Planning ahead when living with cancer – England and Wales

About this booklet

This booklet is about ways you can plan ahead for your future care if you live in England or Wales.

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

This booklet may help you:

- think about what is important to you and ways you can plan ahead
- talk about your plans with the people close to you, and health and social care professionals
- put your plans into action by writing a will, or making a lasting power of attorney or advance decision to refuse treatment.

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 3 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 106 to 114, there are details of other organisations that can help. We also include and explain some some template documents you can use to record your wishes (pages 76 to 96).

There are copies of these documents in the pocket at the back of this booklet, and they are also free to download at **orders.macmillan.org.uk**

There is also space to write down questions and notes for your doctor or nurse (pages 115 to 116).

Quotes

In this booklet, we have included quotes from people who have made plans for their future care, which you may find helpful. These are from people who have chosen to share their story with us. 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 Relay UK on **18001 0808 808 00 00**, or use the Relay UK 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**.

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Why plan ahead?

If you have a serious illness that could shorten your life, such as cancer, you might think about planning ahead for your future care. Even people who do not have a serious illness might want to make decisions about their future care.

Planning ahead means that people will know your wishes, even if you become very unwell and cannot make a decision or communicate.

It can also help people who are important to you, like family or friends, and healthcare professionals make decisions for you. Having a written record of your wishes or an advance care plan helps your healthcare team, family or friends to understand what is most important to you.

For example, if the cancer is very advanced and treatment is not helping, you may not want treatment with antibiotics if you develop an infection. Or you might prefer to be cared for at home or in a nursing home instead of in hospital, if possible. Talking about your options with your healthcare team can help you to plan.

Planning ahead can be hard. But making a plan can help you to talk with your healthcare team, family or friends about what matters to you. It can help everyone to understand the care, treatment and support you might need in the future.

You may also want to make practical plans. For example, you may want to arrange for a family member or friend to pay your bills if you are unwell.

> "I'm a very practical person and while I never thought I was going to die when I was diagnosed with cancer, I did feel that I needed to get my affairs in order. So I've made a will and a list of other things I think should get sorted if I die."
>
> Samixa

How you can plan ahead

There are different things you can do to plan ahead. You do not have to do them all. It may be helpful to start with the ones that are most important to you:

- Write a plan of your wishes for your care. This is sometimes called an advance care plan (pages 15 to 20). You can use a preferred priorities for care document (pages 76 to 83), or another document to do this.
- Write down your wishes about any medical care or treatment you would not want if you could not make or communicate your decision. This is called an advance decision to refuse treatment (ADRT) or a living will (pages 40 to 49).
- Choose (appoint) a lasting power of attorney (LPA) – pages 32 to 37. This needs to be someone you trust to make decisions for you about your health and care or finances.
- Write a will to make sure your loved ones are provided for in the way you want after you die, and that your wishes are followed. It is easier to make a will when you are feeling well (pages 24 to 28).
- Write down any wishes you have about organ and tissue donation or donating your body to research (pages 52 to 54).
- Plan your funeral, and possibly pay for it in advance (pages 58 to 65).

Who can help you 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. Health and social care professionals can help you, as well as family or friends.

To help with these discussions, you could write down your thoughts and feelings. For some people it is a relief to start planning ahead and sharing their plans.

Health and social care professionals

You can talk to your:

- GP or hospital doctors
- specialist nurse or district nurse
- social worker
- other health and social care professional.

Starting a conversation can feel difficult. You could say something like:

"I've been thinking about making plans for my future care, in case I can't make decisions for myself. Could you help me find out my options and explain what I need to do?"

It may take time to discuss things. It may be months before you feel ready to make plans for your future care or treatment. Your healthcare team will not expect you to make any plans until you are sure.

> “I don't shy away from conversations about death and dying, but I will ask, ‘How can we help you to live better, now and in the future?' ”

Katie, Macmillan Advanced Palliative Care Practitioner

Solicitor

A solicitor can help you:

- make a will (pages 24 to 28)
- create a lasting power of attorney (pages 32 to 37)
- write an advance decision to refuse treatment (ADRT) – pages 40 to 49.

For information on finding a solicitor, you could contact the Law Society for England and Wales (page 107).

Family, friends, or people close to you

Try to involve people who:

- you are close to
- you can talk openly to
- could act on your behalf.

They can support you and help you to think about what you need to include. Involving them also helps make sure your wishes are carried out.

Your plans could mean they make decisions on your behalf or take more responsibility for your care.

For example, if you would like to die at home, it's important to discuss this with those close to you. You need to know if they think they will be able to help look after you, and any concerns they might have.

If they find it difficult to talk about

Sometimes family or friends find it hard to talk about a time when you will be very unwell. They may change the subject, or not want to talk about it. Try to explain why it is important for you to plan ahead, and how it would help you to talk about it.

You could try saying something like:

"I know it's difficult, but I want to talk to you about how I would like to be cared for if I became very unwell."

You could also ask them to read this booklet. Or you could write them a letter and ask them to talk to you about it when they feel ready.

Health and social care professionals can also support discussions with family or friends.

> **"Families appreciate these open conversations. They don't usually get upset. They can see things are changing and they want to plan ahead."**
>
> Katie, Macmillan Advanced Palliative Care Practitioner

Coping with your feelings

Talking to family, friends or people close to you about how you feel can help. Health and social care professionals can also give you support. You may also find it helpful to join a support group or talk things through with a support organisation (pages 106 to 114).

If you need more support, ask your healthcare team about finding a counsellor or psychologist. This can be helpful, especially if you find it hard to talk about your feelings with people close to you.

Keep your documents safe

Make sure that family, friends, and health and social care professionals know where important documents are so they can find them easily and quickly.

Your will does not have to be registered to be legal. But registering it means your will can always be found in the National Will Register. Wills can be recorded at **nationalwillregister.co.uk**

Review your documents regularly

Reviewing your documents is important to make sure they include your most recent wishes. These might change over time, especially if your situation changes.

