YOUR LIFE AND YOUR CHOICES: PLAN AHEAD (ENGLAND AND WALES)
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 England or Wales. It is for anyone who wishes to plan ahead, whether they have a serious illness or not.

Planning for your future care (also called advance care planning) is important in case you ever become unable to make choices yourself. For example, if your health were to change and you became unconscious or lost capacity (the ability) to make decisions about treatment.

In this booklet, we tell you about some of the ways you can plan ahead. It includes information on:

• **Your wishes for your care** – these include how and where you would like to be cared for if you become seriously ill or you are reaching the end of your life (see pages 33–41).

• **Lasting Power of Attorney** – this is when you give someone you trust the power to make decisions on your behalf about your property and finances, or your welfare and healthcare, or both (see pages 43–47).

• **Advance Decisions to Refuse Treatment** – these are your decisions about specific treatments you don’t want to have (see pages 49–61).

It also has information about **making a will** (see pages 25–31), **organ and tissue donation** (see pages 63–67), and **funeral planning** (see pages 69–75).
We hope this booklet will help you:

- think about what’s 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 writing down your plans so that the people involved in your care know what’s important to you
- deal with any worries you may have about planning ahead.

**How to use this booklet**

You may want to read the booklet through first and then concentrate on the sections that are most helpful for you. You can use the contents on page 5 to help you.

We can’t advise you about the best ways to plan ahead. You may find it helpful to discuss what’s best for you with a health or social care professional, and someone close to you.

Remember that it’s your choice if you want to plan ahead and use some of the ways we’ve suggested in this booklet. Planning ahead can be daunting. But it is a good way to improve the chances of getting the care you would choose. Most people feel better knowing they have prepared for the future.

If you don’t want to plan ahead, or you need more time to think about it, that’s fine too.
Throughout the booklet we have included comments from people who have been involved in planning ahead. Some are from members of our Online Community (macmillan.org.uk/community) and from the website healthtalk.org Others are from people who have chosen to share their experiences with us – like Dennis’s family on the cover of this booklet. We hope you find these helpful.

There are also three documents at the back of this booklet that you can use to write down some of your wishes and decisions for your future care. One is a planning ahead checklist which you may find helpful to fill in. The others are a Preferred Priorities for Care document and an Advance Decision to Refuse Treatment document. You can read more about these on pages 34–41 and pages 50–58.

**Further information**

Pages 93–99 have contact details for organisations that may be useful to you. There’s also space for you to write down any notes or questions you may have for a health or social care professional (see page 100).

If you have cancer, or care for someone with cancer, you may want to talk about it with one of our cancer support specialists. You can call the Macmillan Support Line free on 0808 808 00 00, Monday–Friday, 9am–8pm. If you’re hard of hearing you can use textphone 0808 808 0121, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit macmillan.org.uk
'We hope this booklet supports you to plan ahead for your future care.'

Adrienne, Macmillan Programme Manager and Dennis’s daughter-in-law
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Julie
PLANNING AHEAD

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Many people think they don’t need to make decisions about their future care unless they reach a time when they have a serious illness. This might include an advanced cancer, heart failure, chronic obstructive pulmonary disease (COPD) or motor neurone disease (MND).

However, planning ahead is important, whether you have an illness or not. This is because none of us can say for sure whether we’ll always be able to make our own decisions about our care. For example, you may become very ill suddenly and be unable to make decisions about your healthcare, or make financial plans for your family or friends.

It’s also important because it’s not always possible for health or social care professionals to know exactly how you would like to be cared for in certain situations. For example, if you became unwell and were unable to talk to them.

Remember that you are the expert on you. Only you know how and where you would like to be cared for. Even your closest family and friends may not know exactly how and where you would wish to be cared for if you haven’t told them in advance. This might mean you aren’t cared for in the place or way you would have chosen.
For example, if you had an illness that couldn’t be cured and your condition suddenly got worse, you may want to be cared for at home. If your family or health or social care team didn’t know this, and you are too ill to tell them, you may be admitted to hospital.

‘My dad was 57 when he died of advanced prostate and bowel cancer. Towards the end of his life he became ill very quickly and was unable to tell us where he wanted to be cared for. He was admitted to hospital and died there. Although he was well cared for, I can’t help thinking that if we could have turned the clock back and asked my father what he wanted, he would have told us that he wanted to die at home with his family, not in hospital.’

Julia
If you plan your care in advance, there’s 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 on.

‘Maggie, a resident at a care home, had told staff that if her health condition changed, her preferred place of care was the care home, rather than hospital or somewhere else. This was recorded in her care plan. Sometime later, Maggie had a fall. She was admitted to hospital with a broken hip. Maggie was not fit enough for surgery and quickly became too unwell to talk to staff about her care. Instead of remaining in hospital, staff followed Maggie’s documented wishes for her preferred place of care and she was transferred back to the care home. Four days later, Maggie died peacefully, being cared for by the staff she knew.’

Jason, a healthcare professional
Ways to plan ahead

There are several ways you can make plans in advance. We’ve listed these over the next few pages, but it’s important to remember that you don’t have to use them all. Many people find it helpful to start with the ones that are most relevant to them.

A will

A will is the only way to make sure that your wishes are carried out after you die. It can make sure your family and friends are provided for in the way you want. A will includes who you would like your property, personal things and money to go to after you die. It may also include who you’d like to look after anyone dependent on you (your dependants) and any specific funeral arrangements you want. We have more information about making a will on pages 25–31.

Your wishes for your care

You can either tell people your wishes, or write them down. These will be your specific wishes about how you would like to be cared for if you ever become unwell. They can include your choice about where you would like to be cared for. 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. For example, a Preferred Priorities for Care document. There’s more information about your wishes for your care on pages 33–41.
Lasting Power of Attorney

Creating a Lasting Power of Attorney means appointing in writing the name of someone you trust to make decisions on your behalf. There are two types of Lasting Power of Attorney:

- A **Property and Financial Affairs LPA**, to manage your finances and property.
- A **Health and Welfare LPA**, to manage your personal welfare, which may include your health.

