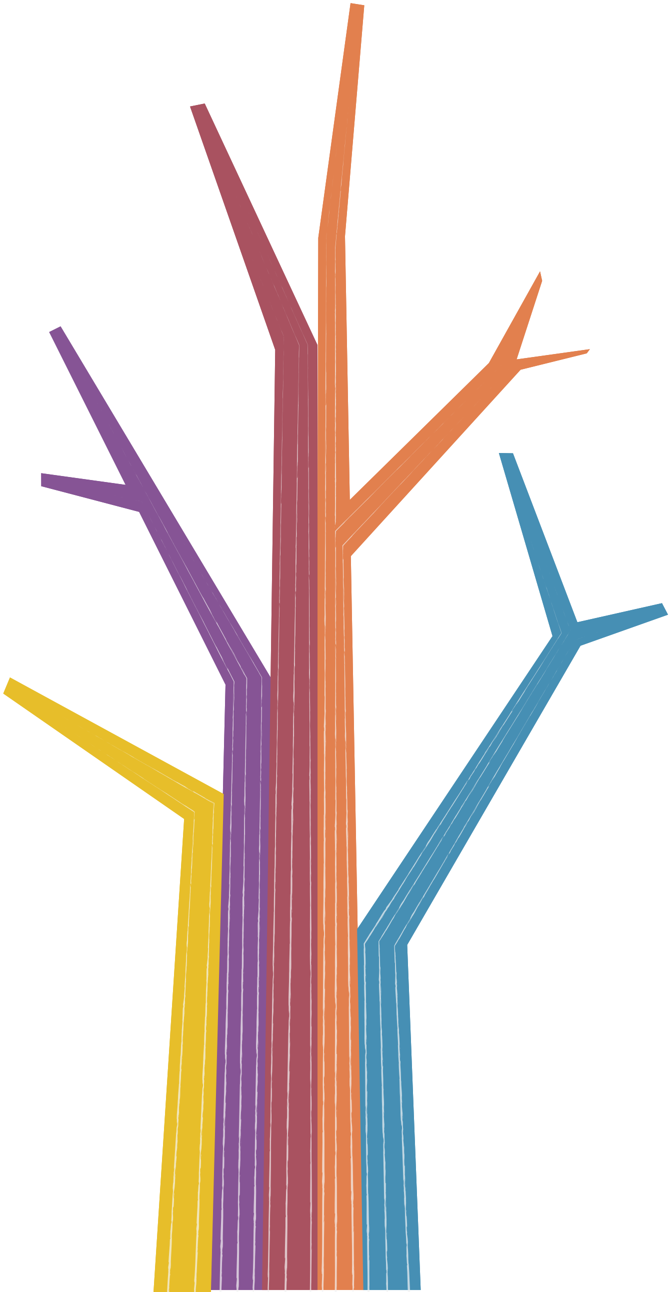
Your life and your choices: plan ahead



About this booklet

This booklet is about planning ahead and making choices about your future care if you live in Northern Ireland. It is for anyone who wishes 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.

This booklet was produced by Palliative Care in Partnership, the Public Health Agency, and Macmillan Cancer Support. It 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 you trust, and with the health and social care professionals involved in your care
- start making plans so that the people involved in your care know what is important to you – for example by writing a will, or making a power of attorney or advance directive.

We hope it helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

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.

There are 3 documents available at be.macmillan.org.uk. You can use them to help you think about and write down your wishes and decisions for your future care:

- **Your checklist for planning ahead**
- **Record of my wishes document**
- **Advanced Decision to Refuse Treatment (ADRT) document.**

On pages 100 to 106 there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse on pages 109 to 112.

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.

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, interactive PDFs, easy read, Braille, large print and translations. To order these, visit macmillan.org.uk/otherformats or call **0808 808 00 00**.

Changes to planning ahead in Northern Ireland

In Northern Ireland, the way people can plan ahead for their future is changing.

The Department of Health have a new policy about this. It is called For Now and For the Future: An Advance Care Planning Policy for Adults in Northern Ireland.

The policy was published in October 2022. This means some of the processes you and your healthcare professionals can use to plan ahead may still be changing.

ReSPECT is one of the new processes that will be available. ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment. This will replace the Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) process. You can read about these on pages 64 to 67.

At the time of printing, ReSPECT was not yet operational in Northern Ireland. However, to help you, we mention ReSPECT where it will apply in the future.

You can find information about the new Advance Care Planning policy, including when changes will happen, at the Department of Health website.

Visit health-ni.gov.uk/advance-care-planning-now-and-future or talk to your healthcare professional.

