may want to donate your body for medical teaching or research. If you are thinking about donating your body, you should discuss it with your GP, hospital team or palliative care team. You should also discuss it with your close family or friends.

You and your next of kin will be asked to sign a consent form. You can get this form from your local medical school. A copy should be kept with your will.

You may want your tissue to be used for a specific type of research. You need to tell this to the healthcare professional who is dealing with the consent form. Your wishes need to be written on the consent form.

Not everyone who wishes to donate their body for teaching or research will be able to. This may be due to medical reasons. So, it is still a good idea to make other funeral plans. The Human Tissue Authority can give you more information about donating your body for medical research (see page 90).

FUNERAL PLANNING

Funeral planning

Funerals allow family, friends and others to pay their respects to the person who has died. They can help people to:

- express their grief
- acknowledge the person's death
- celebrate the person's life
- say goodbye.

Many people die without making any plans for their funeral. It can be stressful for family or close friends to arrange a funeral. They may not know what type of funeral service you wanted.

If you tell your family or friends what you want, your funeral is much more likely to reflect your wishes. It may be one less thing for your family or friends to worry about. Funerals can also be expensive, so planning ahead can be helpful (see page 75).

> 'I've planned my funeral. I've planned where I want my funeral to be, who I want to be there, and how I want it to be organised. I have lived a fun and lively life. There will be lots of prosecco and a jazz band.'
>
> **Alejandra**

What you might include in a funeral plan

Although it can be hard to talk about, discussing your funeral plans with close family and friends can be helpful. They may have suggestions for ways to help them celebrate your life, say goodbye and remember you.

Here are some suggestions of what you may want to decide on and include in a funeral plan.

A burial or cremation

A burial is usually in a churchyard or other designated burial place. It is also possible to be buried in other places, such as a garden. You may want to be buried on property that you own or in a place you love. In this case you can get information from The Natural Death Centre (see page 92). The centre also has details of some natural burial grounds, including woodlands.

A cremation happens in a crematorium, which usually has one or more chapels where a service can be held. After a cremation, your ashes are given to your next of kin in a container. You can talk to your family or friends about what you want done with your ashes. For example, you may choose to have them scattered in a favourite place.

Mygov.scot has more information about this. The organisation Good Life, Good death, Good grief also has information about planning ahead, for anyone living in Scotland (see page 90).

A religious or non-religious service

If you have a spiritual or religious faith, you may have a clear idea of who you want to carry out the funeral. Even if you do not have a faith, you can contact your local minister, priest, imam, rabbi or other religious leader to discuss your funeral. Most funeral directors can provide you with contact details.

However, you do not have to have a religious service or a religious leader for a funeral or memorial service. You could choose a humanist service instead. The Humanist Society Scotland can give you more information about humanist funerals and memorials (see page 90).

Other things to include

You may also want to think about whether you want:

- specific songs or readings
- flowers
- donations to be given to specific charities
- to wear certain clothes that are significant to you, such as a military uniform.

Recording your funeral plans

You can write your wishes for your funeral in your will. Our booklet **Your step-by-step guide to making a will** has more information about this (see page 86). Or you can write them down and leave them in a safe place that your family or friends know about. The organisations Dying Matters and the National Association of Funeral Directors (NAFD) have a form called My Funeral Wishes, which you can use to record your wishes (see pages 90 to 91).

If you do not want to write down your plans, you can tell your family or friends your wishes.

Paying for a funeral and choosing a funeral director

Funerals can be expensive. You may want to pay for your funeral in advance by taking out a funeral pre-payment plan. You can find out more from:

- your local funeral directors
- the National Association of Funeral Directors (NAFD) – see page 91
- the National Society of Allied and Independent Funeral Directors (SAIF) – see page 92

It is best to find out about prices first. Make sure you know what services are included in the price, as these can vary.

You may find choosing a funeral director difficult if there are several in the area where you live. Some people choose one they have used before. It is best to choose a funeral director that has a high standard of practice. Those that are members of the NAFD or SAIF are regularly monitored to make sure their practice standards are high. You can contact the NAFD to find out if a funeral director is a member.

You do not need to use a funeral director. But it can be hard to arrange a funeral at such a distressing time. The Natural Death Centre has more information about this (see page 92).