It’s a legal document and needs to be registered. A Health and Welfare LPA can only be used if you become unable to make decisions yourself. A Property and Financial Affairs LPA can be used when you still have the ability to make your own decisions. You can find more information about Lasting Power of Attorney on pages 43–47.

Advance Decision to Refuse Treatment

You can also write down your wishes about any treatment you don’t want to have, in case you’re not able to tell your doctors or family later. These are known as Advance Decisions to Refuse Treatment or ADRT (see pages 49–61). These decisions used to be known as a living will. Advance Decisions to Refuse Treatment are legally binding if they meet certain requirements in the Mental Capacity Act 2005 (see page 84).
Organ and tissue donation

Some people choose to write down their wishes about organ and tissue donation, or whether they would like to donate their body for medical research. We have more information about organ and tissue donation on pages 63–67.

Funeral planning

You may wish to be involved in planning your funeral. This can be helpful if you know how you would like your funeral to be carried out. It’s also possible to pay for your funeral in advance. We have more information about funeral planning on pages 69–75.
‘Macmillan nurses are fantastic. They can point you in the right direction of what you need to consider. The local hospice also had a solicitor who provided a free will service.’
Who can help you with planning ahead?

Planning ahead for our healthcare isn’t something we usually think about. If we’re well, we don’t expect to become seriously ill. We may assume that we’ll always be able to make decisions for ourselves even when we’re unwell. But this isn’t always the case.

For many people with cancer or other illnesses, planning ahead may be particularly difficult. You may already be struggling to cope with fears and uncertainties about the future. It’s important that you don’t feel alone when planning ahead. Remember that there are many professionals who can help you, as well as your family and friends.

Professionals

There are many professionals who can help you plan ahead. You can ask your GP, district nurse, specialist community nurse, social worker or your hospital doctors who is the best person to speak to. If you’re thinking about making a will or creating a Lasting Power of Attorney, you can contact a solicitor to help you.

It’s fine to talk about your plans with one of these professionals. But starting a conversation about your future plans may feel difficult. You may want to start with something like this:

‘I’ve been thinking about planning ahead for the future, just in case something happens to me and I can’t make my own decisions. I wonder whether you could help me understand what options I have and what I need to do to make sure any decisions I make now are carried out? Or suggest someone else who could help with this?’
Family and friends

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

If your plans involve your family or friends taking on more responsibility for your care, it’s important to discuss this with them. For example, you may want to die at home and need them to look after you. You can ask them whether they think this extra responsibility will be too much for them. If it is, you can ask your health and social care team for advice. They can tell you more about the support that might be available to help your family or friends, and about other care options.

Sometimes family and friends don’t want to talk about planning ahead. They may appear to ignore the fact that you want to think about the future, perhaps by playing down your worries and changing the subject. If this upsets or hurts you, try explaining to them why it is important for you to plan ahead. You could ask them to read this booklet, so that you can talk about it together when you all feel ready. Perhaps start by reassuring them that this is something you want to do and it will help if you could talk to them about it. You could try saying something like this:

‘I know it’s difficult to talk about this, but I’d really like to chat through how I would like to be cared for if my health was to suddenly get worse.’
Coping with your emotions

Planning ahead can make you feel all sorts of emotions, particularly if you’re already coping with an illness. You may be feeling sad, anxious and scared. These are normal reactions that people often have when coping with uncertainty about their future. Even if you’re well, thinking about how you would like to be cared for if you were to become seriously ill can cause lots of different feelings.

There are many people who can help you cope with your emotions. Talking to close family or friends can help. Health and social care professionals can also give you support. This could be your GP, nurse specialist, social worker or hospital doctor. You may also find it helpful to join a support group or talk things through with one of the organisations on pages 93–99.

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

Planning ahead can be hard. But it may help give you a feeling of control over your life and your future.

Our cancer support specialists are here for you if you have questions, need support or just want a chat. Call our support line for free on 0800 808 00 00, Monday–Friday, 9am–8pm.
How to plan ahead

You can plan ahead in simple steps. Don’t feel you need to follow all these steps in order – just do what feels right for you and take your time:

• **Find out about the different ways you can plan ahead.** You can find more information on pages 11–13 or you may want to contact one of the organisations on pages 93–99. Remember it’s your decision whether you use just one or two of these ways to plan ahead, or all of them.

• **Talk to your family and friends.** They will 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 and talk it all through. The professionals helping you won’t expect you to rush into making any plans unless you’re sure about them. Some people can take several months before they feel happy to make plans for their future care or treatment.

• **Write your plans down.** You may want to use the documents for Preferred Priorities for Care and Advance Decisions to Refuse Treatment at the back of this booklet. Or you can ask a health or social care professional if there is a local advance care plan document you can use. If you want to make a will (see pages 25–31) or create a Lasting Power of Attorney (see pages 43–47), it’s a good idea to see a solicitor as these are important legal documents.
• **Keep your documents safe.** Make sure they can easily be found by your family, friends, and health or social care professionals. Your family should know where they are kept.

• **Review your documents regularly.** This is to make sure they still follow your wishes. Your wishes can vary over time, especially if your circumstances change. You can review your documents with your health and social care professionals. It’s important to include the people close to you too.

• **You can change the plans you’ve made at any time.** This includes your will, Preferred Priorities for Care, Advance Decision to Refuse Treatment or your wishes for organ and tissue donation. If you do change any of your plans, you need to make sure that everyone involved in your care knows. You should also officially write down (document) your new wishes, even if this isn’t a legal requirement for the particular plan you want to change. Writing down your wishes officially and sharing them makes sure that everyone who’s involved in your care knows what they are.

You may find it helpful to use the planning ahead checklist at the back of this booklet. You can use it to keep a record of the ways you’ve planned ahead, important contacts and where you keep certain documents. Make sure someone close to you knows where you keep this checklist.
'My father was diagnosed with a progressive neurological illness that would leave him unable to make decisions for himself. The progression of his condition would mean that there would be important decisions to be made in his best interests. He understood the likely course of his illness, and at the time of writing was able to make decisions for himself.

It was his choice to document that he didn’t want to be resuscitated if anything were to happen that made his breathing or his heart stop, and to let us know where he wanted to be cared for during the rest of his life. As part of his planning he nominated his wife and daughters as Power of Attorney for health and welfare so that we could be involved in decisions important to him in the event that he lost capacity.