You can review them with your health and social care professionals as part of your planning conversations. They can help you write down any changes and make sure your documents are up to date. It is also important to talk to the people close to you about any changes in your wishes.

You may find it helpful to use our planning ahead checklist (pages 93 to 96). Make sure someone close to you knows where you keep this checklist.

Your advance care plan

When planning ahead, you can talk to people about your wishes and what matters to you, but it is usually better to write them down. You can use the forms on pages 76 to 96.

A written record of your wishes (preferences) for your care and what is most important to you is sometimes called an advance care plan. 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.

There are different documents that can be used. These include a:

- record of advance care plans and preferences
- preferred priorities for care document (pages 76 to 83)
- statement of wishes and care preferences
- advance decision to refuse treatment (ADRT) – pages 84 to 92.

Your team may also help you to complete a ReSPECT document. It records what you would want to happen in emergency situations. For example, it sets out what treatment should be given if your heart and breathing stop suddenly.

You can ask your health and social care professionals if there is a document they use. These statements about your preferences and wishes are not legally binding. This means they cannot be enforced by law. But healthcare professionals use them to help guide their decisions about your care.

An ADRT is legally binding, as long as it is valid and applicable. This means it must be followed by your healthcare team, if they know about it.

Talking about your advance care plan

Before you write down your wishes, try to talk about your plan with a family member or close friend. 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 health and social care professionals looking after you (page 9). You may want to ask them how serious your illness is and what might happen in the future.

You can ask them 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. This may depend on having family or friends who are able to care for you.

> **"It has been empowering to take back responsibility and control in my life. I also feel better having been able to exercise some control and make decisions about my death, while I'm still in a position to do so."**
>
> Mandy

What to include in your advance care plan

Try to include what is most important to you. The plan might include the following:

- Where you would most like to be cared for when you cannot look after yourself or when you are dying.
- What kind of care and treatments you would prefer, although you cannot request specific treatments.
- Any tests or treatments you would not want to have if you became more unwell.
- Who you would like to be involved in your care – for example, family members or close friends.
- Who you would like to make decisions about your care if you are unable to make the decisions yourself. You may want to choose a lasting power of attorney so that others can act on your behalf (pages 32 to 37).
- Any spiritual, religious or cultural practices you would like to be included in your care.
- Who should look after anyone you care for.
- Instructions about caring for your pets.

If it is not possible to follow your plan

It may not always be possible to follow your plan or 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. Or you may have a symptom that cannot easily be managed at home.

Your healthcare team will do their best to help you stay at home. But sometimes the best possible care for you may be in hospital, a hospice or a care home. If you are already in a care home, you may want to stay there.

Sharing the information

Once you have completed the document, share it with people who are important to you and anyone likely to be involved in your care.

This may include a:

- family member or a close friend
- GP or hospital doctor
- specialist nurse or district nurse
- social worker
- other health and social care professionals.

Your healthcare team will keep a copy of some of the information for their records.

Where to keep your plan

Keep a copy in a safe place at home along with any other important documents. Tell people involved in your care where it is.

You might have a fridge sticker or note somewhere obvious in your home to tell an emergency doctor or paramedic where you keep your documents. Your family or carers can also help make sure your wishes are followed.

Review your plan regularly

It is important to regularly review your wishes and keep them up to date. You can change your mind at any time, but remember to record your changes. If you make changes to your plan, tell all the people involved and give them an updated copy.

A preferred priorities for care document should record:

- what has been happening to you, in regard to your health
- what is important to you about your future care
- where you would like to be cared for in the future.

There is a template preferred priorities for care document on pages 76 to 83, and another one in the pocket inside the back cover.

You may also find it helpful to use our planning ahead checklist on pages 93 to 96 (and inside the back cover).

Other sources of help

Different organisations provide information and support to people planning ahead. Some provide documents or care plans. You can complete these by yourself, or with support from family, friends and healthcare professionals.

These include:

- Marie Curie (page 108)
- Hospice UK (page 107)
- Age UK (page 113).

Making a will

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What is a will?

A will is a legal document. It gives instructions about who you want to give your money and belongings (possessions) to when you die. 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, after any debts are repaid. For example, the value of a mortgage would be taken off.

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.

Macmillan works with trusted will-writing providers to offer a free service. Visit **macmillan.org.uk/willwriting** to find out more.

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 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 England and Wales (page 107). It is a good idea to look around or ask for a few quotes to find the right solicitor for you.

Things to think about when making your will

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

Who to include in your will

Make a list of all the people, charities or organisations you would like to include in your will. Think about what you want to leave them. This may be a specific amount of money, or something with financial or sentimental value.

The value of your estate

You need to find out the value of your estate. Your estate is everything you own when you die. Make a list of everything you own, and how much each thing is worth. These are your assets.

They might include your:

- property (house or flat)
- car
- jewellery and watches
- furniture, antiques or collectables
- other possessions
- bank and building society accounts – current balance
- ISAs, savings accounts, certificates, Premium Bonds and stocks and shares
- life insurance policies.

Then make a list of everything you owe. These are your liabilities.

They may include:

- how much is left on your mortgage
- any overdrafts
- credit card debts
- bank loans
- other debts.

Add up the value of everything you own and take away the total amount you owe. This will give you the estimated value of your estate. This will need to be updated if anything changes.

Meeting with a solicitor

You can make a will by meeting a solicitor face to face, or over the phone.

When you talk to your solicitor, it will help to have the following information ready:

- names of people you want to carry out the instructions in your will (executors)
- things you want to leave in your will (assets)
- names of people you want to include in your will
- if relevant, who you want to be guardians for children aged under 18
- any instructions you want to leave for your funeral.

When should I update my will or make a new one?

In England, Northern Ireland and Wales, getting married or entering into a civil partnership cancels your existing will. Unless your will specifically states that it takes a future wedding or civil partnership into account, you will need to make a new will.

If you get divorced or end a civil partnership, any will you made while married or in a civil partnership is still valid. But if you have left a gift in your will to your spouse or civil partner, they may not receive this. This applies in all parts of the UK.