LA11
LA12
Way Out →
Staff Only

MANAGING YOUR CARE IF YOU HAVE NOT PLANNED AHEAD

Who will make decisions about your care?

Usually your family, close friends or carers, will be involved in making everyday decisions about your care. However, sometimes a very important or difficult decision may need to be made about any medical care or treatment.

If you do not have capacity to make your own decisions and there is an emergency, a senior healthcare professional will make the decision about your treatment. They will use the principles set out in the Adults with Incapacity (Scotland) Act 2000 to make their decision. This means they must do their best to make sure any treatment they give you will be of most benefit to you.

Their decision should consider:

- your wishes, if your healthcare professionals know them or can find them out
- the views of people who know you well and can tell the health professional about what they think you would prefer.

In a non-emergency situation, the same principles apply.
But the doctor recommending the treatment must assess your capacity to make a decision for yourself. If you are unable to make the decision yourself, the doctor will complete a certificate of incapacity. Your doctor will then make the treatment decision on your behalf. They will do this with your attorney, if you have one (see pages 43 to 49). If possible, they will find out what your wishes are likely be.

MENTAL CAPACITY

The Adults with Incapacity (Scotland) Act 2000

The Adults with Incapacity (Scotland) Act 2000 applies to people aged 16 and over in Scotland.

The Act aims to protect people who cannot make a decision for themselves. It means a person can plan ahead for a time when they may be in this situation (see pages 11 to 13).

It explains:

- who can make decisions for them
- in which situations they can make decisions
- the process to follow when making decisions.

There are many parts to the Act, including information on powers of attorney (see page 43 to 49).

The Act states that a person lacks capacity if they are unable to:

- act
- make decisions
- communicate decisions
- understand decisions
- remember making decisions.

This may be because of a mental disorder or a physical disability that prevents communication. The Act also takes into account that a person's ability to make decisions (mental capacity) can change. For example, this could be if their health improves.

A person has capacity if they can meet one of the following criteria:

- understand what a treatment is, what it is for and why it is being suggested
- understand the benefits or risks of a treatment, or if there are other options
- understand what will happen if they do not have a treatment
- remember the information for long enough to use or consider it, so that they can make a decision.

Healthcare professionals will do everything they can to help you make decisions about your treatment and care. If the decision is not urgent and you do not have capacity, it may be delayed. This is to see if your condition improves enough for you to be involved in decision-making.

FURTHER INFORMATION AND SUPPORT

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**
If you would like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That's why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Book reviews

Our volunteers review many books about cancer. These include people's stories of living with cancer, and books for children. Visit **publications.macmillan.org.uk** and search 'book reviews'.

> 'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'
>
> **Mal**

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Macmillan Organiser

This includes a records book to write down information such as appointments, medications and contact details. You can also download the app on IOS or Android.

Other useful organisations

There are lots of other organisations that can give you information or support.

Planning ahead and end of life support organisations

Dying Matters
Tel 0800 021 4466
Email info@dyingmatters.org
www.dyingmatters.org
Promotes public awareness of dying, death and bereavement.

Good Life, Good Death, Good Grief
www.goodlifedeathgrief.org.uk
Aims to raise awareness of ways of dealing with death, dying and bereavement and promote community involvement. Links to organisations that can help and provides information on wills, Power of Attorney and more.

Human Tissue Authority
Tel 0207 269 1900
(Mon to Fri, 9am to 5pm)
www.hta.gov.uk
Provides information about tissue donation. Licenses and inspects organisations that store and use human tissue for research, treatment and teaching.

Humanist Society Scotland
Tel 0300 302 0680
(Mon to Fri, 9am to 5pm)
Email admin@humanism.scot
www.humanism.scot
Represents non-religious people and supports those who wish to live humanist lives. Can help provide humanist ceremonies. Promotes equal treatment, regardless of religion and belief.

The Law Society of Scotland

Tel 0131 226 7411
(select option 1)
www.lawscot.org.uk/find-a-solicitor
Provides details of regulated solicitors in Scotland.
Use their website to find details of local solicitors.

Marie Curie

Helpline 0800 090 2309
(Mon to Fri, 9am to 5pm, and Sat, 11am to 5pm)
www.mariecurie.org.uk
Marie Curie nurses provide free end-of-life care to people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.
Call their helpline for support or to ask questions about care or symptoms.