We realised that his choices may change over time and that we would need to review things over time. He stated simply where he wanted to be cared for and why, and also some arrangements for his funeral. Talking about his wishes and writing them down, gave him the opportunity to remain in more control of his ongoing care.

These conversations about advance care planning were difficult and took time. However, they meant our father’s choices were central, and that we would be involved in each stage. Knowing that he told us his wishes bravely and openly, and we did our best to make his choices a reality, made an uncertain future more acceptable.'
‘My father spent the last three years of his life in a nursing home. He became increasingly frail and ultimately wheelchair-bound. His illness made him more likely to get chest infections which made him very unwell.

He was mostly capable of making his own decisions and we involved him in daily decisions about his routines and activities.

As his condition progressed we reviewed his advance care plan with his GP and my father stated he would rather not be admitted to hospital for intravenous fluids or antibiotics but kept in the care home and have anticipatory treatment there to keep him comfortable. The GP signed the advance care plan that we had written and the nursing home, his GP, ambulance service and out-of-hours doctor were aware this was in place. As a result he avoided hospital admission several times.

At the end of life he wanted to be cared for in the best place to meet his needs. When the nursing home staff couldn’t provide specialised care he was transferred to a palliative care unit for the last three weeks of his life.

My father’s advance care plan gave him a voice when he couldn’t make his heard. It gave us confidence that we were carrying out his wishes, and it gave guidance to the medical team. It was a very necessary process to go through as a family, helping us to gain at least some control over what often felt like a very unpredictable time for Dad. It also ensured Dad’s dignity and choice were uppermost in the decisions taking place about him as he came to the end of his life.’
‘Knowing that he told us his wishes bravely and openly, and we did our best to make his choices a reality, made an uncertain future more acceptable.’

Jane
MAKING A WILL

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Why make a will?

Whatever your age, having an up-to-date and valid will is important. Dying without a will means that your wishes for who you would like to leave your estate to (your property, personal things and money) can’t be guaranteed.

If you die without a will, it is known as **dying intestate**. When someone dies intestate, it often takes much longer to deal with the estate and it can be more complicated. There are strict rules known as **intestacy rules**, which set out who should deal with the deceased’s affairs and who should inherit their estate. This may mean that the people who inherit the estate aren’t the people you would have chosen.

‘Although I found it difficult to make a will, I now know that when I do die, the people who I love and care for will be able to benefit from my material possessions.’

Michael
Involving a solicitor

A professionally written will can help reduce any problems or arguments in the future. Although you can write a will yourself, it’s best to use a solicitor when making or updating your will. This is to make sure you follow legal procedures. The process doesn’t have to be lengthy or expensive. It’s worth looking around or asking for a quote before committing to a specific solicitor.

If you need help finding a local solicitor, you can contact the Law Society of England and Wales (see page 94).

Macmillan has a discounted will writing service. We suggest some organisations you can trust and who offer will writing at a reduced price. You don’t have to leave a gift to Macmillan to get a discount. The organisations offer a range of online, telephone and face-to-face services. Visit macmillan.org.uk/willwriting or call 0300 1000 200 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.

What you have to leave in your will and what is the value of your estate

You may want to start by making a list of everything you own (assets) and how much they’re worth. This might include your house, car, jewellery, bank and building society accounts, saving accounts and life insurance policies.

Then make a list of everything you owe (liabilities) and how much these add up to. This includes your outstanding mortgage balance and any overdrafts, credit card debts and bank loans.

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

Make a list of the family and friends you want to remember in your will and think about what you want to leave them. For example, you might want to give someone a specific amount of money, or a piece of jewellery. You may also want to think about leaving money to an organisation or a charity.

Other important information

Other things you’ll need to think about include:

• who you want to be responsible for carrying out the instructions in your will (known as executors)

• who you want to be the legal guardian(s) of your children (if you have children and they are under 18)

• who you want to look after anyone dependent on you (your dependants)

• what, if any, funeral instructions you may have

• who you would like to look after your pets (if you have any).

We have more information about making a will that has a useful checklist of what to include. Call our support line on 0808 808 00 00 to order this.
Meeting with a solicitor

When you meet with your solicitor it will help to take your completed lists of:

• the things you want to leave in your will
• who you want to include in your will
• names of the people you want to be responsible for carrying out the instructions in your will (your executors)
• names of who you want to be guardians for your children and who you want to look after anyone dependent on you.

After your first meeting with a solicitor, you should arrange a follow-up appointment to check that your will has been drafted according to your wishes. Once you’re happy with it, it will need to be witnessed and signed.

It’s important to keep your will updated to reflect any big changes in your life. For example, if you’ve had children or grandchildren, or met a new partner, you might want to update it to include them. Or you may need to update it to take account of changes in your finances.

It’s a good idea to leave your up-to-date will somewhere safe and easily found. For example, with your solicitor. Keep a copy for yourself and make sure those responsible for carrying out the instructions in your will know where it is.
‘Dennis died at home, in his own bed, with his dog Murphy lying beside him and his granddaughter Lauren holding his hand.’

Adrienne
YOUR WISHES FOR YOUR CARE

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Thinking about how you would like to be cared for

As part of planning ahead, it’s important to think about how and where you would like to be cared for. This is in case your health changed and you were unable to tell other people what you wanted to happen.

It’s best to write down your wishes and preferences. This is so your family and health or social care professionals know how you’d like to be cared for.

These statements about your preferences aren’t legally binding. But they will be very helpful for health or social care professionals when they make decisions about your care.

There are a number of documents that can be used to record your wishes. These include a:

- Record of Advance Care Plans and Preferences.
- Statement of Wishes and Care Preferences.
- Preferred Priorities for Care document.

You can ask your health care professional which documents are used in your area.

Before you write down your wishes and preferences, it may help to talk through your plans with your family or a close friend. This can be particularly helpful if you want them to be involved in your care or make decisions on your behalf. You should also talk through your plans with one or two of the professionals looking after you, such as your GP or nurse.
It’s also important to discuss whether your wishes are realistic. If they aren’t, try to think of some alternatives. For example, if you would prefer to die at home, but you don’t have any family or close friends able to support you there. So it may be more realistic for you to be cared for in a care home, hospital or hospice.

