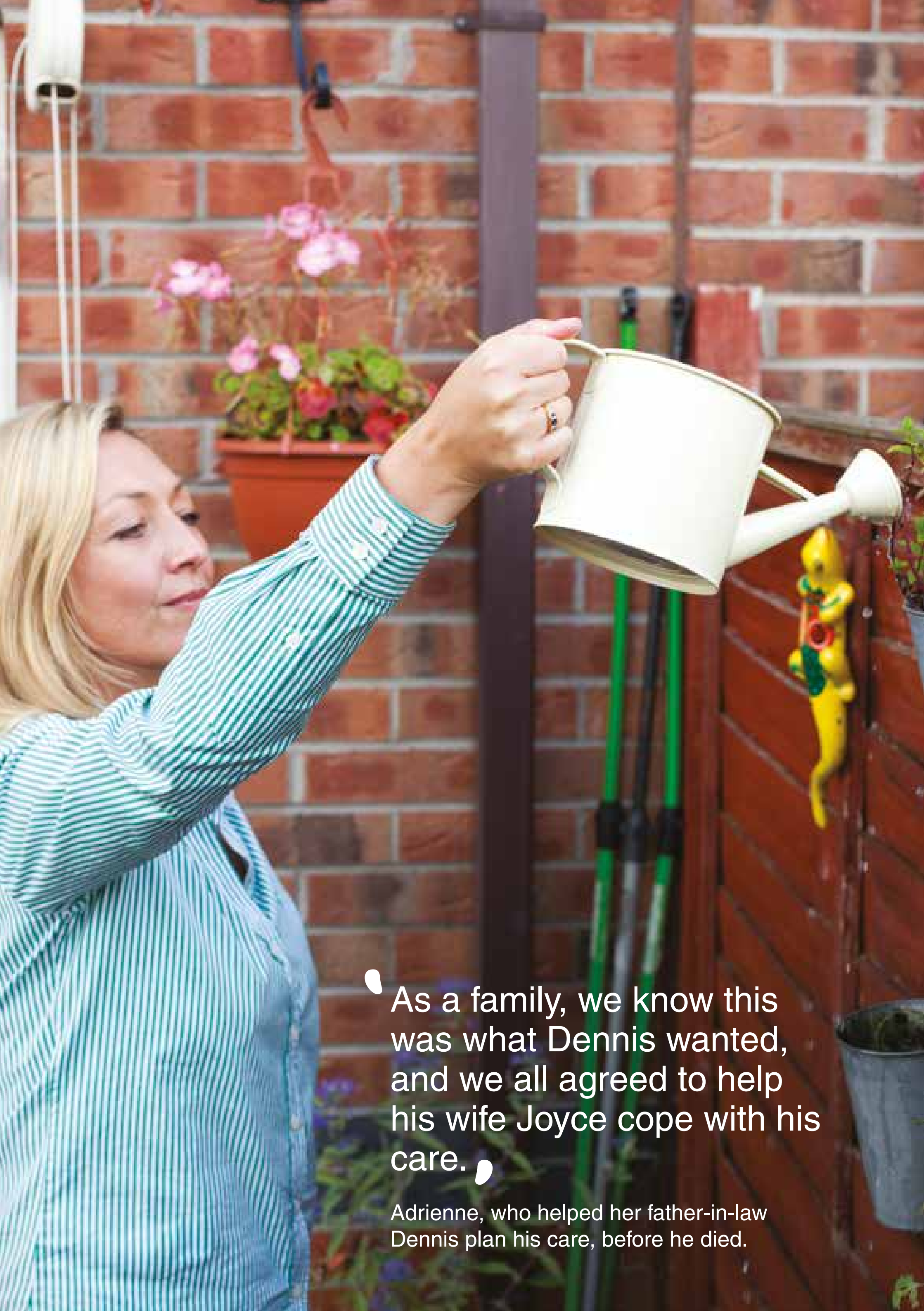
MACMILLAN
CANCER SUPPORT

PLANNING AHEAD FOR THE END OF LIFE

England and Wales



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

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

About this booklet

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

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

This booklet should help you to:

- think about what is important to you and the ways you can plan ahead
- talk about your plans with the people close to you, and with the health and social care professionals involved in your care
- start making plans so that the people involved in your care know what is important to you – for example by writing a will, or making a 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 5 to help you.

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

On pages 90 to 95, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (see page 96).

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

Quotes and cover

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

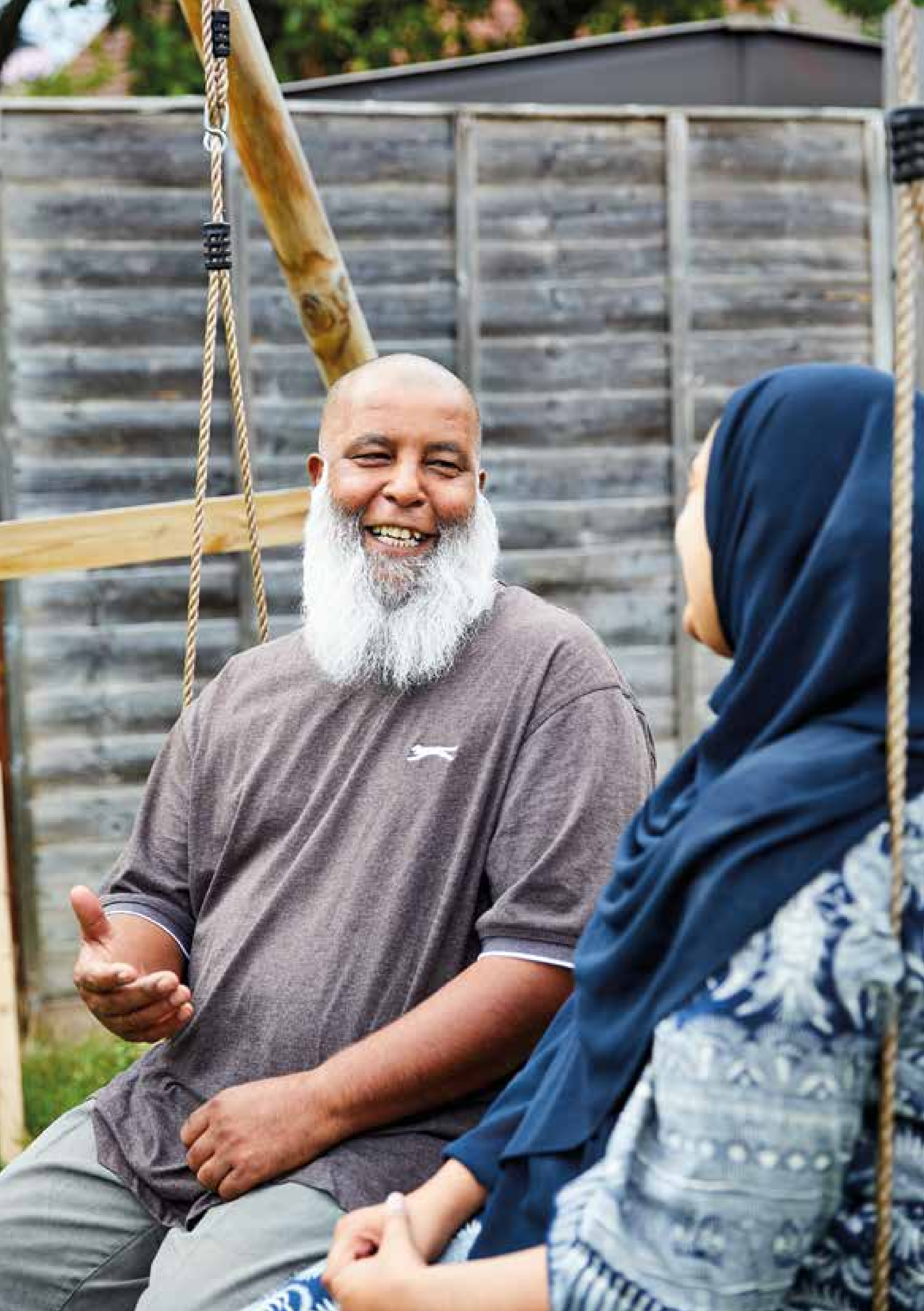
For more information

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

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

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

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



Contents

PLANNING AHEAD

Why is it important to plan ahead

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

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

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

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

Your healthcare

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

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

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

Your finances

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

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

How you can plan ahead

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

Writing a will

Writing a will makes sure your wishes are followed after you die. It means that your loved ones are provided for in the way you want. It is easier to make a will when you are feeling well. You may find our booklet **Your step-by-step guide to making a will** useful (see page 86).

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

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

> 'I'm a practical person and while I never thought I was going to die, I felt I needed to get my affairs in order. I've made a will and a list of other things to be sorted. For me it's about making the burden more manageable for my family.'
>
> **Samixa**

Your wishes for your care

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

Lasting power of attorney

A power of attorney lets you choose (appoint) someone to make decisions for you.

A lasting power of attorney (LPA) is a legal document. It needs to be registered with the Office of the Public Guardian before it can be used (see page 92).

In England and Wales, there are two types of LPA. You can make one of them or both.

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.

LPA for health and welfare decisions

This includes things like giving consent for treatment, care, medication and where you will live or be cared for. This LPA can only be used if you become unable to make decisions for yourself.

Advance decision to refuse treatment

You can write down your wishes about any treatments you do not want to have in the future. This is in case you are not able to tell your doctors or family yourself at the time. This is called an advance decision to refuse treatment (ADRT) – see pages 46 to 55. An ADRT is sometimes called a living will. An ADRT is legally binding, if it meets certain requirements in the Mental Capacity Act 2005 (see page 82).