If you get divorced or end a civil partnership you should review your will, as it may need updating.

You may also need to update your will to include:

- any new children or grandchildren
- a new partner
- any changes in your finances.

Making an official change to your existing will is called a codicil. If you need to make any major changes, get advice from a solicitor and write a new will.

Our financial guides can give you guidance and information on wills, estate planning and personal finance issues. Contact them on **0808 808 00 00**. But if your will needs updating, it is always a good idea to get help from a solicitor.

We have more information about making a will in our booklets **Your step-by-step guide to making a will** and **Sorting out your affairs** – page 100.

You can also get information and advice on wills from:

- Citizens Advice – page 106
- Age UK – page 113.

> **"I have sorted out my will and organised power of attorney. And I've got my kids Mexican nationality so they can go and live there if they want."**

Alejandra


Whatever

Lasting power of attorney

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What is a lasting power of attorney (LPA)?

A lasting power of attorney (LPA) is a written legal document. It lets you choose (appoint) someone you trust to make decisions for you, if you become unable to make decisions yourself. The person you appoint is called your attorney.

Who can be an attorney?

Your attorney must be over the age of 18. It is important to appoint someone you trust to make these decisions for you. They must also agree to be your attorney. They could be:

- a family member
- your husband, wife, civil partner or partner
- a friend
- a professional, such as a solicitor or accountant.

It is usually a good idea to have more than 1 attorney. Or you could have a substitute attorney to step in if your attorney can no longer act on your behalf.

You can find out more about making an LPA at **gov.uk/power-of-attorney**

What are the types of lasting power of attorney?

In England and Wales, there are 2 types of LPA. You can make 1 of them, or both:

- An LPA for financial decisions. This includes things like paying bills or selling your home. It can be used when you are still able to make your own decisions. Or you can set it up to start once you become unable to make decisions for yourself. The LPA cannot be used to manage your property or finances after you have died. These will be looked after according to the instructions in your will (pages 24 to 28).
- An LPA for health and welfare decisions. This includes things like giving consent for treatment, care, medication and where you live. This LPA can only be used if you become unable to make decisions for yourself. Some people also make an advance decision to refuse treatment.

How an LPA for health and welfare can help

Having a health and welfare LPA can reassure you that someone you trust will make decisions about your health and welfare for you, if you cannot.

This should be someone who will:

- understand and respect your wishes
- act in your best interest.

Talk to the person you want to choose about what being an attorney involves, and your wishes for any future care. You may want to make notes about what you discuss, and share them with your attorney.

Make sure they understand what is important to you. The law says that your attorney must make decisions that will benefit you and are in line with your wishes.

Having an attorney means family or friends will not have to go to court to apply for power of attorney at a later stage. This can be a long and expensive process.

Making an LPA can also help to avoid conflict if there is likely to be any disagreement among family members.

Making a lasting power of attorney (LPA)

You need to be aged over 18 to set up a lasting power of attorney (LPA). You must also be able to make your own decisions. This is called having mental capacity (pages 69 to 70).

You can make an LPA online at **gov.uk/power-of-attorney** Or you can get a form from the Office of the Public Guardian (OPG) – page 108.

Although you can make your own LPA, it is a legal document and must be prepared properly. Getting help from a solicitor means 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 England and Wales (page 107).

If you have made an advance decision to refuse treatment (pages 40 to 49) and a health and welfare LPA (page 33), one may make the other invalid.

Registering your LPA

An LPA must be registered with the OPG before it can be used. It can take up to 20 weeks to process.

A registered LPA can only be used if the person who made it does not have mental capacity anymore.

If the person who made it still has mental capacity, they can contact the OPG and ask for the LPA to be ended, or for a particular attorney to be removed.

There is a fee to register an LPA. You may not have to pay the fee, or the fee may be reduced, if you:

- have a low income
- get certain benefits.

If you become unable to make your own decisions and have no lasting power of attorney in place, someone else can apply for similar legal powers as an attorney.

To find out more, visit **gov.uk/power-of-attorney/register**

Advance decision to refuse treatment (ADRT)

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What is an advance decision to refuse treatment (ADRT)?

An advance decision to refuse treatment (ADRT) is a written statement of your wishes to refuse a certain treatment. It is a way of making sure everyone knows what treatments you do not want to have, if you become unable to make your own decisions. It will only be used if you cannot make or communicate a decision for yourself.

It is also called an advance decision or living will. In Scotland, it is called an advance directive. We have more information in our booklet **Planning ahead when living with cancer Scotland** (page 100).

An advance decision to refuse treatment can include the situations in which you wish to refuse the treatment. For example, if:

- you become very unwell after having all possible treatments, and you do not want to be kept alive by having a feeding tube or drip
- your condition and quality of life is getting worse, and you do not want to continue having a feeding tube or drip
- you are very ill and you do not want to be given antibiotics for an infection.

We have an example of how some of this information could be written in an ADRT document on pages 84 to 92.

It is important to be as clear as possible about:

- treatments you would like to refuse
- the situations when you would like your ADRT to apply.

You should include as much detail as possible to make your wishes clear to anyone reading the document. In England and Wales, an ADRT is legally binding if it meets the requirements set out in the Mental Capacity Act 2005 (pages 69 to 70). This means if your healthcare team know about it, they must follow it.

You cannot insist on being given specific treatments, or request to have your life ended. You can request a treatment, but doctors will decide the most appropriate medical treatment for your condition.

If you refuse a certain treatment, you will still have the best possible care and support, and medicines to help control your symptoms.

Who can make an ADRT and who should be involved?

You can only make an ADRT if you are aged 18 or over, and are able to understand what it is and what it means for you. This is called having mental capacity.

Before making an ADRT, it is important to talk with a member of your healthcare team. This may be your GP, cancer 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 ADRT meets legal requirements.

It is also important to discuss your decisions with the people close to you, so they understand your wishes. This can be important to prevent any confusion or distress at a later stage. It also makes it more likely that your wishes will be followed.