Mental Welfare Commission for Scotland

Tel 0800 389 6809
(Mon to Thu, 9am to 5pm, and Fri, 9am to 4.30pm)
Email enquiries@mwcscot.orguk
www.mwcscot.org.uk
Supports and promotes decision-making for people with mental impairment or disability who would like to plan for their future.

National Association of Funeral Directors (NAFD)

Tel 0121 711 1343
(Mon to Fri, 9am to 5pm)
www.nafd.org.uk
Monitors standards of funeral directors in the UK and gives help and advice on what to do in the event of a death.
Also advises on arranging funerals and has information on what you should expect from a funeral director.

The Natural Death Centre

Tel 0196 271 2690
Email rosie@naturaldeath.org.uk
www.naturaldeath.org.uk
Aims to support those dying at home and their carers. Also helps people to arrange inexpensive, family-organised and environmentally-friendly funerals.

National Society of Allied and Independent Funeral Directors (SAIF)

Tel 0345 230 6777
(Mon to Fri 9am to 5pm)
Email info@saif.org.uk
www.saif.org.uk
SAIF represents independent funeral directors across the UK that offer different funeral options. Ensures a high standard of funerals is provided by its members and provides advice about funerals and what to do when someone dies.

The Office of the Public Guardian (Scotland)

Tel 0132 467 8300 (Mon to Fri, 9am to 5pm)
Email opg@scotcourts.gov.uk
www.publicguardian-scotland.gov.uk
Has a range of functions under the Adults with Incapacity (Scotland) Act. It provides information, advice and guidance with regard to Powers of Attorney.

Organ Donation Scotland

Tel 0300 123 2323
www.organdonationscotland.org
Provides information about organ and tissue donation. You can also register to be a donor.

General cancer support organisations

Cancer Support Scotland

Tel 0800 652 4531
Email info@cancersupportscotland.org
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland.
Offers free complementary therapies and counselling to anyone affected by cancer.

Maggie's Centres

Tel 0300 123 1801
Email enquiries@maggiescentres.org
www.maggiescentres.org
Provides information about cancer, benefits advice, and emotional or psychological support.

General health information

Alzheimer's Scotland

Helpline 0808 808 3000
Email helpline@alzscot.org
www.alzscot.org
Provides a wide range of specialist services for people with dementia and their carers.

Chest, Heart & Stroke Scotland

Helpline 0808 801 0899
www.chss.org.uk
Improves the quality of life for people in Scotland affected by chest, heart and stroke illness.

NHS Inform

Helpline 0800 22 44 88
(Mon to Fri, 8am to 10pm, and Sat and Sun, 9am to 5pm)
www.nhsinform.scot
Provides health information for Scotland. Has a service directory where you can search for health and wellbeing services in Scotland. Also has a webchat service.

NHS 24

Tel 111
www.nhs24.scot
111 is the NHS non-emergency number. It is available 24 hours a day, 365 days a year.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)

Tel 0145 588 3300
(Mon to Fri, 9am to 5pm)
Email bacp@bacp.co.uk
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services. You can also search for a qualified counsellor on their 'How to find a therapist' page.

COSCA (Counselling & Psychotherapy in Scotland)

Tel 0178 647 5140
Email info@cosca.org.uk
www.cosca.org.uk
Use the website to find a COSCA registered counsellor or psychologist.

Samaritans

Tel 116 123
Email jo@samaritans.org
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

UK Council for Psychotherapy (UKCP)

Tel 0207 014 9955
Email info@ukcp.org.uk
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements. You can search for a therapist using their 'Find a therapist' form.

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030
(Mon to Fri, 10am to 6pm)
Email helpline@lgbt.foundation
www.lgbt.foundation

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events. You can also visit their centre to chat.

Support for older people

Age Scotland

Tel 0800 124 4222
(Mon to Fri, 9am to 5pm)
Email helpline@agescotland.org.uk
www.ageuk.org.uk/scotland

Provides information and advice for older people. Also publishes impartial and informative information and advice guides.

Financial or legal advice and information

Citizens Advice Scotland

Helpline 0808 800 9060
www.cas.org.uk

Provides advice on a variety of issues including financial, legal, housing and employment issues. Find details for your local office on their website.