Organ and tissue donation

You might want to write down your wishes about organ and tissue donation (see pages 62 to 64). You may want to donate your body for medical research or teaching (see page 65). You might also want to write this down.

Funeral planning

You may want to be involved in planning your funeral (see pages 67 to 73). It is also possible to pay for your funeral in advance.

Who can help you with planning ahead?

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

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

Professionals

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

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

They will be able to tell you the best person to speak to. If you are thinking about making a will (see pages 21 to 27) or creating a lasting power of attorney (see pages 39 to 43), you can contact a solicitor to help you.

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

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

Family and friends

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

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

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

If they do not want to talk about it

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

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

You could try saying something like:

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

Coping with your emotions

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

There are many people who can help you cope with your emotions. Talking to close family members or friends can help. Health and social care professionals can also give you support. This could be your GP, specialist nurse, social worker or hospital doctor. You may also find it helpful to join a support group, or talk things through with a support organisation (see pages 90 to 95).

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

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

How to plan ahead

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

Find out about the different ways you can plan ahead

We have information about the different ways you can plan ahead on pages 8 to 15. For more information and support, you may find it helpful to contact an organisation such as Dying Matters (see page 90). Or for information on finding a solicitor, you could contact The Law Society (see page 91). It is your decision whether you use just one way or many ways to plan ahead.

Talk to your family and friends

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

Talk to a health or social care professional

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

Write your plans down

You may want to use the Preferred Priorities for Care document (see page 36) and the advance decision to refuse treatment document in 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. It is a good idea to speak to a solicitor if you want to:

- make a will (see pages 21 to 27)
- create a lasting power of attorney (see pages 39 to 43).

This is because these are important legal documents.

Keep your documents safe

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

Review your documents regularly

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

Make changes to your plans if you need to

You can make changes to your plans at any time. This includes:

- your will (see pages 21 to 27)
- Preferred Priorities for Care document (see page 36)
- advance decision to refuse treatment (see pages 46 to 55)
- wishes for organ and tissue donation (see pages 62 to 64).

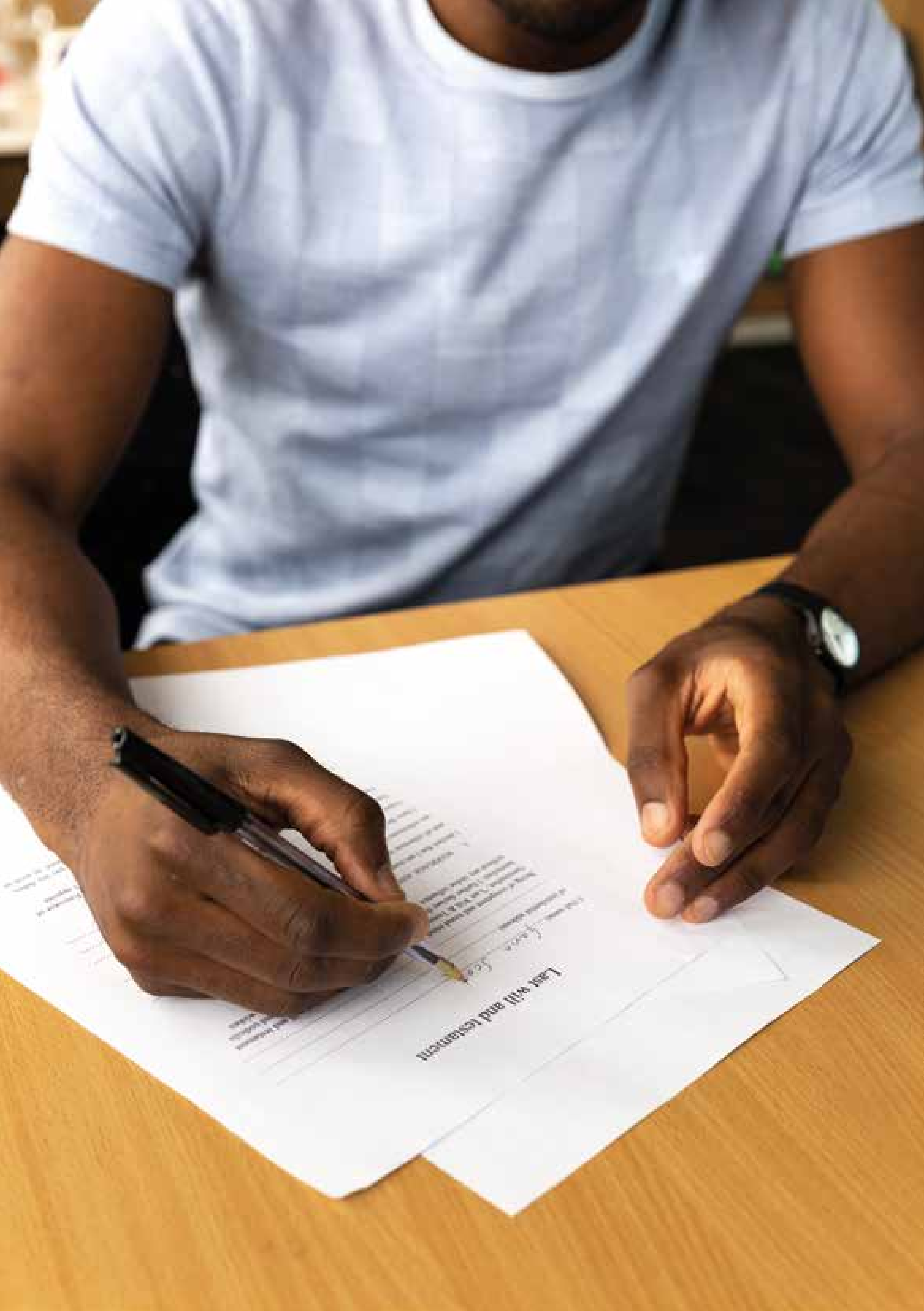
If you do change any of your plans, you may want to talk to your family and friends first. You will need to make sure that everyone involved in your care knows. This includes your GP and other health professionals.

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

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

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

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


Last will and testament

MAKING A WILL

Why is making a will important?

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

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

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

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

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

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

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

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

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

> ‘I went to make a will because I didn’t want to leave any worries for my children. Without a will they’d have had to guess what I wanted. It would have added to their stress while they were grieving. Writing it was about taking a little of the burden off them.’
>
> **Teresa**

Involving a solicitor

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

If you need help finding a local solicitor, you can contact the Law Society of England and Wales (see page 91). It is a good idea to look around or ask for a few quotes to find the right solicitor for you.

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

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

Things to think about when making your will

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

The value of your estate

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

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

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

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

Who to include in your will

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

Other important information

Other things you will need to think about include:

- who you want to follow the instructions in your will – this person is called an executor, and should be someone you trust
- who you want to be the legal guardians of any children you have who are under the age of 18
- who you want to look after any relatives who are dependent on you
- what, if any, funeral instructions you have
- who you would like to look after your pets, if you have any.

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

You may find our booklet **Sorting out your financial affairs** useful (see page 86).

You can also find more information about making a will from organisations such as:

- Age UK
- Citizens Advice
- the Law Society of England and Wales.

Meeting with a solicitor

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

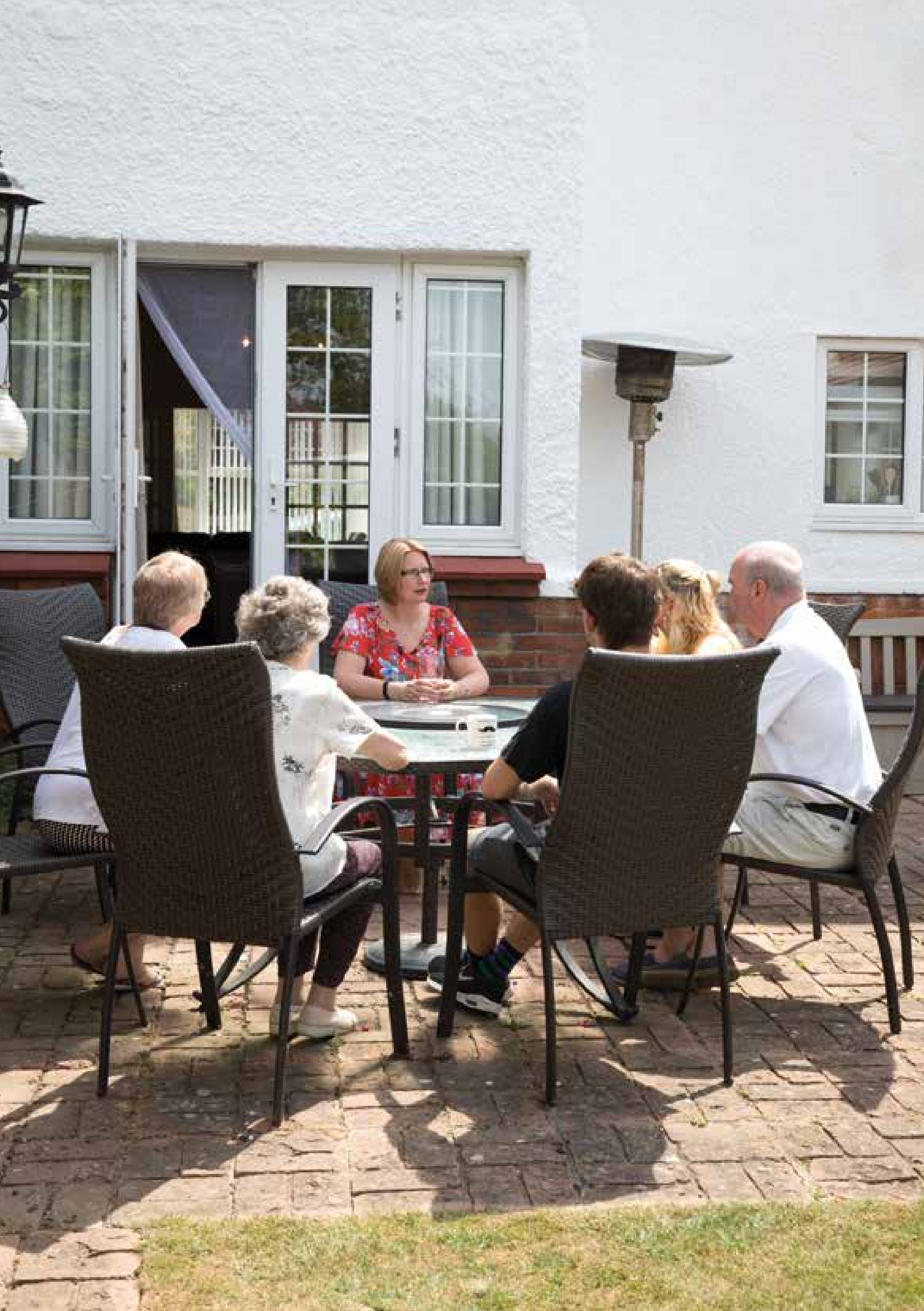
When you talk to your solicitor, it will help to have your completed lists of:

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

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

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

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



YOUR WISHES FOR YOUR CARE

Your wishes

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

It is best to write down your wishes and what is important to you (see forms at the back of this booklet). This will help your family, friends and health or social care professionals know how you would like to be cared for.