It may not always be possible for your wishes and preferences to be met when you become less well. 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 care for you. In this case, health or social care professionals may be able to arrange care for you so you can stay at home. However, if this isn’t possible they will plan for you to get the best possible care somewhere else. This may be in a care home or hospice.

‘One of the things my wife said to me was, “I know I’m dying but I want to die in my own home”. And my response was, “If we can manage to bring that wish to fulfilment, we will do that”. And with the help of my two daughters, the local community nurses and the doctor, we managed to achieve that. It was hard work. It was very emotional but we managed to carry out her last wish, so I see the element of nursing at home is important if it can be coped with without too much strain.’

Graeme
What to include in your wishes for your care

As far as possible, you should include anything that’s important to you. If you’re worried about a particular part of your care, you can make a plan for what you would like and write this down. You could include the following:

- Where you would like to be cared for when you can no longer look after yourself. For example, at home, or in a hospital, care home or hospice.

- Where you would like to be cared for when you are dying. For example, at home, or in a hospital, care home or hospice.

Unfortunately, it may not always be possible for you to be cared for in the place you would prefer. In this case, your health and social care professionals will arrange for you to get the best possible care somewhere else.

- What kind of care and treatments you would like. You can’t demand particular treatments however.

- Information about specific spiritual or religious practices that you’d like to be carried out or reflected in your care.

- Who you would like to be involved in your care. For example, family or close friends.
• Who you would like to be asked if decisions need to be made about your care and you are unable to make them yourself. You may want to create a Lasting Power of Attorney (see pages 43–47) so that others can act on your behalf.

• Who you would like to look after any pets.

• Whether you would like someone to tell you how serious your condition is and what might happen in the future.
Writing down your wishes for your care

You can ask your health or social care professionals for a document so that you can record your wishes and preferences. Or you can use the *Preferred Priorities for Care* document at the back of this booklet.

Once you have completed the document, you should 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 GP or hospital doctor.

Your health or social care team should keep a copy for their records. You should also keep a copy in a safe place and let people involved in your care know where it is.

It’s important to regularly review your wishes and keep them up to date. You can change your mind at any time. But remember you’ll need to make sure you record your changes. You will also need to let your family, community nurse, GP and/or hospital doctor know, and give them an updated copy of the document.

If you’re admitted or transferred to a hospital or hospice, take your document with you. This will let the staff know what your wishes and preferences are for your care.
Here is an example of some of the information included on a Preferred Priorities for Care 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. Curing my illness is no longer possible.*

**What are your preferences and priorities for your future care?**

*If I were to become less well I’d like my wife to be involved in making decisions about my care and I’d like to be kept fully informed about what’s happening to me.*

**Where would you like to be cared for in the future?**

*I don’t mind where I am cared for as long as my family are close by.*

**Signed**  
*Jo Smith*  

**Date**  
*23.2.15*
‘In February, my father-in-law Dennis was diagnosed with small cell lung cancer. Unfortunately, the treatment didn’t work and in August the doctors told him that he wouldn’t benefit from any further active treatment. Although disappointed, Dennis was relieved to stop as it was exhausting him.

During the course of the next few months, Dennis was referred to the Community Macmillan Nurse who 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 but when I spoke again to them 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 document them 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 we all agreed to help Joyce cope.
Over the next few weeks Dennis grew 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.'
LASTING POWER OF ATTORNEY

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What is a Lasting Power of Attorney?

A Lasting Power of Attorney (LPA) is a legal document. It allows a person to choose other people to make decisions on their behalf, should they ever lack the mental capacity (see page 84) to make decisions for themselves. The people chosen to make decisions on your behalf are known as attorneys. You can have more than one attorney.

There are two types of LPA in England and Wales:

- **A Health and Welfare LPA** – this allows your attorney(s) to make decisions about things such as treatment, care, medication and where you live.

- **A Property and Financial Affairs LPA** – this allows your attorney(s) to make decisions about things such as paying bills, dealing with the bank and selling your house.

Many people who choose to make an LPA will make both LPAs at the same time. But you can make just one of them if you prefer.
Why a Health and Welfare LPA may be helpful

A Health and Welfare LPA can give you peace of mind because you know that someone you trust will act on your behalf if you become seriously ill.

For example, a person may decide to give a Health and Welfare LPA to their adult son or daughter, or both. They can then discuss their thoughts about any future care decisions with their children. The person can then be sure that their care instructions will be followed if they’re unable to make their own decisions.

If you do appoint someone to be your attorney, choose someone who is like-minded and has a good idea of your wishes. They are more likely to make the decisions you would want.

‘She made me the executor of her will and set up Power of Attorney should she become unable to manage her own affairs. With everything in place, we were able to forget about legalities and concentrate on her care.’

Julie
Making an LPA

You can only create an LPA if you are aged 18 or over, and are able to understand what it is and what it means for you (have mental capacity – see page 84). You can get forms for each of the LPAs from the Office of the Public Guardian (see page 94).

Although you can create your own Lasting Power of Attorney, you may want to get help from a solicitor. The solicitor will make sure that it meets all the requirements of the law. If you don’t have a solicitor, you can find one by contacting The Law Society (see page 94).

LPAs must be registered with the Office of the Public Guardian before they can be used. This can take up to 10 weeks. If you’re the person making the LPA (also known as the donor), you can register it while you’re still able to. Or your attorney can apply to register the LPA at any time before they need to use it. There is a fee to register an LPA. You can phone the Office of the Public Guardian to find out the exact fees involved. If you’re on certain benefits, you may not have to pay the fee or you may only have to pay part of the fee. The Office of the Public Guardian will be able to give you advice about this (see page 94).
LPAs and Advance Decisions to Refuse Treatment

If you have made an Advance Decision to Refuse Treatment (ADRT, see pages 49–61) **before** creating a Health and Welfare LPA, in which you give someone else the power to refuse medical treatment on your behalf, your ADRT will be invalid.