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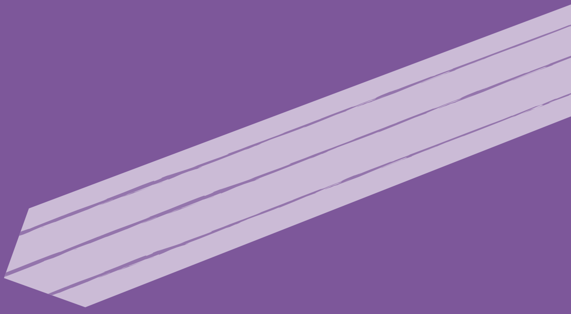
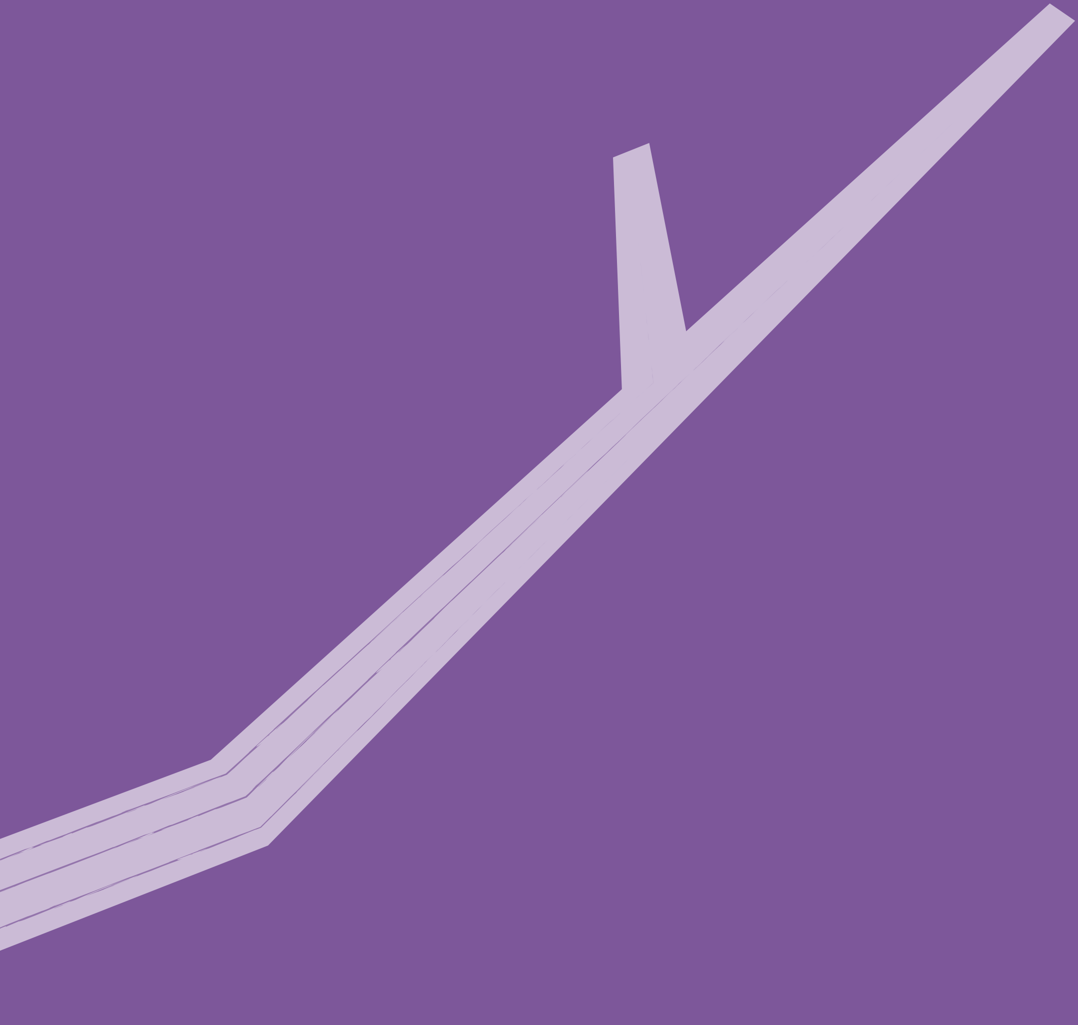


Planning ahead



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)
- early dementia.

Planning ahead is important, whether you have a serious illness or not. This is because 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.

If you plan your care in advance, there is more chance that your care will be right for you. Some plans may be legally binding, such as a will or an Advance Decision to Refuse Treatment. Others are a way of telling people your wishes for your care and what matters to you. Planning ahead can help you to feel more in control of your life. You will still be able to change your plans if you if you wish to, at a later stage.