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

There are different 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.

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

Talking about your plan

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

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

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

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

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

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

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

If it is not possible to follow your wishes

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

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

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

What to include in your wishes for your care

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

The plan might include the following:

- Where you would most like to be cared for when you cannot look after yourself. For example, you might want to be cared for at home, or in a hospital, care home or hospice.
- Where you would prefer to be cared for when you are dying. Again, this could be at home, or in a hospital, care home or hospice.
- What kind of care and treatments you would like. But remember, you cannot demand specific treatments.
- Any spiritual, religious or cultural practices that you would like to be included in your care.
- Who you would like to be part of your care. For example, you might want family members or close friends to be involved.
- Who you would like to make decisions about your care if you become unable to make the decisions yourself. You may want to create a lasting power of attorney so that others can act on your behalf (see page 39 to 43).
- Whether you want to choose more than one attorney or a replacement attorney, in case the original attorney is unable to act on your behalf.
- Who you would like to look after any pets. We have more information about this on our website.

Writing down your wishes for your care

Ask your health or social care professionals if they have a document where you can write down your wishes and preferences. Or you can use the Preferred Priorities for Care document (see page 36).

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

This may include:

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

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

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

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

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

On the next page is an example of some of the information included on a 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. It is no longer possible to cure my illness.	
What are your preferences and priorities for your future care?	
If I were to become more unwell, I would like my wife to be involved in making decisions about my care. I would also like to be kept fully informed about what is happening to me.	
Where would you like to be cared for in the future?	
I do not mind where I am cared for, as long as my family are close by.	
Date	18/01/20

An example of writing down your wishes for your care

Here, Adrienne talks about how her father-in-law Dennis wrote down his wishes for his care.

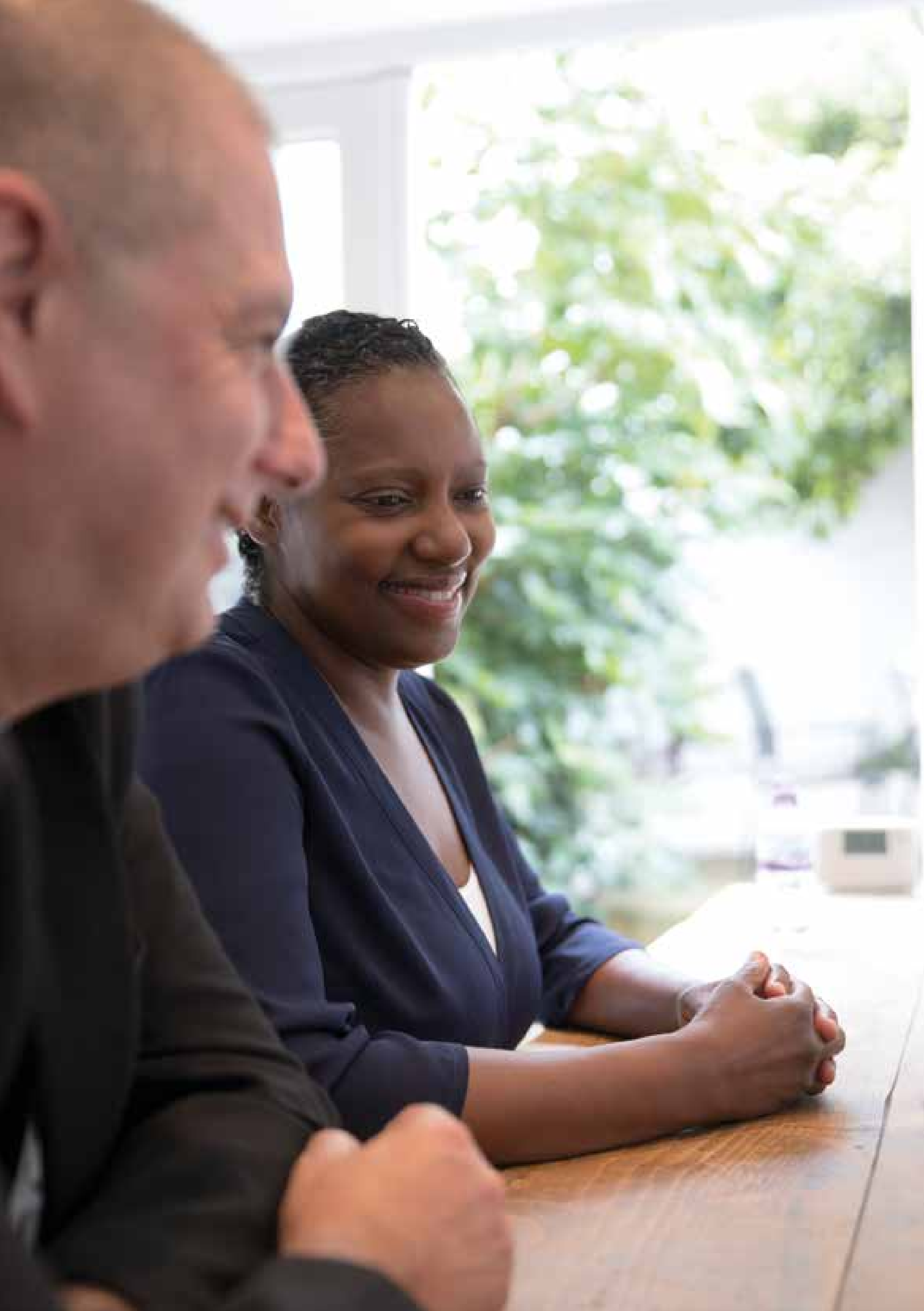
‘In February, my father-in-law Dennis was diagnosed with small cell lung cancer. Unfortunately, the treatment did not work and in August the doctors told him that he would not benefit from any further treatment. Although disappointed, Dennis was relieved to stop, as it was exhausting him.

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

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

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

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



LASTING POWER OF ATTORNEY

What is a lasting power of attorney (LPA)?

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

Setting up a power of attorney can give you more control over what happens to you if you cannot make your own decisions, or if you become unable to tell people about them.

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

- An LPA for financial decisions. This includes things like paying bills or selling your home.
- An LPA for health and welfare decisions. This includes things like giving consent for treatment, care, medication and where you live.

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

Lasting power of attorney replaced enduring power of attorney (EPA) in England and Wales in 2007. If you have an existing enduring power of attorney, it can still be used. However, this only applies to your financial affairs. Your attorney, or attorneys, cannot make decisions about your health and welfare using an EPA.

Why a health and welfare LPA may be helpful

A health and welfare LPA can give you reassurance that someone you trust will make decisions for you if you become seriously ill.

For example, you may decide to give a health and welfare LPA to your adult children. You can then discuss your thoughts about any future care decisions with them. So you can be sure your instructions for your care will be followed if you are unable to make your own decisions.

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

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

They are more likely to make the decisions you would want.

Making an LPA

You must be aged over 18 to set up a lasting power of attorney. You must also be able to make your own decisions. This is called having mental capacity. This means you can:

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

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

You can make an LPA online at **lastingpowerofattorney.service.gov.uk** Or you can get a form from the Office of the Public Guardian (see page 92).