If you make an Advanced Decision to Refuse Treatment **after** creating a Health and Welfare LPA, your LPA will be invalid. This means that your attorney can’t make a decision about any treatment that you’ve decided to refuse in your ADRT.
As a family we knew this was what he wanted and we all agreed to rally around to help Joyce cope with his care. Adrienne

‘Whatever your loved one decides, that’s the way forward really.’

Carl
ADVANCE DECISIONS TO REFUSE TREATMENT

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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 particular treatment in a specific situation. It is a way of making sure that everyone knows what treatment you don’t want to have if you’re unable to make your own decisions in the future.

For example, you may decide that:

• If your illness couldn’t be cured and you became very unwell after all possible treatment, you wouldn’t want to be kept alive by being fed or given fluids through a feeding tube or drip.

• If you are being fed or given fluids through a feeding tube or drip, you do not want this to continue if your condition were to get worse and it isn’t improving your quality of life.

• You do not want to be given antibiotics for an infection if you’re only expected to live for a few days.

See page 58 for an example of how some of this information could be written in an ADRT document.

An ADRT can’t include a request to have treatment or to have your life ended. You can request, but not insist on, treatment in your wishes for your care (see page 36).
It’s important to be as clear as possible about:

• the circumstances when you’d like your ADRT to apply
• what type of treatment you would want to refuse.

This is to make it clear to anyone reading the document what your wishes are. It will also help them decide whether your ADRT meets all the legal requirements of the Mental Capacity Act 2005 (see page 84). If it does meet these, it is legally binding. This means it must be respected by your doctors and those involved in your care.

If you make an Advance Decision to refuse a specific treatment, you will still be given the best possible care. You will have support, comfort and medicines to control your symptoms.

‘I feel strongly that I don’t want to be kept alive artificially. I’m now 85, I’ve had a very good time and I don’t want to be a burden in a sort of inanimate way. And so I would rather just die cleanly as it were. We’ve arranged this with our solicitor and I’m very happy with those arrangements.’

Percy
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 (have mental capacity – see page 84).

Before making an ADRT, it’s important to discuss the decisions you’d like to make with one of your healthcare professionals. This may be your GP, or a doctor or nurse specialist looking after you at the hospital. They will be able to tell you what the likely effects of stopping a treatment are and will make sure your ADRT meets legal requirements.
Advance Decisions to Refuse Treatment
What should be included in an ADRT?

Although most Advance Decisions to Refuse Treatment can be made verbally (spoken), it’s better to write it down. This helps avoid confusion later on.

There are certain situations where the law says that an ADRT must be in writing. For example, an ADRT that refuses treatment to keep you alive (life-sustaining treatment), such as resuscitation or being put on a ventilator (breathing machine), must be:

- written down
- signed by you or someone else with you at the time
- witnessed.

It must say exactly what treatment you want to refuse and in which situation. For example, you may want to refuse a treatment in a particular situation but not in another. It must also contain a statement such as, ‘I refuse this treatment even if my life is at risk as a result’ to make it legal.
There’s nothing in law that says what must be included in an ADRT if it doesn’t relate to life-sustaining treatment. However, it’s advisable to include the following:

- Your name, date of birth, address and any obvious distinguishing features. This is in case you’re unconscious or unable to communicate, and healthcare professionals need to identify you.

- The name, address and phone number of your GP, and whether they have a copy of your ADRT document.

- A statement that the document should be used if you ever don’t have the capacity to make decisions.

- A statement of which treatment(s) is to be refused and the circumstances when your decision would apply.

- The date your ADRT was created.

- Your signature and a dated signature of at least one witness (if it’s a written statement).

- If it’s an ADRT that will keep you alive, it must also include the statement, ‘I refuse this treatment even if my life is at risk as a result’.

Sometimes, a person may wish to refuse a specific treatment in all circumstances, rather than identifying a specific circumstance. For example, you may want to refuse a specific medication in all circumstances if you have an allergy or a religious objection to it.

If you want to make a statement about refusing a treatment in all circumstances, you should talk this through with a healthcare professional first. They will make sure that your ADRT will be clear to any health professional 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 one that has a set format. There are various organisations that have created forms for people to use. Hospitals and hospices often have written information and forms that people can use to prepare their own ADRT.

At the back of this booklet, we have included an ADRT document that has been adapted from the National End of Life Care Programme.

Remember to review your ADRT regularly so you can be sure it’s up to date and reflects your current wishes.
ADRT and Lasting Power of Attorney

An ADRT may become invalid if:

• you have made a Lasting Power of Attorney after making an ADRT and

• you have given your attorney the authority to accept or refuse treatment on your behalf.

You should let all the relevant people know if you’re in this position. It’s important to keep written records of when you made decisions and what they were. Make sure that everyone who may need to make decisions for you in the future knows where to find all your documents.
Here is an example of some of the information included on an ADRT document.

### My Advance Decision to Refuse Treatment

<table>
<thead>
<tr>
<th>I wish to refuse the following specific treatments</th>
<th>In these circumstances</th>
</tr>
</thead>
<tbody>
<tr>
<td>*If you wish to refuse a treatment that is or may be life-sustaining, you must state in the box: ‘I am refusing this treatment even if my life is at risk as a result.’</td>
<td></td>
</tr>
</tbody>
</table>

**Cardiopulmonary resuscitation** –
| I refuse cardiopulmonary resuscitation if my heart and lungs stop functioning, 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 spontaneously. |

**Artificial feeding or hydration** –
| I refuse artificial feeding or hydration even if my life is at risk as a result. | If I have terminal cancer, become unconscious and am unable to swallow fluids or food unaided. |

---

**An ADRT refusing life-sustaining treatment must be signed by you (or by another person in your presence and by your direction) and witnessed by someone else. The witness must sign the ADRT in the presence of you, or the nominated person directed by you to sign.**
Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

You may hear doctors or nurses talk about a **DNACPR request**. These may also be referred to as **DNARs**. A DNACPR is a written statement to not give cardiopulmonary resuscitation (CPR) if someone has a cardiac arrest.

A **cardiac arrest** is when the heart stops beating. If the breathing stops, it is called a respiratory arrest. They commonly happen together, which is known as a cardiopulmonary arrest. **Cardiopulmonary resuscitation (CPR)** is a way of trying to restart the heart and breathing when they have stopped.