What should be included in an ADRT?

Although you can usually make advance decisions to refuse treatment by speaking to your healthcare team, it is better to write it down. This helps avoid confusion later.

An ADRT must be in writing if it states that you refuse treatment to keep you alive.

You must write down your wishes if you do not want:

- to have your heart restarted (cardiopulmonary resuscitation) – pages 49 to 49
- to be put on a breathing machine (ventilator).

It must say exactly what treatment you want to refuse and in which situation. This is because you may want to refuse a treatment in one situation, but not in another.

In these situations, an ADRT must also be signed:

- by you, or someone else who was with you at the time of it being written
- in the presence of a witness
- by the witness, with the date – this must happen while you, or the person signing for you, are there.

ADRT checklist

If an ADRT is not about treatment that will keep someone alive, the law does not state what must be included. However, it is helpful to include the following:

- Your name, date of birth, address and any obvious distinguishing features you have – for example, a birthmark. This is in case you are unconscious or unable to communicate. It will help healthcare professionals identify you.
- The name, address and phone number of your GP, and whether they have a copy of your ADRT.
- A statement saying that the ADRT should be used if you cannot make or communicate a decision for yourself.
- A statement with the exact treatment or treatments to be refused and the circumstances when your decision would apply. This is because you may want to refuse a treatment in one situation, but not in another.
- The date your ADRT was created.
- Your signature and a dated signature of at least 1 witness, if it is a written statement.
- If it is a decision to refuse treatment that would keep you alive, your ADRT must also include the statement, 'I refuse this treatment even if my life is at risk as a result'.

If you refuse a treatment in all circumstances

You might wish to refuse a specific treatment in all situations, rather than in just one specific situation.

For example, you may want to refuse a specific medication if you:

- have an allergy
- do not want the medication for religious reasons.

If you want to make a statement about refusing a treatment in all circumstances, you should talk with a healthcare professional first. They will make sure that your ADRT is clear for any healthcare professionals who may need to use it in the future.

Writing an ADRT

You can write your own ADRT, but you may find it easier to use a form. Hospitals and hospices often have information and forms that you can use to prepare your own ADRT.

Other organisations, such as Marie Curie, Hospice UK and Age UK have also created forms you could use (pages 107 to 113).

We have an ADRT document that has been adapted from the National End of Life Care Programme on pages 84 to 92. There is also a copy in the pocket on the inside back cover of this booklet.

Example ADRT document

My advance decision to refuse treatment

If you wish to refuse a treatment that is, or may be, life-sustaining (could keep you alive), you must state in the box: 'I refuse this treatment even if my life is at risk as a result'.

I wish to refuse the following specific treatments	**In these circumstances**
Cardiopulmonary resuscitation – I refuse cardiopulmonary resuscitation if my heart and lungs stop working, even if my life is at risk as a result.	If I have terminal cancer and my heart and lungs stop functioning in a way that allows me to breathe on my own.
I wish to refuse antibiotics if I develop a chest infection, even if my life is at risk as a result.	If I have terminal cancer and become confused or unconscious due to a chest infection.

Reviewing your ADRT

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

Reviewing your ADRT regularly makes 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 ADRT, tell your healthcare team and the people close to you.

ADRT and lasting power of attorney

If you have made an ADRT and a health and welfare lasting power of attorney (pages 32 to 37), one may make the other invalid. The document you made most recently takes priority over the other. Whenever possible, try to make sure your wishes match in documents.

You should tell any doctors, nurses, family or friends who will be involved in your care what you have done. It is important to keep written records of when you made decisions and what they were. Make sure you tell everyone who may need to make decisions for you in the future where to find all your documents.

Cardiopulmonary resuscitation (CPR)

Cardiopulmonary resuscitation (CPR) is a way of trying to restart someone's heart and breathing if they have stopped suddenly.

CPR may be successful in some situations but not in others. Discussing and recording a decision about CPR means it is more likely to be given only when it is useful. And it is less likely to be given to someone who:

- does not want to be resuscitated
- is too ill or frail to benefit from CPR.

This is why you may be asked about CPR. It can leave some people in much poorer health if they have other health conditions. CPR is not suitable for someone who has very advanced cancer and is in their final days. It is very unlikely to work and can cause harm and distress.

Your doctor or nurse may talk to you about this decision. They may give you information about what the best treatment is likely to be if your heart and breathing stop suddenly. They may ask what you would prefer.

This can be hard and upsetting to talk about. But it helps your healthcare team understand what is important to you. In an emergency, you may not be able to explain what you want to happen. If they already know what is important to you, this can help them make the best decisions for you. The final decision will be made by a senior doctor. They should also involve your family, unless you have asked them not to.

You may not want to be involved in making decisions about CPR. Your healthcare team will ask you how much information you want.

We have more detailed information about cardiopulmonary resuscitation for people with cancer on our website. Visit **macmillan.org.uk/cpr**

Where is the decision recorded?

You may hear doctors or nurses talk about a 'do not attempt CPR' (DNA CPR) decision or form. They may also use a document called ReSPECT.

These are written documents that record the decision not to give CPR if someone's heart or breathing stops. The information is stored in your patient record. It is also usually written on a standard form that you keep with you.

If you go into hospital, take the form with you. If you are at home or in a care home, keep it somewhere safe where it can easily be found. This means emergency services will know your wishes.

A CPR decision can also be included in an advance decision to refuse treatment (pages 40 to 47).


MET

Understanding organ and tissue donation

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Organ and tissue donation

Only a few people die in a situation where they can donate their organs. Donors are usually people who have died in a hospital intensive care unit or emergency department.

If you have active cancer, you cannot donate organs. You can still usually donate tissue, such as your cornea (the clear tissue at the front of the eye). If the cancer was treated a few years ago and has not come back, it may be possible to donate your organs.

The process of organ or tissue donation is complex. Your healthcare team will be able to give you more information about your situation.

In May 2020, the law around organ donation was changed in England. If you do not want to be an organ donor, you now need to opt out. This means you must register and record your decision not to be a donor. Wales introduced an opt-out system in 2015.