Although you can make your own LPA, it is a legal document and must be prepared properly. So you may want to get help from a solicitor. They will make sure your wishes are clear and are carried out exactly as you want. If you do not have a solicitor, you can find one by contacting the Law Society of England and Wales (see page 91). For more information, visit **lawsociety.org.uk**

An LPA must be registered with the Office of the Public Guardian before it can be used. This can take between 8 and 10 weeks. There is a fee to register an LPA. You may not have to pay the fee, or you may only have to pay part of the fee, if:

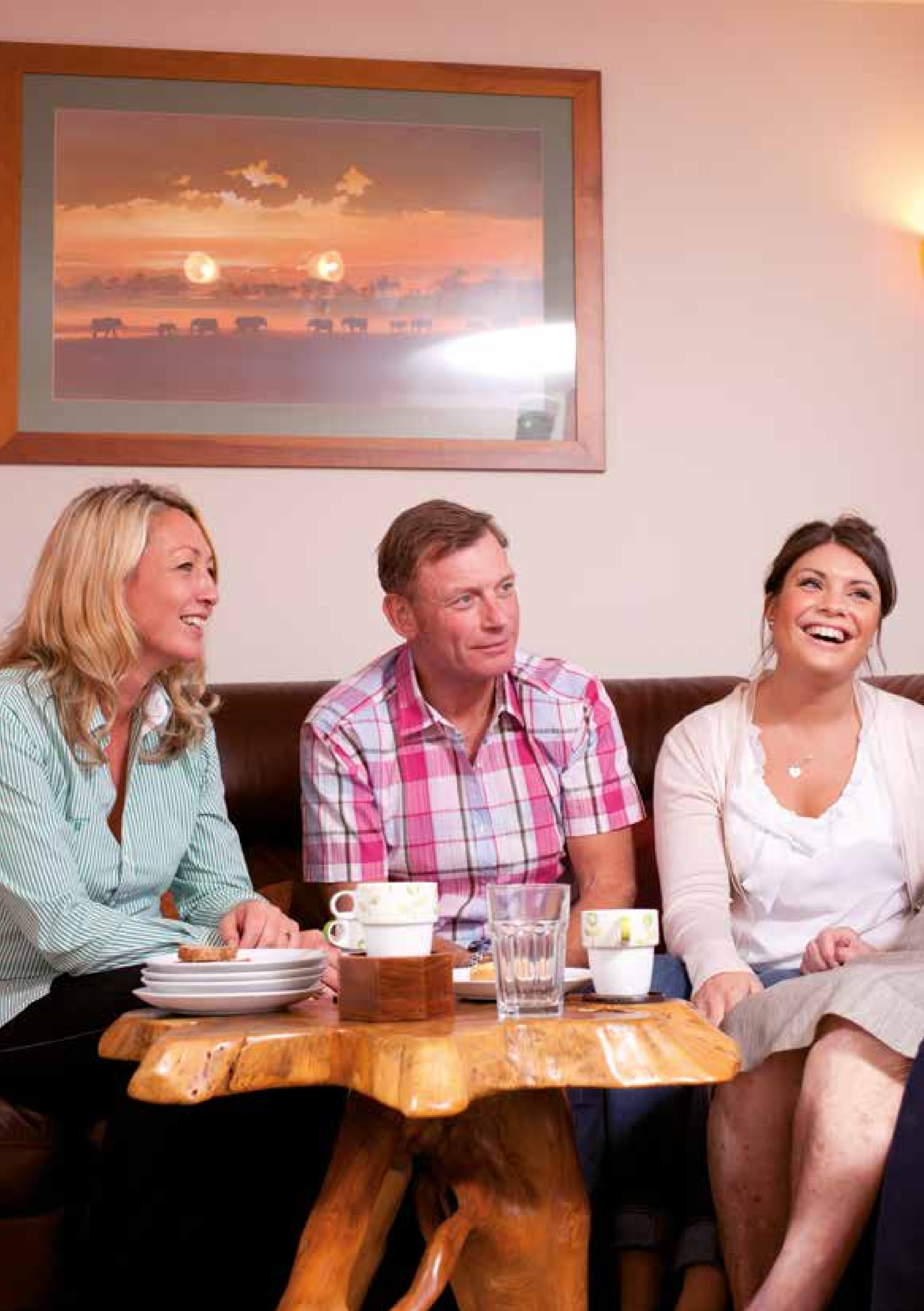
- you are on a low income
- you are on certain benefits.

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

Other things to think about

If you have made an advance decision to refuse treatment (ADRT) and a health and welfare LPA, one may make the other invalid (see page 54).

If you have a financial power of attorney, your attorney cannot manage your property or finances after you have died. This means that your property and finances will be looked after according to the instructions in your will. Bank accounts are also frozen at the time of a person's death and cannot be used. If you have a partner or close family member, you may want to consider putting bank accounts into both your names.



ADVANCE DECISION TO REFUSE TREATMENT

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 in a specific situation. 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.

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

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

We have an example of how some of this information could be written in an ADRT document (see page 55).

It is important to be as clear as possible about:

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

It is helpful to include as much detail as possible to make your wishes clear to anyone reading the document. This will help them decide whether your ADRT meets the legal requirements of the Mental Capacity Act 2005 (see page 82). If it does, it is legally binding. This means it must be followed by your healthcare team, if they know about it.

An ADRT cannot include a request to be given specific treatments, or to have your life ended. You can request, but not insist on, treatment in your wishes for your care.

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 (see page 82).

Before making an ADRT, it is important to talk with a member of your healthcare team. This may be your GP, specialist doctor or specialist nurse. They will be able to tell you what the likely effects of stopping a treatment will be. They will also make sure your ADRT meets legal requirements. It is also important to discuss your decisions with your family, 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.

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

What should be included in an ADRT?

Although you can usually make most advance decisions to refuse treatment verbally (spoken), it is better to write it down. This helps avoid confusion later.

There are certain situations where the law says an ADRT must be in writing. For example, it 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)
- do not want to be put on a breathing machine (ventilator).

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
- signed in the presence of a witness
- signed by the witness, with the date.

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. 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.

ADRT checklist

If an ADRT is not about treatment that will keep someone alive, there is nothing in law that says what must be included. However, it is advisable to include the following:

- Your name, date of birth, address and any obvious distinguishing features – for example, a birth mark. 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 one 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 circumstances, rather than in just one specific situation.

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

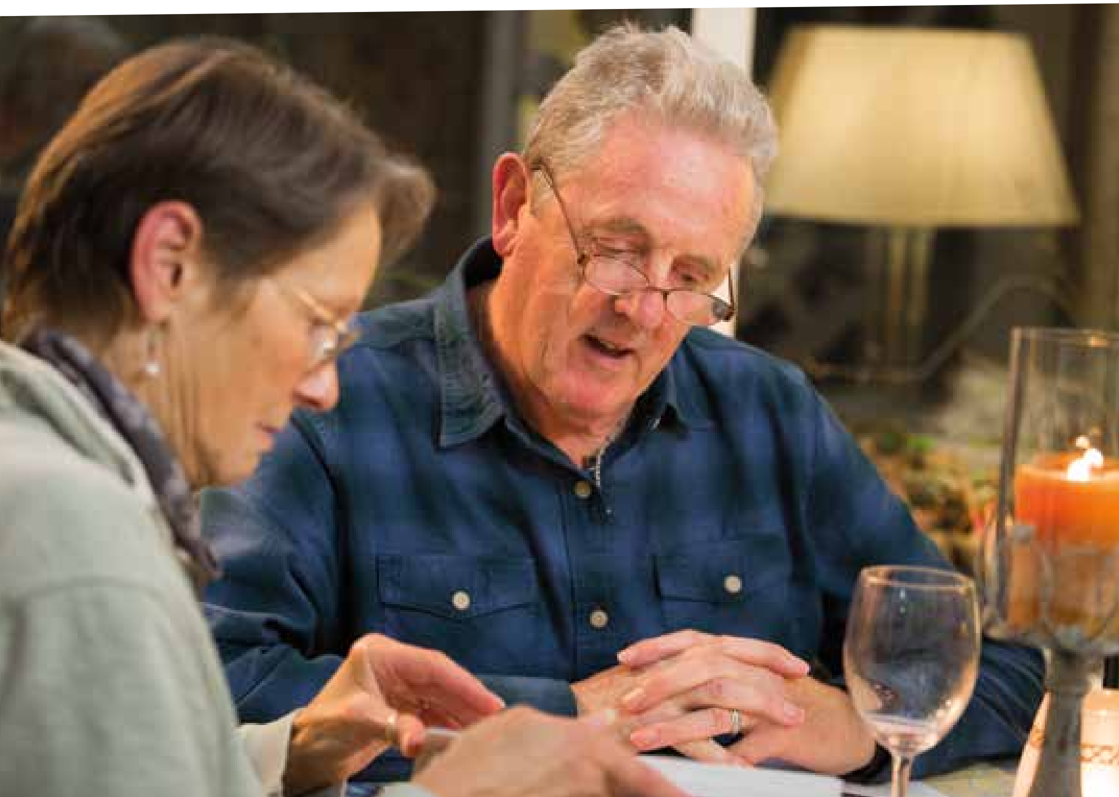
- have an allergy
- do not want the medication for religious reasons.

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 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 a form. There are organisations that have created forms for people to use. Hospitals and hospices often have information and forms that you can use to prepare your own ADRT.

We have created an ADRT document that has been adapted from the National End of Life Care Programme. For more information, see the forms at the back of this booklet.



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

An ADRT may become invalid if:

- You have made a lasting power of attorney (LPA) for health and welfare decisions after making an ADRT.
- You have given your attorney the authority to accept or refuse treatment on your behalf.

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.

Example ADRT document

My advance decision to refuse treatment

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.'

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.
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. 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.

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

What is cardiopulmonary resuscitation (CPR)?

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

When the heart stops beating suddenly, this is called a cardiac arrest. If breathing stops, this is called a respiratory arrest. Usually, both happen at the same time. This is called a cardiopulmonary arrest. If a person’s heart and breathing are not restarted quickly, they will die. CPR involves different treatments to help restart a person’s heart or breathing.

It can work well in some situations but not in others. For example, if someone’s cancer is very advanced, giving CPR is very unlikely to restart the heart.

What is a DNACPR decision?

You may hear doctors or nurses talk about a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision. This is a written record stating the decision not to give CPR if someone’s heart or breathing stops. These may also be called DNARs (do not attempt resuscitation).