You may have already made a decision about not wanting to be resuscitated in a specific situation and included this in your ADRT (see pages 54–55). However, if you haven’t made a decision about CPR and you want to, you should discuss this with your medical team or specialist nurse. You may also want to talk this through with your family, a close friend or a spiritual carer such as a chaplain. Your medical team will be able to tell you how successful CPR is likely to be in different situations. They will take into account any other health problems you have.
A senior healthcare professional may sometimes ask if you want CPR to be attempted if you were to have a cardiac arrest. This may happen if the doctor believes that you might have a cardiac arrest and resuscitation could be successful. For example, you may have a cancer that can’t be cured but you are expected to live with the condition for a long time, sometimes years. In this situation, the doctor will make sure that you have all the information you need to make an informed decision. They will tell you what is likely to happen if you have CPR, how this might extend your life and what your quality of life might be.

If, after discussion with your medical team, you make the decision not to have CPR attempted, this is written as a DNACPR or not for CPR (NFCPR) order. After meeting with you, a senior doctor or nurse who has responsibility for your care will make, write and sign the DNACPR. This might be a hospital consultant, a palliative care doctor, a specialist or consultant nurse, or your GP. The decision will be clearly written in your medical and nursing notes.

If you’re at home, you’ll be asked to keep a written record of your DNACPR where it can easily be found. This is so emergency services, such as out-of-hours ambulance services and doctors, will know your wishes.
Your decision about CPR won’t affect any other care or treatment you have. You can change your mind at any time about whether CPR should be attempted. If you do change your mind, it’s important to discuss this with a member of your healthcare team. They will discuss their views on your changed decision with you. If they agree with your changed decision, they will make sure this is recorded in your medical notes. Remember to also tell your family or the person looking after you as this will help to avoid any confusion.

If your doctor feels that CPR is unlikely to be successful and doesn’t believe it should be attempted, but you don’t agree, you can ask for a second medical opinion from another senior doctor. They should also let your family know what they recommend, unless you have asked them not to.

Your healthcare team will take your wishes about CPR into account. However, you cannot insist a doctor attempts CPR if, in their clinical judgement, they think it’s not appropriate.

**We have more information about cardiopulmonary resuscitation for people with cancer – call our support line on 0808 808 00 00 to order this.**
ORGAN AND TISSUE DONATION

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Thinking about organ and tissue donation

Many people think that if they have a medical condition such as cancer, they won’t be able to donate their organs (such as a kidney) or tissue (such as the corneas of the eye) to another person when they die. Having, or having had, cancer does not mean you can’t donate your organs or tissue, but it may affect what you can donate.

If 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’re alive, you won’t know whether your organs or tissues will be suitable. Only your family will know this after you have died.
Corneal transplants

The cornea is one type of tissue that’s 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 the cornea becomes damaged, it can mean you may no longer be able to see. Corneal transplants can replace the damaged tissue with a disc of healthy tissue from a donor’s eye(s). This can successfully allow the person to see again.
Finding out more about organ and tissue donation

You can find out more about organ and tissue donation by visiting the NHS Blood and Transplant website (organdonation.nhs.uk). They keep a register for people who wish to donate their organs or tissue, or both, after their death. You can join the register online, by phone or by texting (see page 94).

From 1 December 2015, the way people in Wales choose to donate their organs will change. People living in Wales will be expected to opt out if they do not want to be an organ donor.

If you live in Wales and want to be a donor, you can:

• choose to be a donor by registering your decision, as you do now (opting in)
• do nothing, which means you have no objection to being a donor (deemed consent)

If you do not want to be a donor, then you must register a wish not to be a donor (opting out).

You can find more information at organdonationwales.org
Donating your body for medical research

Some people want to donate their body for medical research. If you’re thinking about donating your body, it’s important to talk about it with your GP, hospital or palliative care team. You can also talk about it with your family or close friends. As part of the donation process, 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.

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

Not everyone who wishes to donate their body will be able to do so. This may be due to medical reasons. The Human Tissue Authority (see page 93) can give you more information about donating your body for medical research.
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Why plan your funeral

Funerals allow family, friends and others to pay their respects to the person who has died. They play a big part in helping people to:

• express their grief
• acknowledge the death of someone
• celebrate their life
• say goodbye.

Many people die without making any plans for their funeral. For family or close friends who are left behind, arranging a funeral can be a stressful time. They may not know exactly what type of funeral the person wants or how they would like it carried out.

If you tell your family or friends what you want, your funeral is much more likely to follow your wishes. It may also be one less thing for your family or friends to worry about.

‘My husband and I planned his funeral together before he passed away and I can say it was a great comfort to me in those early days to know I was doing exactly what he wanted. It made things so much easier not to have to make the decisions on my own.’

Lynda
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 ideas and suggestions for arrangements that may help them celebrate your life, say goodbye and remember you.

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

A burial or cremation

A burial is usually in a churchyard or other designated burial place. It’s also possible for people to be buried in other places, such as a garden. If you want to be buried on property that you own or in a place that you love, you can get information from the Natural Death Centre (see page 95). The centre also has details of a number of natural burial grounds, such as woodlands.

A cremation takes place in a designated 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 about what you want done with your ashes. For example, you may choose to have them scattered in a favourite place.
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 don’t have a faith, you can still contact your local minister, priest or religious leader to discuss your funeral. Most funeral directors can provide you with contact details. However, you don’t have to have a religious service or a religious leader for the funeral or memorial service. You could choose a humanist service instead. The British Humanist Association can give you more information about humanist funerals and memorials (see page 94).

Other things to include

You may also want to think about whether you want:

• specific songs or readings
• flowers
• donations given to specific charities
• to wear certain clothes – for some people this can be important, for example a person may want to wear clothes that were significant to them in their lives, such as a military uniform.
Recording your funeral plans

You can document your wishes for your funeral in your will (see page 29). Or you can keep a record of them and leave them in a safe place that your family or friends know about. The Dying Matters Coalition and the National Association of Funeral Directors (NAFD) have a form called My Funeral Wishes, which you can use to record your wishes. You can download it at dyingmatters.org/page/my-funeral-wishes

If you don’t want to write down your plans, you can tell your family members or friends what your wishes are.