You still have a choice about whether you want to become an organ donor. But if you have not opted out when you die, the law allows for the donation of certain organs and tissue for transplantation. This does not apply if:

- you are aged under 18
- you lack mental capacity (ability to make a decision) – pages 69 to 70
- donation would be against your views – your faith, beliefs and culture will always be respected.

Only you can decide if you wish to donate your organs or tissue. But it is important to talk to your family or friends about what you want. They can then follow your wishes.

You should record your donation decision on the NHS Organ Donor Register for England or NHS Organ Donation Register for Wales. You can change your donation decision or preferences at any time at **organdonation.nhs.uk**

Donating your body for medical research

Some people want to donate their body to help with medical training or research.

If you are thinking about donating your body, talk about it with your close family or friends so they know what you want. You should also tell your healthcare team. Make sure this is included in any advance care planning document so your wishes can be followed.

Start by contacting the closest medical school or university to you. They will answer any questions and give you the legal papers to sign. You can search for your nearest medical school on the Human Tissue Authority website. Visit **hta.gov.uk/medical-schools**

Not everyone who wishes to donate their body for teaching or research will be able to. This may be due to medical reasons. Or the medical school or university may not be able to take your body at the time. So you need to make other plans in case the donation is not accepted.

You cannot ask for your body to be used only for research into a certain disease.

The Human Tissue Authority (page 107) or local university anatomy department can give you more information about donating your body for medical research.

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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.

Talking to your family or friends about your funeral helps them celebrate your life in the way you would have wanted. Knowing they are following your wishes can help them avoid worry and possible disagreements.

There are different funeral traditions across different religions, faiths and cultures. You can talk to your religious or faith leader about your funeral and wishes.

Funerals can also be expensive, so planning ahead can be helpful. Age UK, GOV.UK and Marie Curie all have advice about planning a funeral (pages 108 to 113).

> "My mum arranged her funeral with me and outlined everything she wanted. She wanted people to wear the brightest colours. „
>
> Kevin

What might be included in a funeral plan

Here are some suggestions of what you might want to include in a funeral plan.

A burial or cremation

A burial is usually in a cemetery or other designated burial place. It is also possible to be buried in places such as a garden, on property you own, or in a place you love. The Natural Death Centre has more information and details about natural burial grounds, including woodlands (page 108).

A cremation happens in a crematorium. A service can also be held here. You can talk to your family or friends about what you want to be done with your ashes. For example, you may choose to have them scattered in a garden of remembrance, a graveyard or a favourite place.

You can scatter ashes almost anywhere in the UK if you have permission from the landowner. People may choose to keep some of the ashes. For example, they can be kept in a piece of jewellery or a small pot.

The funeral service or ceremony

Funeral services may be religious or non-religious (secular).

Some people may decide not to have a funeral service. Or they may only want a simple committal service. This is a brief service at the graveside or in the crematorium.

Not having a funeral service

Some people decide to have a cremation or burial without a funeral. This is called a direct cremation or burial. The body goes to be cremated or buried straightaway without a service. This is a much cheaper option, and there are different reasons you may choose this.

There could still be some form of farewell or remembrance ceremony of your choice. Or family or friends could arrange a ceremony later on. Some people may want the ashes present for this.

A religious or non-religious service

If you have a spiritual or religious faith, you may know who you want to lead the funeral. Even if you do not have a faith, you can contact a local minister, priest, imam, rabbi or other religious leader to talk about your funeral.

Some people choose a multi-faith funeral to reflect their life or the life of their loved one. It could include any combination of religious music, readings, prayers, or traditions. The ceremony can be led by 1 or more religious leader.

A humanist service does not include acts of worship and does not mention any faith. The service focuses on celebrating the life of the person who has died. Humanists UK can give you more information about humanist funerals and memorials. Visit **humanists.uk** (page 107).

Other things to include

You may also want to think about whether you want:

- specific music, songs or readings
- flowers
- donations to be given to specific charities
- your body to be dressed in clothes that are significant to you, such as a military uniform.

> **"I love prosecco and parties, that's just who I am. I've planned where I want my funeral to be, who I want to be there, how I want it to be organised. There will be lots of prosecco and a jazz band."**
>
> Alejandra

Recording your funeral plans

You can write your wishes for your funeral in your will, or in another document. Leave them in a safe place that your family or friends know about. You can also write your funeral wishes in your advance care plan (pages 15 to 20).

Dying Matters and the National Association of Funeral Directors (NAFD) have produced a form you can use to record your funeral wishes. Download it from **nafd.org.uk/funeral-advice/planning-ahead**

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

Paying for a funeral

Funerals can be expensive. If you are able to, you may want to pay for your funeral in advance with a funeral pre-payment plan.

You can find out more from:

- your local funeral director
- the National Association of Funeral Directors (NAFD) – page 108
- the National Society of Allied and Independent Funeral Directors (SAIF) – page 108.

Services that are included in the price can vary, so make sure you know what you are paying for. The Financial Conduct Authority (FCA) regulates firms that provide and arrange pre-paid funeral plans. If you have a funeral plan, or are thinking about buying a new one, check the list of funeral plan providers on the FCA website first. Visit **fca.org.uk**

Help with funeral costs

If the person organising the funeral is on low income and getting certain benefits, you may be able to get help with funeral costs from the government.

You can find more information at **gov.uk/funeral-payments**
Or Macmillan's welfare rights advisers can tell you more (pages 102 to 104).

Charities that can help with funeral costs include:

- Turn2us (page 109)
- Down to Earth Quaker Social Action (page 106).

Choosing a funeral director

If you use a funeral director, you may choose one you have used before. Members of the National Association of Funeral Directors (NAFD) or National Society of Allied and Independent Funeral Directors (SAIF) are regularly monitored to make sure their standards are high (page 108). You can contact the NAFD to find out whether 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 arranging a funeral without a funeral director (page 108).