Making a decision about CPR

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

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

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

Your doctor or nurse can explain to you:

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

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

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

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

After a decision has been made

Your healthcare team will discuss the DNACPR decision with you and those close to you. Then a senior doctor or nurse who is responsible for your care will write and sign the DNACPR form. This person might be:

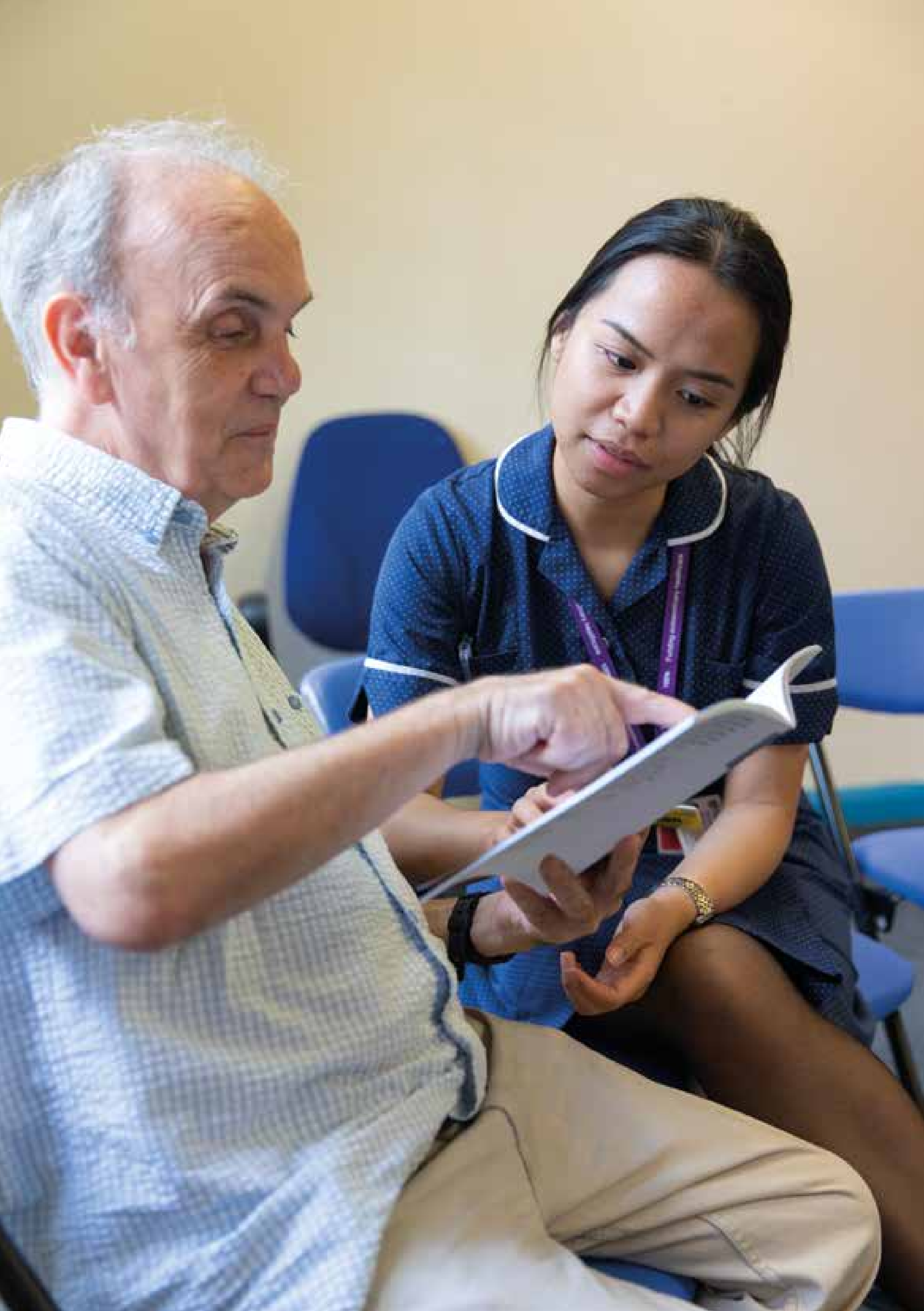
- a hospital consultant
- a palliative care doctor
- a specialist or consultant nurse
- your GP.

They will write your decision clearly in your medical and nursing notes.

If you are at home, your doctor or nurse will ask you to keep a written record of your DNACPR where it can easily be found. This is so emergency services will be able to easily know your wishes.

Your decision about CPR will not affect any other care or treatment you have. You may change your mind and want to review your decision about CPR. You will need to talk about this with your healthcare team. If there is a change following your discussion, your doctor will record it in your medical notes. Remember to also tell your family or the person looking after you. This will help to avoid any confusion.

We have more information about cardiopulmonary resuscitation for people with cancer at **macmilllan.org.uk**



ORGAN AND TISSUE DONATION

Thinking about organ and tissue donation

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

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

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

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

Corneal transplants

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

The cornea is the clear tissue at the front of each eye. It lets light into the eye and focuses it on the retina so we can see.

If someone's cornea becomes damaged, it can mean they are no longer able to see. Corneal transplants can replace the damaged tissue with a disc of healthy tissue from a donor's eye (or eyes). This can allow the person to see again.

Finding out more about organ and tissue donation

In England, you choose to donate organs. However, the law on consent for organ donation is changing. No changes are expected before Spring 2020.

You can find out more about donation on the NHS Blood and Transplant website, visit **nhsbt.nhs.uk** They keep a register of people who wish to donate their organs or tissue after their death. You can join the register online, by phone or by text.

In Wales you are expected to opt out if you do not want to be an organ donor. This means you must register a wish to not be a donor. This is called opting out.

If you want to be a donor, you can:

- register your decision – this is called opting in
- do nothing, which means you have no objection to being a donor – this is called deemed consent.

You can find more information about this on Organ Donation Wales website. Visit **organdonationwales.org**

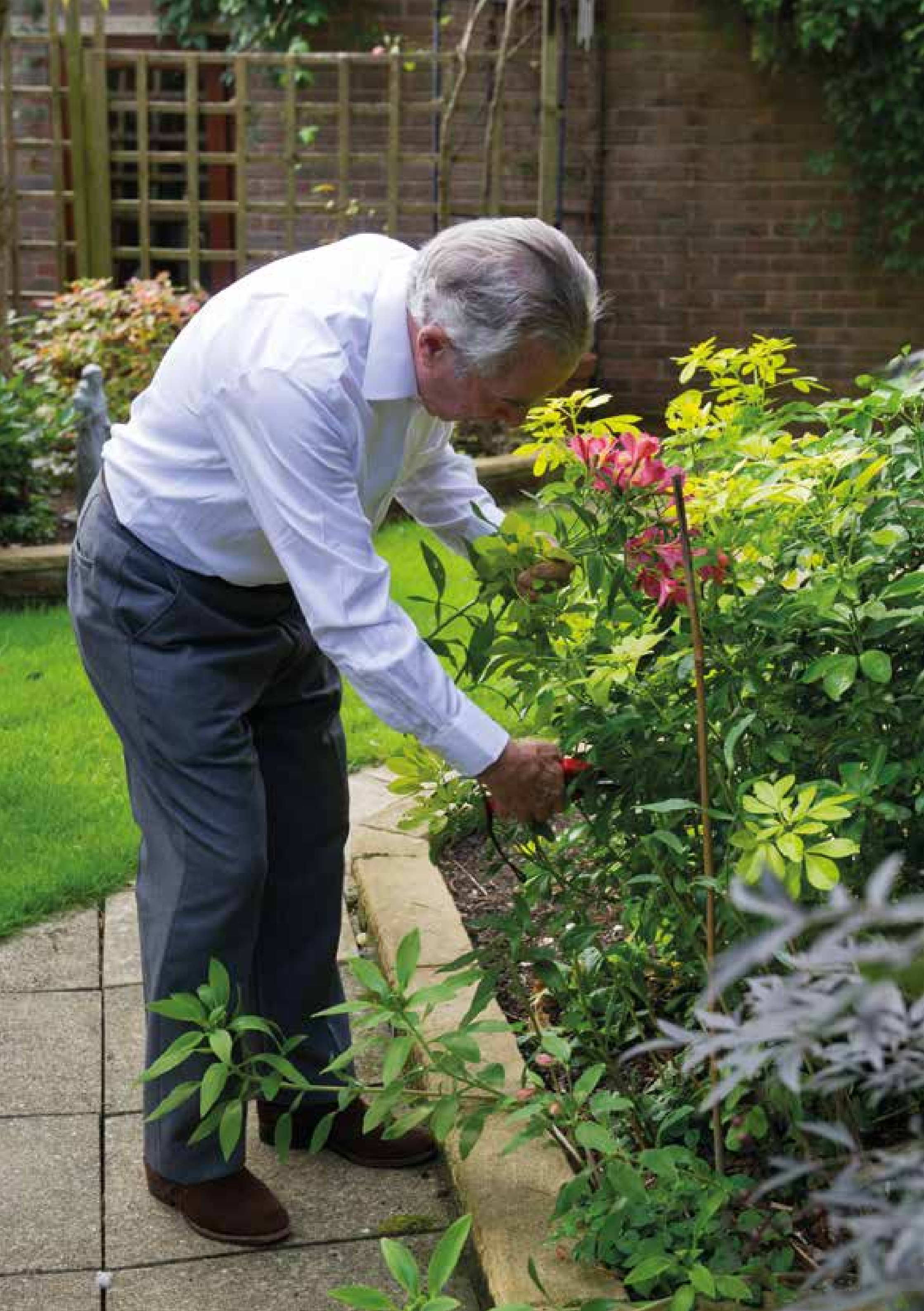
Donating your body for medical research

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

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

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

Not everyone who wishes to donate their body for teaching or research will be able to. This may be due to medical reasons. So, it is still a good idea to make other funeral plans. The Human Tissue Authority can give you more information about donating your body for medical research. For more information, visit **gov.uk/donating-your-body**



FUNERAL PLANNING

Why plan your funeral?

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

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

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

If you tell your family or friends what you want, your funeral is much more likely to reflect your wishes. It may be one less thing for your family or friends to worry about. Funerals can also be expensive, so planning ahead can be helpful (see page 72).