‘I have all of my wishes written down – the music, where I would prefer to be cremated and my ashes scattered. I know what my husband wants too, and we have both discussed it, in a light hearted manner, to our two daughters. Hopefully when the time comes, it won’t be such a heavy burden for them to arrange.’

Chris
Paying for a funeral and choosing a funeral director

Funerals can be expensive so 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 or the NAFD (see page 93). It’s best to look into prices first. Make sure that 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 use one they have used before. If you don’t have any experience of using funeral directors, it’s best to choose one that has a high standard of practice. Those that are members of the NAFD are regularly monitored to make sure their practice standards are high. You can contact the NAFD to find out if a particular funeral director is a member.
‘As a family we knew this was what he wanted and we all agreed to rally around to help Joyce cope with his care.’

Adrienne
MANAGING YOUR CARE IF YOU HAVEN’T PLANNED AHEAD

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Best interests decisions

You may worry about who will make decisions about your care if you haven’t planned ahead and were to become seriously ill and unable to make decisions for yourself.

Usually your carers and family will be involved in making everyday decisions about your care. However, sometimes a decision may need to be made about your medical care or treatment.

If this is the case, a senior healthcare professional will make the decision about giving you a treatment. They will base this decision on their experience and understanding of your circumstances. They will discuss the decision with your family, friends and anyone else who might be involved in your care. These decisions are known as **best interests decisions**.

The Mental Capacity Act 2005 (see page 84) sets out several factors that should be considered when making a best interests decision. These include:

- all the relevant circumstances
- your past and present wishes, and values and beliefs
- the views of anyone caring for you, such as a family member, friend or carer.

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

It has safeguards to make sure 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 proper and in your best interests.
Decisions made by healthcare professionals

If a best interests decision is about life-sustaining treatment (see page 54), a health professional can’t be motivated by a desire to bring about someone’s death. They should look at the appropriate treatment options available to make sure that the best interests of a person are met.

The views of family members and friends will be considered in any best interests decision. But the final responsibility for the decision remains with the decision maker. This is usually a senior healthcare professional. Occasionally, this will mean that the views of family members are not followed. In this situation, the healthcare professional should explain the law regarding best interest decisions and the reason for the decision to the family.
Independent Mental Capacity Advocates

In some situations, medical staff may need to appoint someone as an Independent Mental Capacity Advocate (IMCA). This person acts as your advocate and represents your interests if you can’t do so yourself. This will usually only happen if you don’t have a Health and Welfare Lasting Power of Attorney and have no family or friends able or willing to represent you.

IMCAs are usually appointed if a non-urgent decision needs to be made on your behalf that involves serious medical treatment, such as:

• giving new treatment
• stopping treatment that has already started
• withholding treatment that could be offered.

In this situation, the IMCA will consider how giving, stopping or withholding treatment will affect you and whether your life is likely to be made better or worse. For example, giving you a new treatment may cause side effects such as sickness or pain and may give you a longer life by only a few weeks. The IMCA will work with your medical team to make sure that your civil, human and welfare rights are respected and all options are considered before a decision is made.
IMCAs may also be appointed if an NHS body or local authority is proposing to arrange accommodation or a change of accommodation in hospital or a care home, and:

- the person will stay in hospital longer than 28 days, or
- they will stay in the care home for more than eight weeks.

IMCAs may also be appointed to input into decisions in relation to care reviews and adult protection cases.

You can find out more information about the IMCA service from www.gov.uk
MENTAL CAPACITY AND THE MENTAL CAPACITY ACT 2005
The Mental Capacity Act

The Mental Capacity Act 2005 came into force in 2007 and applies to people aged 16 and over in England and Wales.

The Act aims to protect people who can’t make a decision for themselves. It means that a person can plan ahead for a time when they may not be able to make decisions themselves. It clarifies who can make decisions, in which situations, and how they should go about it. There are many parts to the Act, including information on Lasting Power of Attorney (see pages 43–47) and Advance Decisions to Refuse Treatment (see pages 49–61).

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

A person will lack capacity if they cannot do one of the following:

- understand the information about the decision
- retain that information
- use or weigh up that information as part of the process of making the decision
- communicate their decision (by talking, using sign language or any other means).
WHEN SOMEONE CLOSE TO YOU HAS CANCER
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 leaflets or booklets like this one. Visit be.macmillan.org.uk or call us on 0808 808 00 00.

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

All of our information is also available online at macmillan.org.uk/cancerinformation

There you’ll also find videos featuring real-life 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
• large print
• translations.

Find out more at macmillan.org.uk/otherformats

If you’d 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.
Help us improve our information

We know that the people who use our information are the real experts. That’s why we always involve them in our work. If you’ve been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you’d like to hear more about becoming a reviewer, email reviewing@macmillan.org.uk You can get involved from home whenever you like, and we don’t ask for any special skills – just an interest in our cancer information.
Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we’re here to support you. No one should face cancer alone.

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 Monday–Friday, 9am–8pm. Our cancer support specialists can:

- help with any medical questions you have about your cancer or treatment
- help you access benefits and give you financial advice
- 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](http://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](http://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.

‘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 advice
Our financial guidance team can give you advice 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

Macmillan’s My Organiser app
This free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search ‘My Organiser’ on the Apple App Store or Google Play on your phone.
Other useful organisations

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

Organisations for support with planning ahead

Dying Matters
Tel 08000 21 44 66
Email info@dyingmatters.org
www.dyingmatters.org
Promotes public awareness of dying, death and bereavement.

Human Tissue Authority
151 Buckingham Palace Road,
London SW1W 9SZ
Tel 020 7269 1900
Email enquiries@hta.gov.uk
www.hta.gov.uk
Provides information about tissue donation. Licenses and inspects organisations that store and use human tissue for research, patient treatment and teaching.