Your healthcare

Planning ahead is also important because health and social care 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 might 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 what your wishes are, unless you have 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 health and social care team do not know this, and you are 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 or unable to be at home. You may want to arrange for a family member or friend to do this for you.

Ways 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. You may find it helpful to start with the ones that are most relevant or important to you.

Writing a will

A will is a legal document that gives instructions about who you want to give your money and belongings (possessions) 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.

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.

We have more information on making a will on pages 30 to 37. You may also find the Macmillan Cancer Support booklet Your step-by-step guide to making a will.

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.

If you are ready to plan your wishes, it is important to tell your GP or health and social care professional. They can record them, so that other health and social care professionals involved in your care know what your wishes are.

There is more information about your wishes for your care.

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 or ADRT.

Enduring Power of Attorney

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

An Enduring Power of Attorney (EPA) lets you choose other people to make decisions for you about your property and financial affairs. If you become unable to make decisions because you lack mental capacity, the person you name can make them on your behalf. We have more information on mental capacity.

An EPA needs to be registered. You can find more information on pages 70 to 75.

In some parts of the UK, there is another type of power of attorney called lasting power of attorney (LPA). An LPA lets you choose other people to make decisions for you about healthcare as well as about your property and finances.

LPA is not used in Northern Ireland right now, but it will be in the future. At the moment the law says that no one can consent to treatment on behalf of another person in Northern Ireland. When an adult does not have the mental capacity to make a specific decision themselves, a best interests decision is made by a senior healthcare professional.

Mental capacity

When people are unwell, their mental capacity can change. Mental capacity means ability to do the following:

- understand decisions
- make decisions
- communicate decisions.

Your health and social care team needs to make sure you are able to make decisions about your treatment. If your doctor is concerned about your mental capacity, they may ask you some questions to help them assess it. There is more information about mental capacity.

Organ and tissue donation

Organ and tissue donation means giving part of your body to someone else who needs it. Unless you have opted out, you will usually be considered a possible organ and tissue donor after death. We have more information about organ and tissue donation.

Some people decide to donate their body for medical teaching or research. If this is something you are thinking about, we have more information on pages 84 to 85.

Funeral planning

You may want to be involved in planning your funeral. It is also possible to pay for your funeral in advance. We have more information about funeral planning.

Who can help you plan ahead?

Planning ahead for our healthcare is not something we usually think about. When we are feeling fit and healthy, we do not expect to become seriously ill. We may assume that we will always be able to make decisions for ourselves, even when we are unwell.

But if you have cancer or another illness, you might find it hard to plan ahead. You may 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. They may ask you if you want to talk about your plans for the future. Or you may want to start the conversation yourself.

Health and social care professionals

If you want to start planning ahead, you can talk to anyone involved in your care that you feel comfortable talking to. This could be 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 or creating an Enduring Power of Attorney, you can contact a solicitor to help you.

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

> 'I have been thinking about making plans for my future care, just in case something happens to me and I cannot make decisions for myself. I wonder whether you could help me? If not, could you please tell me who might be able to help me find out my options, and explain what I need to do?'

Family and friends

If you want to, it is helpful to involve people you trust, such as family and friends. They may be able to help you think about some of the issues, so you can plan ahead. It will also help them know what your wishes are, so they can explain them in the future if you are not able to.

Your plans may involve family members or friends taking on more responsibility for your care. For example, if you decide you would like to die at home, a family member or friend may come and stay with you or help with your care. 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 your health and social care professionals. 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 planning ahead

Sometimes family and friends do not want to talk about planning ahead. They may:

- not want to think about the future
- not want to talk about your worries
- 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 both of 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 this:

> 'I know it is difficult, but I would really like to talk to you about how I would like to be cared for if I become 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, angry, anxious and scared. These are normal reactions when coping with uncertainty about the future. Even if you are not currently unwell, 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 family members or friends that you trust 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.

If you feel you need more support, ask a health or social care professional about finding a counsellor. For example, you could ask your GP, a specialist nurse or hospital doctor for information. Counsellors can be very helpful if you do not feel like talking about your feelings with people close to you. You can search for counsellors on The British Association for Counselling and Psychotherapy website. Visit bacp.co.uk/about-therapy/how-to-find-a-therapist

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

Spiritual and religious support

Any life crisis can challenge our beliefs and values. We may find ourselves questioning what life means to us and our purpose in life.

Spirituality can mean different things to different people. It may be religious, or it may be expressed other ways. This may include music, arts, nature, or how you relate to your family or community.