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

What you might include in a funeral plan

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

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

A burial or cremation

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

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

A religious or non-religious service

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

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

Other things to include

You may also want to think about whether you want:

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

Recording your funeral plans

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

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

Paying for a funeral and choosing a funeral director

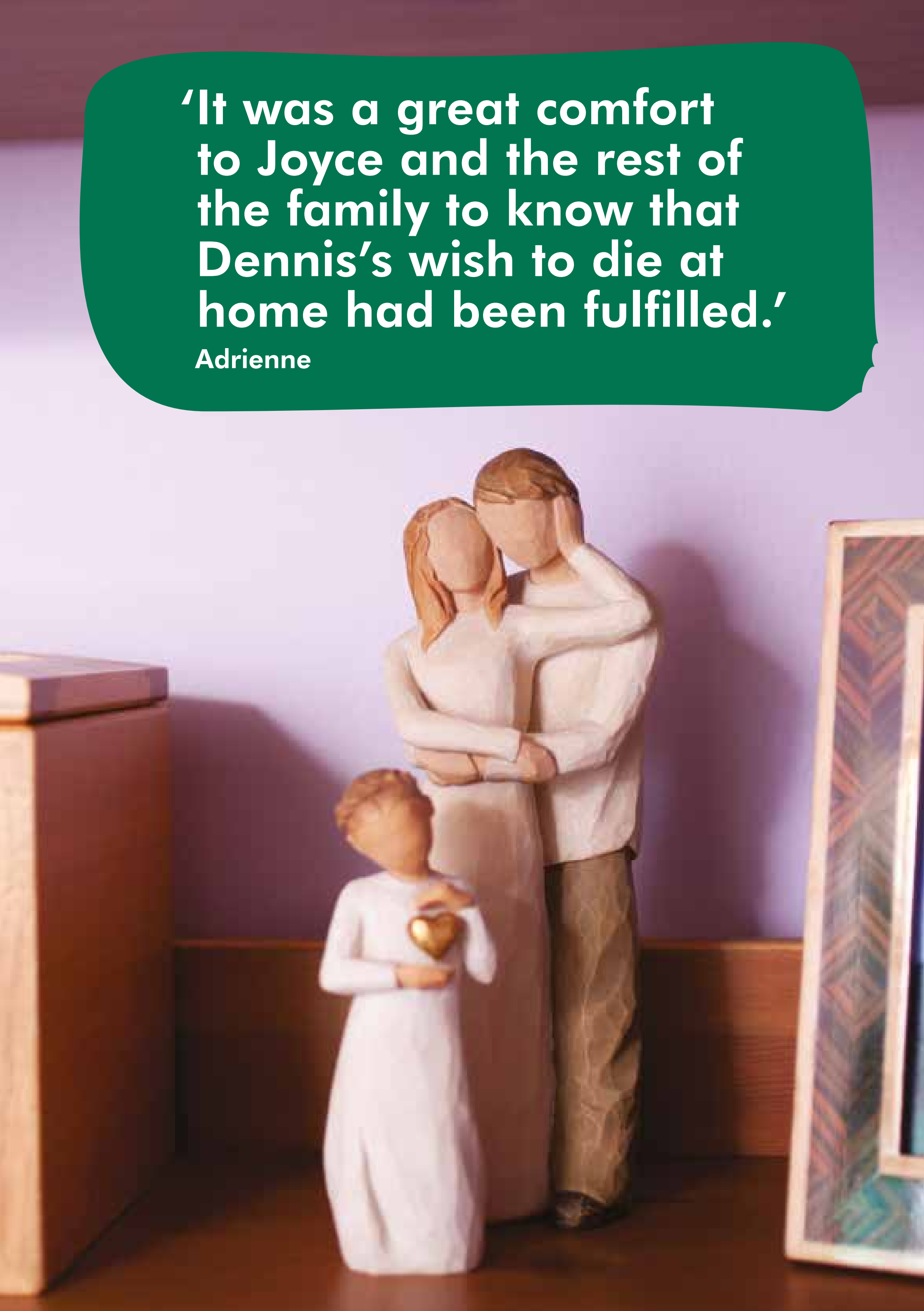
Funerals can be expensive. You may want to pay for your funeral in advance by taking out a funeral pre-payment plan. You can find out more from:

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

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

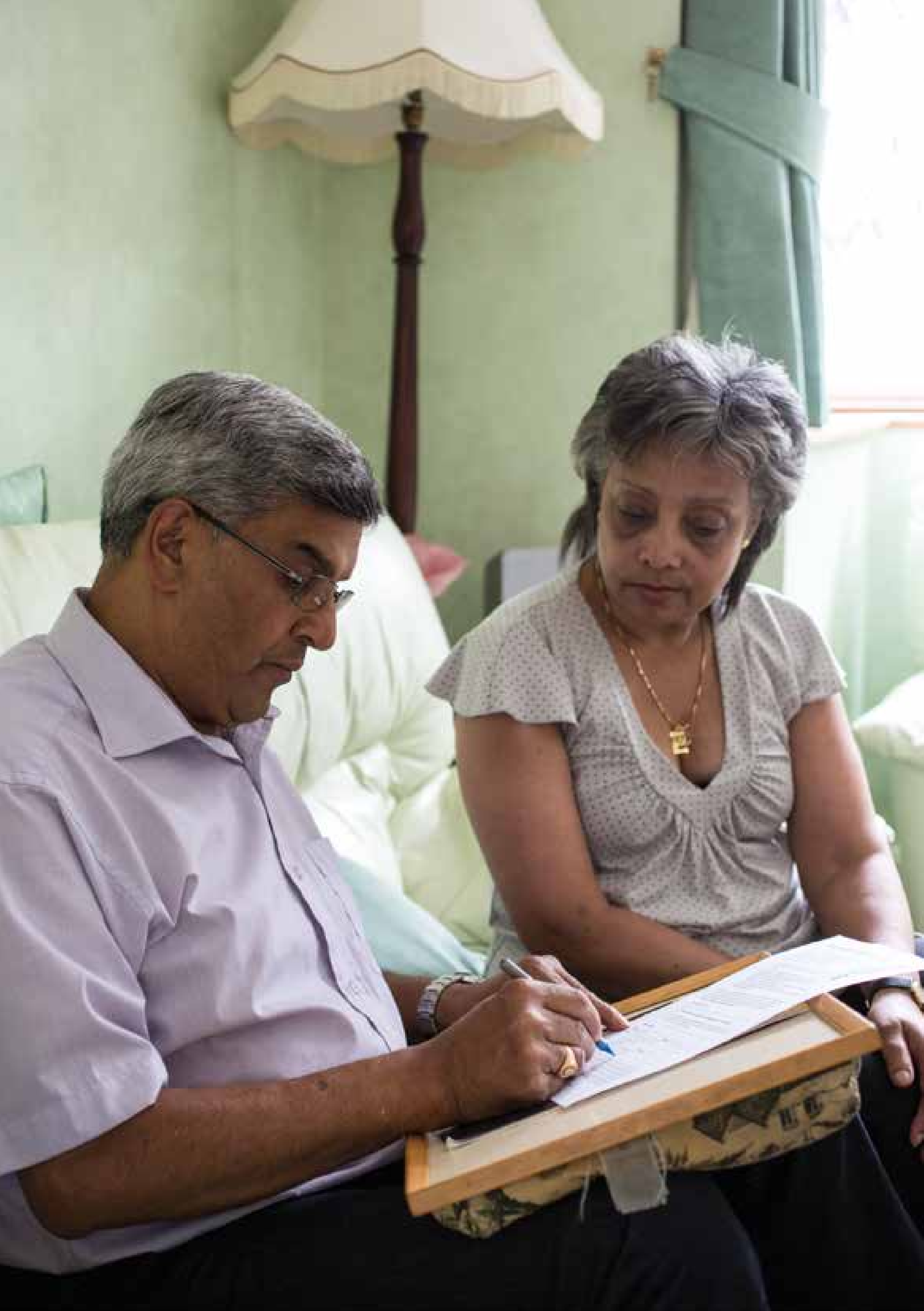
You may find choosing a funeral director difficult if there are several in the area where you live. Some people choose one they have used before. It is best to choose a funeral director that has a high standard of practice. Those that are members of the NAFD or SAIF are regularly monitored to make sure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

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



‘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.’

Adrienne



MANAGING YOUR CARE IF YOU HAVE NOT PLANNED AHEAD

Best interests decisions

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

In this case, a senior healthcare professional makes the decision. They base this decision on their experience and what they know about your situation. They will discuss the decision with your family, friends and anyone else involved in your care. These decisions are called best interests decisions.

The Mental Capacity Act 2005 (see page 82) lists factors that need to be considered when someone is making a best interests decision. These include considering:

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

A best interests decision must not be based on your age, condition, appearance or any aspect of your behaviour. This is stated in the Mental Capacity Act. 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.

Decisions made by healthcare professionals

If a best interests decision is about life-sustaining treatment, a health professional cannot 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 are considered in a best interests decision. But the person making the decision has the final responsibility. This is usually a senior healthcare professional. Sometimes this means that what the family wants is not what happens. In this situation, the healthcare professional should explain the law regarding best interest decisions and their reasons for the decision.

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 cannot do so yourself. This usually only happens if you do not have:

- a health and welfare lasting power of attorney (see page 41)
- family or friends able or willing to represent you.