NHS

Managing your care if you have not planned ahead

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If you do not make a plan for your future care

You might want to know how decisions are made if you are unable to make them, and you have not:

- planned ahead for any medical care
- made a lasting power of attorney for health and welfare (pages 32 to 37)
- made an advance decision to refuse treatment (pages 40 to 49).

If you cannot communicate or make a decision for yourself, you are protected by the Mental Capacity Act 2005. This Act makes sure any medical decisions will benefit you and are made in your best interests.

Who will make decisions about your care?

Usually, you, your family, carers or close friends will be involved in making everyday decisions about your care. But sometimes, an important or difficult decision may need to be made about your medical care or treatment in an emergency.

If you are not able to make and communicate your own decisions, a senior healthcare professional usually decides about your care in an emergency situation. Decisions must be made in your best interests and guided by the Mental Capacity Act. They must do their best to make sure any treatment will be of most benefit to you.

What is mental capacity?

Mental capacity means being able to make decisions for yourself. In England and Wales, the Mental Capacity Act aims to protect people who cannot make a decision for themselves (do not have capacity).

The Act allows other trusted people to make decisions for you, in your best interests. This might include decisions about your medical treatment or managing your finances and property.

The Mental Capacity Act 2005

The Mental Capacity Act 2005 came into force in 2007. It applies to people aged 16 and over in England and Wales who cannot make a decision for themselves (do not have capacity).

The act 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 about lasting power of attorney (pages 32 to 37) and advance decisions to refuse treatment (pages 40 to 49).

The Act states that a person lacks capacity if they are unable to make a decision for themselves about a specific matter. This may be because of an impairment of, or a disturbance in, the functioning of the mind or brain.

A person lacks capacity if they cannot do 1 of the following:

- understand information about the decision
- remember the information
- use or consider the information as part of the decision-making process
- communicate their decision by talking, using sign language or any other means.

Best interests decisions and healthcare professionals

Sometimes a senior health professional will need to make a decision about your medical care and treatment. They will base their decision on what they know about:

- your situation
- your wishes
- any advance statements you may have made (pages 40 to 49)
- their experience.

They will discuss the decision with your family, friends and anyone else involved in your care. This is to make sure any care or treatment will provide the most benefit to you. But a senior health care professional will have the final responsibility for the decision. These decisions are called best interests decisions.

Sometimes this means that what the family might want is not able to happen. In this situation, the healthcare professional should explain the reasons for their decision and the law regarding best interests decisions.

Making a best interests decision

If a best interests decision is about life-sustaining treatment, a health professional looks at the treatment options to make sure that the best interests of a person are met.

The Mental Capacity Act gives healthcare professionals a list of things to think about when making a best interests decision. These include:

- all the relevant circumstances
- your past and present wishes
- your values and beliefs
- the views of people caring for you, such as family members, friends or carers.

The Mental Capacity Act also states that a best interests decision must not be based on your age, condition, appearance or any aspect of your behaviour.

The Act also ensures that those who make decisions think about all the relevant circumstances about your care. It also makes sure that the motives of the person making the decision are correct and in your best interests.

Independent mental capacity advocates

In some situations, medical staff may need to appoint an independent mental capacity advocate (IMCA). This person acts as your advocate and represents your interests and views, if you cannot do so yourself.

IMCAs are usually only appointed if:

- you do not have a health and welfare lasting power of attorney
- you do not have family or friends who are able or willing to represent you
- you need a non-urgent decision made on your behalf about serious medical treatment, such as giving a new treatment, stopping treatment that has already started, or choosing not to allow treatment that could be offered.

The IMCA considers how these actions will affect you. They think about whether your life is likely to be made better or worse. For example, a new treatment may cause side effects such as sickness and pain, but only give you a few more weeks to live. The IMCA works with your medical team to make sure that your civil, human and welfare rights are respected. They consider all the options before making a decision.

IMCAs may also make decisions about where you are cared for. They can be appointed if an NHS body or local authority suggests moving you so that you stay in:

- hospital for longer than 28 days
- a care home for more than 8 weeks.

IMCAs may also be appointed to help make decisions about care reviews and adult protection cases. You can find out more about the IMCA service by visiting **gov.uk and searching** for 'independent mental health advocate'.

Forms and documents

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Preferred priorities for care document

Advance care planning makes sure people know what your wishes are for future treatment and care. Ask your healthcare 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. If you live in England or Wales, you can use a preferred priorities for care (PPC) document.

About this document

A preferred priorities for care (PPC) document can help you think about the future. It gives you the chance to talk about and write down your preferences and priorities for care at the end of your life. You do not need to do this unless you want to.

A PPC document can help you and anyone who is involved in your care understand what is important to you when planning your care. This could include family members, friends and professionals. If in the future you become unable to make a decision for yourself, anyone making decisions about your care will have to consider what you have written in your PPC document.

The PPC document is not for recording specific medical treatments you do not want to have in the future. If you decide that you want to refuse any medical treatments in advance, you should discuss this with your doctors. They will tell you how to record this decision.

Remember that your views may change over time. You can change what you have written whenever you wish to. It is a good idea to look at your PPC document regularly, to make sure that it still reflects what you want.

Should I talk to other people about my PPC document?

You may find it helpful to talk about your future care with family members or friends. Sometimes this can be emotional, and people might disagree with your decisions. It can also be helpful to talk about any needs your family or friends may have if they will be caring for you. Your health and social care professionals (your doctor, nurse or social worker) can support you and the people close to you with these decisions.

When you have completed your PPC document, it is best to keep it somewhere safe, and share it with anyone involved in your care. This means people will know what is important to you and consider your wishes when planning your care.

Will my preferences and priorities be met?

People planning your care will always try to follow what you have written in your PPC document. However, it may not always be possible to meet a particular need. Or things can change unexpectedly – for example, a carer may become over-tired or ill.

What should I include in my PPC document?

You should include anything about your future care that is important to you, or that you are worried about. It is a good idea to think about:

- your beliefs and values
- what you would and would not like to happen
- where you would like to be cared for at the end of your life.