National Association of Funeral Directors (NAFD)
618 Warwick Road,
Solihull, West Midlands
B91 1AA
Helpline 0845 230 1343
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.
NHS Blood and Transplant
Organ Donation and
Transplantation Directorate
Fox Den Road,
Stoke Gifford,
Bristol BS34 8RR
Tel 0117 975 7575
Text SAVE to 84118
Email enquiries@nhsbt.nhs.uk
www.organdonation.nhs.uk
Manages the UK Transplant Registry and national Organ Donor Register. Also raises public awareness of the importance of organ donation.

Office of the Public Guardian
PO Box 16185,
Birmingham B2 2WH
Tel 0300 456 0300
(Mon–Fri, 9am–5pm, Wed, 10am–5pm)
Email customerservices@publicguardian.gsi.gov.uk
www.justice.gov.uk
Supports and promotes decision-making for people with mental impairment or disability who would like to plan for their future.

The British Humanist Association
39 Moreland St,
London EC1 8BB
Tel 020 7324 3060
www.humanism.org.uk
Represents non-religious people and supports those who wish to live humanist lives, including through the provision of humanist ceremonies. Promotes equal treatment in law and policy regardless of religion and belief.

The Law Society for England and Wales
113 Chancery Lane,
London WC2A 1PL
Tel 020 7242 1222
Email from the website www.lawsociety.org.uk
Represents solicitors in England and Wales and can provide details of local solicitors.
The Natural Death Centre
In The Hill House, Watley Lane, Twyford, Winchester SO21 1QX
Helpline 01962 712690
Email contact@naturaldeath.org.uk
www.naturaldeath.org.uk
Aims to support those dying at home and their carers, and to help people arrange inexpensive, family-organised and environmentally-friendly funerals.

General cancer support organisations

Cancer Black Care
79 Acton Lane, London NW10 8UT
Tel 020 8961 4151
Email info@cancerblackcare.org.uk
www.cancerblackcare.org.uk
Offers information and support for people with cancer from ethnic communities, their friends, carers and families.

Maggie’s Centres
2nd Floor Palace Wharf, Rainville Road, London W6 9HN
Tel 0300 123 1801
Email enquiries@maggiescentres.org
www.maggiescentres.org
Provides information about cancer, benefits advice, and emotional or psychological support.

Penny Brohn Cancer Care
Chapel Pill Lane, Pill, Bristol BS20 0HH
Tel 01275 371 100 (Mon–Fri, 9.30am–5pm)
Email helpline@pennybrohn.org
www.pennybrohn.cancercare.org
Offers a combination of physical, emotional and spiritual support, using complementary therapies and self-help techniques.
Riprap
Att Pauline Hutchinson,
University of Sheffield,
Sykes House office,
St Luke’s Hospice,
Little Common Lane,
Sheffield S11 9NE
www.riprap.org.uk
Developed especially for teenagers who have a parent with cancer.

Tenovus
Head Office,
Gleider House,
Ty Glas Road,
Cardiff CF14 5BD
Tel 0808 808 1010
(Mon–Sun, 8am–8pm)
www.tenovus.org.uk
Aims to help everyone get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, an ‘Ask the nurse’ service on the website and benefits advice.

General health information

Healthtalk
Email
info@healthtalkonline.org
www.healthtalk.org
www.youthhealthtalk.org
(site for young people)
Has information about cancer, and videos and audio clips of people’s experiences.

NHS Choices
www.nhs.uk
The UK’s biggest health information website. Has service information for England.

NHS Direct Wales
www.nhsdirect.wales.nhs.uk
NHS health information site for Wales.
Patient UK  
www.patient.co.uk  
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)  
BACP House,  
15 St John’s Business Park,  
Lutterworth,  
Leicestershire LE17 4HB  
Tel 01455 883 300  
Email bacp@bacp.co.uk  
www.bacp.co.uk  
Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at itsgoodtotalk.org.uk

Samaritans  
Freepost RSRB-KKBY-CYJK,  
Chris, PO Box 9090,  
Stirling FK8 2SA  
Tel 08457 90 90 90  
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)  
2nd Floor, Edward House,  
2 Wakley Street,  
London EC1V 7LT  
Tel 020 7014 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.
Financial or legal advice and information

Citizens Advice
Provides advice on a variety of issues including financial, legal, housing and employment issues. Find details for your local office in the phone book or from the website.  
www.citizensadvice.org.uk

You can also find advice online in a range of languages at adviceguide.org.uk

GOV.UK
www.gov.uk
Has comprehensive information about social security benefits and public services.

Support for carers

Carers UK
Tel (England, Scotland, Wales) 0808 808 7777  
(Wed–Thu, 10am–12pm and 2–4pm)
Email
advice@carersuk.org
www.carersuk.org
Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.

Advanced cancer and end-of-life care

Help the Hospices
Hospice House, 34–44 Britannia Street, London WC1X 9JG
Tel 020 7520 8200
Email
info@helpthehospices.org.uk
www.helpthehospices.org.uk
Provides information about living with advanced illness. Has a directory of hospice services and practical booklets available free from the website.
Marie Curie
89 Albert Embankment,
London SE1 7TP
Tel 0800 716 146
(Mon–Fri, 9am–5pm)
Email supporter.relation@mariecurie.org.uk
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.

Bereavement support

Cruse Bereavement Care
PO Box 800,
Richmond TW9 1RG
Tel 0844 477 9400
(Mon–Fri, 9.30am–5pm)
Email helpline@cruse.org.uk
www.crusebereavementcare.org.uk
Has a UK-wide network of branches that provide bereavement support to anyone who needs it. You can find your local branch on the website, at www.cruse.org.uk/cruse-areas-and-branches

You can search for more organisations on our website at macmillan.org.uk/organisations or call us on 0808 808 00 00.
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 Sara Booth, Honorary Consultant/Associate Lecturer, University of Cambridge and our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

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Sources

We’ve listed a sample of the sources used in the publication below. If you’d like further information about the sources we use, please contact us at bookletfeedback@macmillan.org.uk

Advisory Committee on the Safety of Blood, Tissue and Organs. Transplantation of organs from deceased donors with cancer or a history of cancer. 2014.

Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing (3rd edition). 2014.


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 taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that 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.

If you’d rather donate online go to macmillan.org.uk/donate
More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don’t have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you’re entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit macmillan.org.uk