Support for carers

Carers UK

Helpline 0808 808 7777
(Mon and Tue, 10am to 4pm)
Email advice@carersuk.org
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups.

Carers Trust

Tel 0300 123 2008
Email info@carers.org
www.carers.org
Works to improve support, services and recognition for anyone living with the challenges of caring.

Bereavement support

Cruse Bereavement Care

Helpline 0808 808 1677
(Mon and Fri, 9.30am to 5pm, and Tue to Thu, 9.30am to 8pm)
www.cruse.org.uk
Provides bereavement support to anyone who needs it across the UK. You can find your local branch on the website.

Widowed and Young (WAY)

www.widowedandyoung.org.uk
A UK-wide support network to help young widows and widowers rebuild their lives after the death of a partner.

Winston's Wish

Helpline 0808 802 0021
(Mon to Fri, 9am to 5pm)
Email ask@winstonswish.org
www.winstonswish.org.uk
Helps bereaved children and young people throughout the UK re-adjust to life after the death of a parent or sibling.

Disclaimer

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Senior Medical Editors Dr Sara Booth, Associate Lecturer University of Cambridge and Emeritus Consultant in Palliative Medicine; and Dr Viv Lucas, Consultant in Palliative Care.

With thanks to: Karen Bird, Lead Nurse for End of Life Care Education; David Borrowman, Senior Partner, Caesar and Howie; Dr Kirsty Boyd, Honorary Clinical Senior Lecturer; Michelle Buono, Macmillan End of Life Education Nurse; Janet Dobie, District Nurse and Palliative Link Nurse; Julia Featherstone, Macmillan Financial Guide; Domino MacNaughton, Head of Legacy Promotions, Macmillan Cancer Support; Daniel McCracken, Trainee Solicitor, Wilson Nesbitt Solicitors; Ollie Minton, Macmillan Consultant in Palliative Medicine; Lucie Rudd, Macmillan Specialist Advisor for End of Life; Dr Louise Schofield, Consultant in Palliative Medicine; Fiona Wilson, Partner, Hempsons; and Joanne Wilson, Consultant Nurse.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

We have listed a sample of the sources used in the booklet below. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

General Medical Council. Treatment and care towards the end of life: good practice in decision making. 2010. Available from www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life (accessed August 2019).
Public Office of the Guardian (Scotland). Power of attorney. Available from www.publicguardian-scotland.gov.uk/power-of-attorney (accessed August 2019).
Scottish Government. Adults with incapacity: forms and guidance. Available from www.gov.scot/collections/adults-with-incapacity-forms-and-guidance/ (accessed August 2019).
Scottish National Users Group SNUG. Key information summary. Available from www.snughealth.org.uk/gp-software/ecs-and-kis/key-information-summary (accessed August 2019).
Scottish Partnership for Palliative Care. Scottish palliative care guidelines 2019. Available from www.palliativecareguidelines.scot.nhs.uk/ (accessed August 2019).
Scottish Partnership for Palliative Care. Consultation on the proposed reform of the adults with incapacity act. Available from www.palliativecarescotland.org.uk/content/publications/SPPC-response-FINAL----Reform-of-AWI.pdf (accessed August 2019).

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 WAYS YOU CAN HELP
SOMEONE WITH CANCER

Share your cancer experience
Support people living with cancer by telling your story, online, in the media or face to face.

Campaign for change
We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

Help someone in your community
A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

Raise money
Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

Give money
Big or small, every penny helps. To make a one-off donation see over.

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Don't let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

Registered with
FUNDRAISING
REGULATOR

If you'd rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to:
Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,
89 Albert Embankment, London SE1 7UQ

27530

This booklet is about some of the ways you can plan ahead and make choices about your future care if you live in Scotland. It is for anyone who wants to plan ahead, whether they have a serious illness or not.

Planning for your future care is also called advance care planning. It is important in case you ever become unable to make choices yourself.

The booklet talks about the ways you can plan ahead, for example writing a will, or making a power of attorney or an advance directive. It also tells you how to talk about planning ahead with your family, friends and health and social care professionals.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

MACMILLAN
CANCER SUPPORT

Next planned review November 2022. Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Also operating in Northern Ireland. Printed on sustainable material. Please recycle.