Further information

There is an A4 copy of the Preferred priorities for care document in the pocket at the back of this booklet. You can also download extra copies from **orders.macmillan.org.uk** – search for 'preferred priorities'.

There is space on the Your notes and questions pages at the back of this booklet (pages 115 to 116) to write any further information you need or questions you might want to ask your health or social care professionals.

My details

Name	
Address	
Telephone number	

People who should be asked about my care if I become unable to make decisions

You may have formally appointed somebody to make decisions on your behalf, in case you become unable to do this yourself. This is called a lasting power of attorney (LPA). If you have registered an LPA, please provide their contact details below.

Name	
Relationship to me	
Address	
Telephone number	

If you are unable to make decisions for yourself, is there someone you would like to be asked about your care? If so, please provide their contact details below.

Name	
Relationship to me	
Address	
Telephone number	

My preferences and priorities

Health information – what my healthcare team and family or friends need to know about me to give me the best care and treatment.
Preferences and priorities for my future care – what is important to me. Is there anything I would like, or anything I do not want?
Where I would like to be cared for in the future.
Signature:
Date:
Changes to my preferences and priorities. (Please sign and date any changes)

Further information

You can use the space below to write any further information you need or questions you might want to ask your health or social care professionals.

Contact details

You can use the space below to write contact details of anyone who is involved in your care.

Name	
Relationship to me	
Contact details	

This document was given to me by:

Name	
Organisation	
Telephone number	
Email address	

This form has been adapted, with permission, from the National End of Life Care Programme's Preferred Priorities for Care proforma, which was originally published in 2004 by the Lancashire & South Cumbria Cancer Network and revised in 2007 by the National End of Life Care Programme.

My advance decision to refuse treatment document

About this document

An advance decision to refuse treatment (ADRT) is a statement of your wishes to refuse a particular treatment in a specific situation. It is a way of making sure everyone knows what treatments you do not want, if you become unable to make your own decisions about your care in the future.

This document is for you to write down, in advance, any specific treatments that you do not want to have in the future. It will only be used if you cannot make or communicate a decision for yourself (do not have mental capacity) about your healthcare needs, and so are unable to agree (consent) to or refuse treatment.

You must ensure that this ADRT is up to date and replaces any previous decisions you have made.

By completing this ADRT you are not refusing your right to receive basic care, support and comfort.

Section 1: My details

Name	
Address	
Date of birth	
Telephone number	
Physical features that could identify me if I am unconscious (for example, a birthmark on my face).	

Section 2: My advance decision to refuse treatment

If you wish to refuse a treatment that is, or may be, life-sustaining (could keep you alive), you must state in the box: 'I refuse this treatment even if my life is at risk as a result'.

I wish to refuse the following specific treatments	In these circumstances
Example: Artificial feeding or hydration – I refuse artificial feeding or hydration even if my life is at risk as a result.	Example: If I have terminal cancer, become unconscious and am unable to swallow fluids or food unaided.

An advance decision refusing life-sustaining treatment must be signed by you, or by another person in your presence and by your direction. It must also be witnessed by someone else. The witness must sign the ADRT in the presence of you, or the nominated person directed by you to sign.

Section 3: My signature and witnesses

My signature (or nominated person directed by me to sign), signed in the presence of my witness.	
Date of signature	
Witness name	
Witness signature (signed in my presence)	
Witness address	
Date of signature	
Witness telephone number	

Section 4: Person to be contacted to discuss my wishes (optional)

Name	
Address	
Relationship to me	
Telephone number	

Section 5: Details of healthcare professionals

I have discussed this advance decision to refuse treatment with .... (name of healthcare professional).

Job title	
Contact details	
Date	

I give permission for this document to be discussed with my family members or carers:

Yes **No**

(please circle one and specify if you only wish for it to be discussed with specific people)

My GP (local doctor) is:

Address	
Telephone number	

Section 6: Optional review dates

This advance decision to refuse treatment was reviewed and confirmed by me:

Signature	
Date	
Signature	
Date	
Signature	
Date	
Signature	
Date	

Section 7: Details of people who have been told about this advance decision to refuse treatment and have a copy

Name	Relationship to me	Contact details

Section 8: Further information (optional)

I have written the following information that is important to me. It describes my hopes, fears and expectations of life and any potential health and social care problems. It does not directly affect my advance decision to refuse treatment, but the reader may find it useful.

This form has been adapted, with permission, from the National End of Life Care Programme's Advance Decisions to Refuse Treatment proforma, which was originally published in September 2008.

Your checklist for planning ahead

You may want to use the following checklists to help you plan your future care. Keep this with any other documents about planning ahead.

1. Your planning ahead checklist

Question		More information
Have you made a will?	☐	Where is it? Who knows where it is?
Have you written down your wishes for your future care?	☐	Where are they kept? Who knows where they are?
Have you made a lasting power of attorney (LPA)?	☐	Where is your lasting power of attorney document? Who is your attorney?
Have you written an advance decision to refuse treatment (ADRT)?	☐	Where is it? Who have you talked to about it?

Question		More information
Have you thought about organ and tissue donation? Have you registered and recorded your decision to be a donor or opt out? If you do not want to be an organ donor, you need to record your decision.	☐	Who have you told?
Have you made a funeral plan?	☐	Where is your plan? Who knows about your wishes?

2. Your contacts checklist

Question		More information
Have you spoken to health and social care professionals about your wishes?	☐	Who have you spoken to? What are their contact details?
Have you spoken to a family member or friend about your wishes?	☐	Who have you spoken to? What are their contact details?
Have you involved a solicitor in your plans? For example, have you involved them in your will or lasting power of attorney?	☐	Who is your solicitor? What are their contact details?
Have you appointed someone to be the executor of your will?	☐	Who is it? What are their contact details?

3. Your important information checklist

It can help for family members or friends to know where to find important documents and information. Make sure you only tell people you trust. It is best not to write on this checklist exactly where these documents are, or your passwords.