Many people find their faith offers them emotional support and strength if they are seriously ill. Some people may find they become more aware of religious or spiritual feelings. Other people may find themselves questioning their faith.

Most of us need to have a sense of meaning in our lives and to feel that we are loved and valued. If we are seriously ill, then feeling hope and being at peace with our situation can also be important.

You may find it helpful to talk through your thoughts and feelings with someone you trust. You only need to share as much as you want to, and at a time when you feel ready. You can choose who you want to talk to, and who you feel will be able to support you.

This may be a:

- trusted friend or family member
- health or social care professional
- chaplain or religious leader.

Do not be put off talking to a chaplain or religious leader if you are not religious. They are used to dealing with uncertainty and being with people who are distressed. They are also usually very good listeners. They may be able to help you work through your thoughts and feelings.

You may prefer to talk to someone who is not religious. Northern Ireland Humanists have information about volunteers who provide non-religious pastoral support.

Your GP, specialist nurse or hospital doctor may also be able to help you find a non-religious counsellor or pastoral carer to talk to.

You can find information about spiritual issues on the Marie Curie website at mariecurie.org.uk/spiritualpain Find more information about Marie Curie.

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. You can also find out more about Advance Care Planning at health-ni.gov.uk/advance-care-planning-now-and-future This includes links to videos in British and Irish Sign language and for people with a learning disability.

You may find it helpful to contact another organisation for more information and support. For example, you could contact Dying Matters or the Law Society of Northern Ireland. It is your decision whether you use 1 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. You will not be expected 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.

If you know what your wishes are, talk to your GP or a health or social care professional. With your consent, your wishes can be recorded on an Advance Care Planning summary or ReSPECT form. This can be shared with other health and social care professionals involved in your care.

Write your plans down

You may want to use the Record of my wishes and My Advance Decision to Refuse Treatment (ADRT) documents. It is a good idea to speak to a solicitor if you want to:

- make a will
- create an Enduring Power of Attorney.

This is because these are important legal documents. A solicitor can also help you to write an Advance Decision to Refuse Treatment.

Key Information Summary (KIS)

Your GP can record some of your wishes and plans on your Key Information Summary (KIS). This summary is part of your electronic medical record. It contains information about your medical history, care and preferred treatment options. If you agree, it can also be shared with other professionals who might become involved in your care. For example, your KIS may be useful if you:

- need treatment in hospital or at the hospice
- are admitted urgently to the emergency department.

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 or trusted friends and your GP where they are kept. Wills can be recorded at nationalwillregister.co.uk

Review your documents regularly

Your wishes might change over time, especially if your situation changes. Reviewing your documents is important, as it makes sure they still reflect your most recent wishes. You can review your documents with your health or 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 you trust 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
- a record of your wishes
- Advance Decision to Refuse Treatment
- Advance Care Planning summary or ReSPECT form
- decisions about organ and tissue donation.

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 and social care 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. You can use it to keep a record of

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

Make sure someone you trust knows where you keep this checklist.

Managing your care if you have not planned ahead

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

Best interests decisions

In Northern Ireland, no one has the legal authority to consent to medical care or treatment on your behalf. In this case, a senior healthcare professional makes the decision. They make this decision based 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 known as best interests decisions.

There are several other things a healthcare professional will consider when making a best interests decision. These include:

- your past and present wishes
- your values and beliefs
- the views of people important to you, such as a family member, friend or carer.