IMCAs are usually appointed if you need a non-urgent decision on your behalf about serious medical treatment, such as:

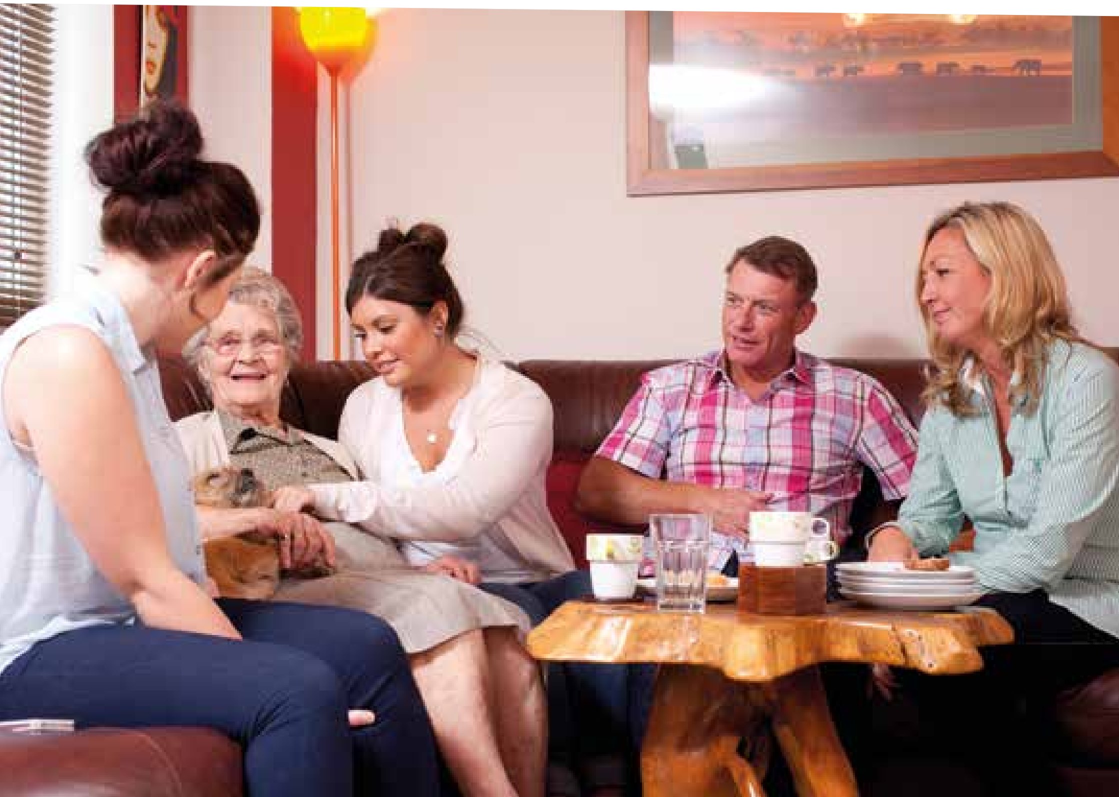
- giving a new treatment
- stopping treatment that has already started
- withholding treatment that could be offered.

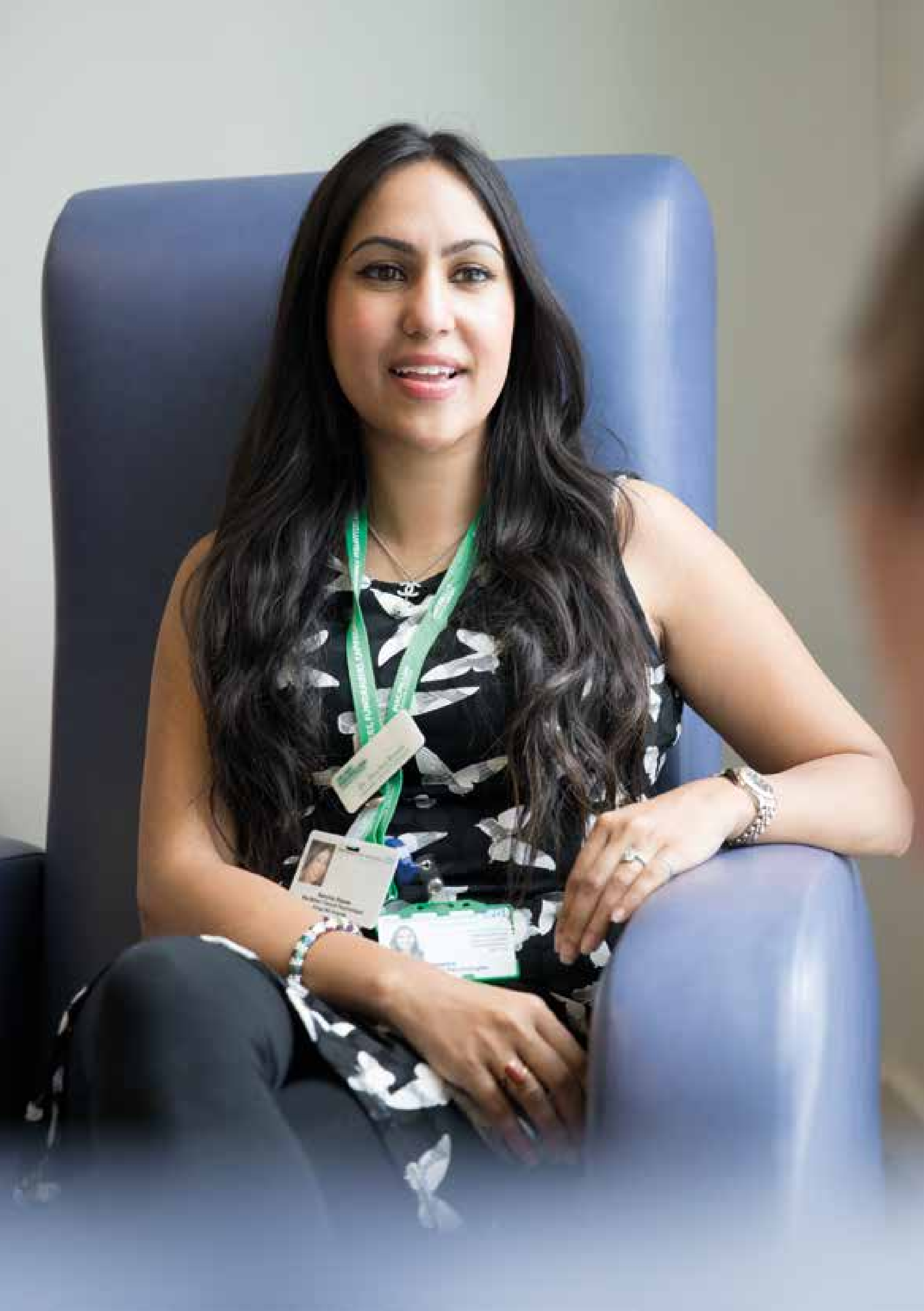
In this situation, the IMCA considers how these actions will affect you. They think about whether your life is likely to be made better or worse. For example, a new treatment may cause side effects such as sickness and pain, but only give you a few more weeks to live. The IMCA works with your medical 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 be appointed if an NHS body or local authority suggests a change of accommodation that means you will:

- stay in hospital for longer than 28 days
- stay in the care home for more than 8 weeks.

IMCAs may also be appointed to help make decisions in relation to care reviews and adult protection cases. You can find out more information about the IMCA service from **gov.uk**





MENTAL CAPACITY

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.

The Act aims to protect people who are not able to make a decision for themselves. It means a person can plan ahead, in case they are ever in that situation in the future (see pages 10 to 19). It explains:

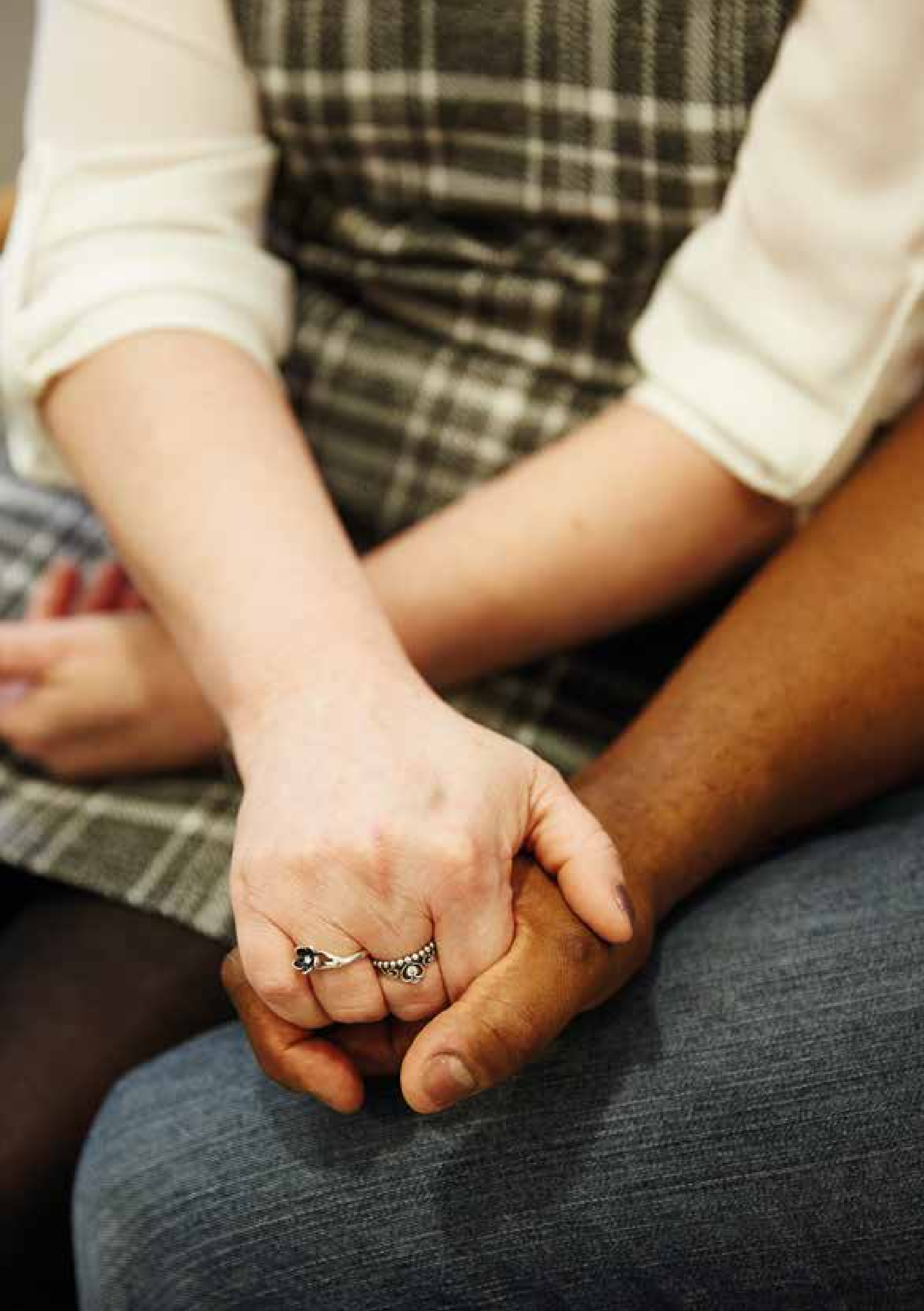
- who can make decisions for them
- in which situations they can make decisions
- the process to follow when making decisions.