Information or document	**Does someone know where it is kept?**	**Who knows where it is?**
Birth certificate	☐	
Marriage or civil partnership certificate	☐	
Bank account details	☐	
NI (National Insurance) number	☐	
Life insurance policy details	☐	
Home insurance policy details	☐	
Car insurance policy details	☐	
Important passwords	☐	

Further information

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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 **orders.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
- interactive PDFs
- 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 **informationproductionteam@macmillan.org.uk** or call us on **0808 808 00 00**.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

You can read more about how we produce our information at **macmillan.org.uk/ourinfo**

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are 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. We 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.

Our trained cancer information advisers can listen and signpost you to further support. Call us on **0808 808 00 00**. We are open 7 days a week, 8am to 8pm.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to **macmillan.org.uk/talktous**

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call **0808 808 00 00** and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Macmillan Information and Support Centres

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

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

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

Financial guidance

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

Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. 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 energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing, to changes needed to your home.

Call us on **0808 808 00 00** to find out more about Macmillan Grants.

Help with work and cancer

Whether you are 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.

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 is why we help bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, family member or friend, 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**

You can also use our Ask an Expert service on the Online Community. You can ask a financial guide, cancer information nurse, work support advisor or an information and support advisor any questions you have.

Macmillan healthcare professionals

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.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Planning ahead support organisations

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use the online webchat or find details for your local office by contacting:

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

Down to Earth Quaker Social Action

Tel **020 8983 5055**
www.quakersocialaction.org.uk
Offers practical support with funeral services.

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.

Hospice UK

Tel **0207 520 8200**
www.hospiceuk.org
Provides information about living with advanced illness. Also provides free booklets and a directory of hospice services in the UK.

Human Tissue Authority

www.hta.gov.uk
Provides information about tissue and organ donation.

Humanists UK

Tel **020 7324 3060**
www.humanists.uk
Can help provide humanist ceremonies.

Law Society

Tel **0207 242 1222**
www.lawsociety.org.uk
Represents solicitors in England and Wales and can provide details of local solicitors.

Marie Curie

Helpline **0800 090 2309**
www.mariecurie.org.uk
Provides practical information and support on all aspects of life with terminal illness, dying and bereavement. Marie Curie nurses provide free end-of-life care to people in their own homes or in Marie Curie hospices.

National Association of Funeral Directors (NAFD)

Tel **0121 711 1343**
www.nafd.org.uk
Monitors standards of funeral directors in the UK and gives advice on what to do when someone dies. Also advises on arranging funerals and has information on what you should expect from a funeral director.

National Society of Allied and Independent Funeral Directors (SAIF)

Tel **0345 230 6777**
www.saif.org.uk
An organisation of 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 arranging a funeral and what to do when someone dies.

Natural Death Centre

Tel **0196 271 2690**
www.naturaldeath.org.uk
Provides information about bereavement and arranging funerals. It also has information on how to arrange inexpensive and environmentally friendly funerals.

NHS Blood and Transplant

Tel **0300 123 2323**
www.organdonation.nhs.uk
Provides information about organ and tissue donation.

Office of the Public Guardian

Tel **0300 456 0300**
www.gov.uk/government/organisations/office-of-the-public-guardian
Protects and safeguards the property and finances of people living in Scotland who may not have the mental capacity to make certain decisions for themselves.

Turn2us

Helpline **0808 802 2000**
www.turn2us.org.uk
Runs a free, confidential and independent helpline, which provides help with benefits, debt, housing and legal issues. Has an online tool to search for funds that may be able to give you a grant. Also offers some grants themselves to people in financial hardship.

General cancer support organisations

Cancer Research UK

Helpline **0808 800 4040**
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 3000 118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Riprap

www.riprap.org.uk
Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

Tenovus

Helpline **0808 808 1010**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

Support for carers

Carers Trust

Tel **0300 772 9600**
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline **0808 808 7777**
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.

Bereavement support

Cruse Bereavement Care

Helpline **0808 808 1677**
www.cruse.org.uk
Provides bereavement support to anyone who needs it across the UK. You can find your local branch on the website.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

UK Council for Psychotherapy (UKCP)

Tel **0207 014 9955**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline **0300 123 3393**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **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.

Support for older people

Age UK

Helpline **0800 678 1602**
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**
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.

OUTpatients (formerly called Live Through This)

www.outpatients.org.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.

Your notes and questions

Your notes and questions

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr Viv Lucas, Consultant in Palliative Care.

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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 **informationproductionteam@macmillan.org.uk**

Sources

Below is a sample of the sources used in our information about planning ahead when you have cancer. If you would like more information about the sources we use, please contact us at **informationproductionteam@macmillan.org.uk**

GOV.UK. Office of the Public Guardian. Make, register or end a lasting power of attorney. Available from: www.gov.uk/power-of-attorney/make-lasting-power [accessed May 2023].

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NHS England. Universal Principles for Advance Care Planning (ACP). 2022. Available from: england.nhs.uk/wp-content/uploads/2022/03/universal-principles-for-advance-care-planning.pdf [accessed May 2023].

Royal College of Physicians. Talking about dying 2021. How to begin honest conversations about what lies ahead. Available from: rcplondon.ac.uk/projects/outputs/talking-about-dying-2021-how-begin-honest-conversations-about-what-lies-ahead [accessed May 2023].

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are 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 are here 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

1. **Share your cancer experience**
   Support people living with cancer by telling your story, online, in the media or face to face.
2. **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.
3. **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?
4. **Raise money**
   Whatever you like doing you can raise money to help. Take part in one of our events or create your own.
5. **Give money**
   Big or small, every penny helps. To make a one-off donation see over.

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
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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.

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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.

If you would rather donate online go to **macmillan.org.uk/donate**

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REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

This booklet is about ways you can plan ahead for your future care if you live in England or Wales. Planning for your future care is also called advance care planning. It is important in case you ever become unable to make decisions for yourself.

This booklet can help you think about what is important to you and put your plans into action.

It also suggests ways to talk about your wishes with the people close to you, and with health and social care professionals.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** 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 Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

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

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