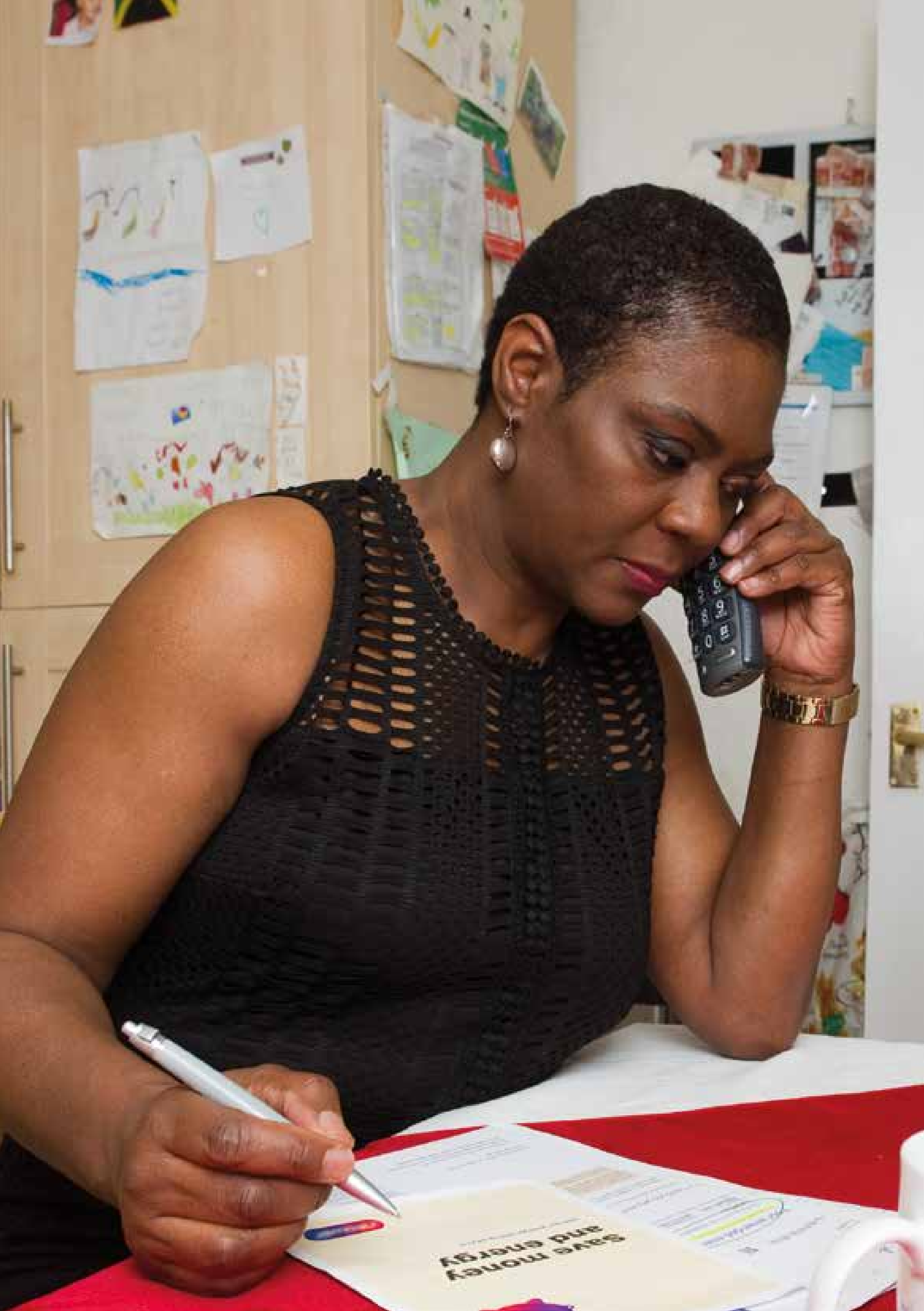
There are many parts to the Act, including information on lasting power of attorney (see pages 39 to 43) and advance decisions to refuse treatment (see page 46 to 55).

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 one 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.




Save money and energy

FURTHER INFORMATION AND SUPPORT

About our information

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

Order what you need

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

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

Online information

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

Other formats

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

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

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

Information centres

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

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

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

Talk to others

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

Support groups

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

Online Community

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

The Macmillan healthcare team

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

Book reviews

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

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

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

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

Help with work and cancer

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

Work support

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

Macmillan Organiser

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

Other useful organisations

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

Planning ahead and end of life support organisations

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

Hospice UK
Tel 0207 520 8200
www.hospiceuk.org
Works to ensure adults and children living with terminal or life-shortening illnesses receive the care and support they need. Provides free booklets and online information.

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

Humanists UK
Tel 0207 324 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

Tel 0207 242 1222
(Mon to Fri, 9am to 5pm)
solicitors.lawsociety.org.uk
Provides details of regulated solicitors in England and Wales. Use their website to find details of local solicitors.

Marie Curie

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

National Association of Funeral Directors (NAFD)

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

National Society of Allied and Independent Funeral Directors (SAIF)

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

The Natural Death Centre

Helpline 0196 271 2690
Email
rosie@naturaldeath.org.uk
www.naturaldeath.org.uk

Offers help, support, advice and guidance on planning a funeral for yourself or someone else. Aims to support those dying at home and their carers, Also helps people arrange inexpensive, family-organised and environmentally-friendly funerals.

NHS Blood and Transplant Organ Donation

Tel 0300 123 2323
(24 hours a day, 7 days a week)
Text chat (SMS)
0786 003 4343
Text relay
18001 0300 1232323
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.

The Office of the Public Guardian (England and Wales)

Tel 0300 456 0300
(Mon, Tue, Thu, and Fri, 9am to 5pm, and Wed, 10am to 5pm)
Email customerservices@publicguardian.gov.uk
www.gov.uk/government/organisations/office-of-the-public-guardian

Has information about making, registering or ending a lasting power of attorney. Protects people in England and Wales who may not have the mental capacity to make certain decisions for themselves.

General cancer support organisations

Cancer Black Care

Tel 0208 961 4151
www.cancerblackcare.org.uk

Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

Maggie's Centres

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

Penny Brohn Cancer Care

Tel 0303 300 0118
(Mon to Fri, 9.30 to 5pm)
Email helpline@pennybrohn.org
www.pennybrohncancercare.org
Offers a combination of physical, emotional and spiritual support, using complementary therapies and self-help techniques.

Tenovus

Tel 0808 808 1010
(daily, 8am to 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

NHS Direct Wales

www.nhsdirect.wales.nhs.uk
NHS health information site for Wales.

NHS UK

www.nhs.uk
The UK's biggest health information website. Has service information for England.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)

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

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

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

LGBT-specific support

LGBT Foundation
Tel 0345 330 3030
(Mon to Fri, 10am to 6pm)
Email helpline@lgbt.foundation
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events. You can also visit their centre to chat.

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 by contacting:

England
Helpline 03444 111 444
www.citizensadvice.org.uk

Wales
Helpline 03444 77 2020
www.citizensadvice.org.uk/wales

GOV.UK

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

Support for carers

Carers UK

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

Bereavement support

Cruse Bereavement Care

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

Widowed and Young (WAY)

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

Winston's Wish

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

YOUR NOTES AND QUESTIONS

Disclaimer

Thanks

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

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

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

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

Sources

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

General Medical Council. Treatment and care towards the end of life: good practice in decision making. July 2010. Available from www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life (accessed June 2019).
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Social care institute for excellence: Advance planning and decision-making Part of: Mental Capacity Act (MCA) directory. July 2015. Available from www.scie.org.uk/mca-directory/advanceplanninganddecisionmaking/ (accessed June 2019).

Can you do something to help?

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

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

5 WAYS YOU CAN HELP
SOMEONE WITH CANCER

Share your cancer experience

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

Campaign for change

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

Help someone in your community

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

Raise money

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

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

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

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Don't let the taxman keep your money

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

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

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

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

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

Registered with FUNDRAISING REGULATOR

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

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

27530

The ways people can plan ahead and record their wishes vary across the four nations of the UK (England, Scotland, Wales and Northern Ireland). This booklet is about the ways people can plan ahead if they live in England and Wales. We have other booklets with information for people living in Scotland or Northern Ireland, which we can send you.

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

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

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

MACMILLAN
CANCER SUPPORT

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