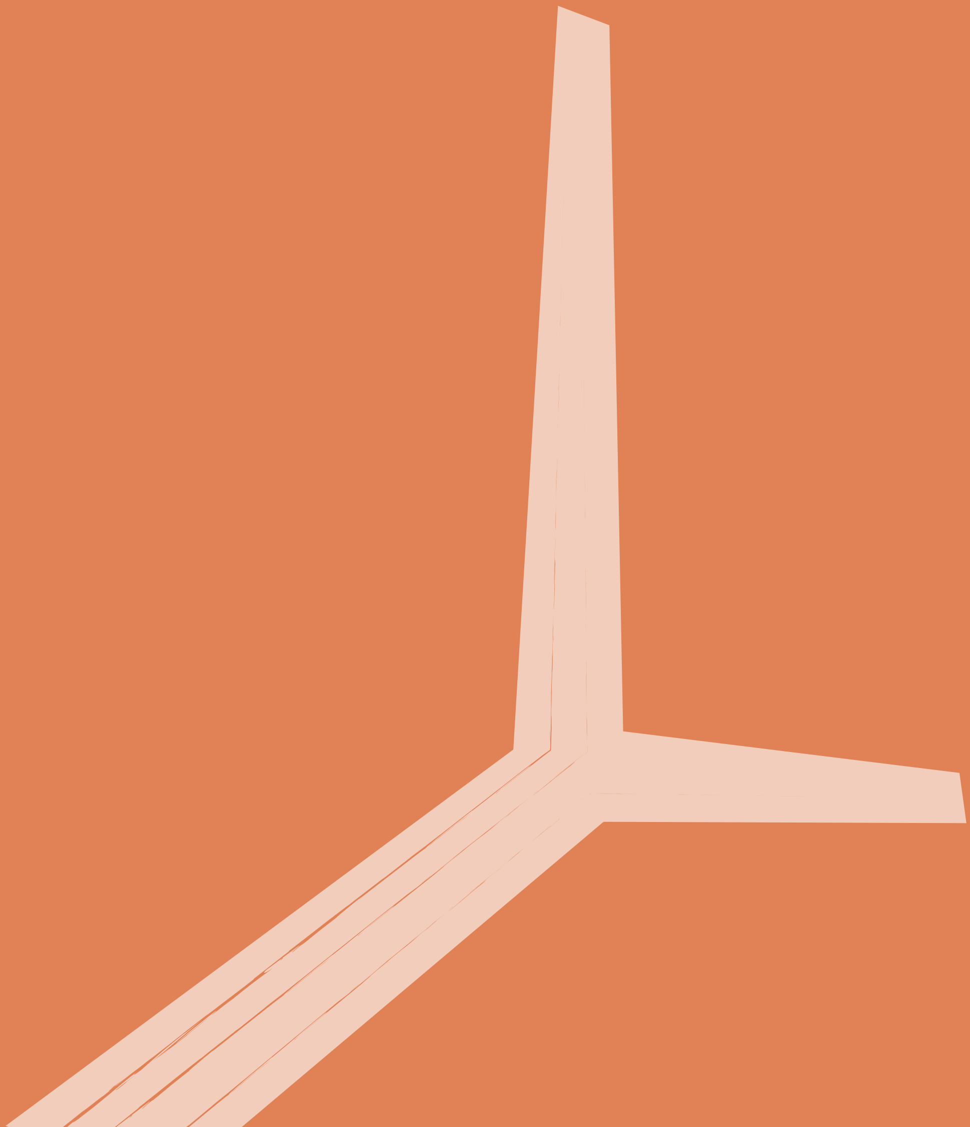
A best interests decision must not be based on your age, condition, appearance or any aspect of your behaviour.

A best interests decision 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.

The views of your family and friends are considered in a best interests decision. But the healthcare professional making the decision has the final responsibility.

Sometimes this means that what the family wants is not what happens. If this happens, the healthcare professional should explain the law regarding best interests decisions and their reasons for the decision.

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. These people are known as your beneficiaries. 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, if you have a mortgage, the value of that mortgage would be taken off your estate.

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 plans
- 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 estate 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 making 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.

If you have a partner but are not married or in a civil partnership with them, they may not get what you wish them to have without a will. This is the case even if you have lived with a partner for years. You should take advice about this from a solicitor.

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 Northern Ireland. 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 may 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. This 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. This may include:

- what is left to pay on a mortgage
- overdrafts
- credit card debts
- 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. Here is a simple example of this:

- If the total value of your assets is £180,000 and the total sum of your liabilities is £150,000, the calculation is 180,000 – 150,000 = 30,000. This means the value of your estate is £30,000.

Who to include in your will

Make a list of 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, you may want to leave a person a specific amount of money, or an item with financial or sentimental value. When you have provided for your loved ones, you may want to consider supporting your favourite charities or causes.

Macmillan Cancer Support has more information in our booklets Your step-by-step guide to making a will and A guide to gifts in wills.

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 the Macmillan Cancer Support booklet Sorting out your financial affairs useful.

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

- Age NI
- NI Direct.

Meeting with a solicitor

You can make a will by either meeting with a solicitor in person or over the phone.

When you talk to your solicitor, it helps to have 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 if you have young children
- names of people you want to look after any relatives who are dependent on you.

After your meeting or phone call, the solicitor should arrange a follow-up appointment with you. This is to check that they have written your will the way you want it. The will then needs 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 your will with your solicitor. Keep a copy yourself and make sure your executors know where to find it.

Online accounts

Many people use the internet for messaging, sharing photos, paying bills, shopping and banking. You may want to think about what will happen to any online accounts if you become unable to use them, or after your death. This may include deciding what you want to happen to photos, videos, emails or other information you have stored online.

There are some passwords that you should never share. For example, do not share your password for an online bank account. If you want someone to manage your money and finances for you, set up an Enduring Power of Attorney.

But you may want to share a list of certain passwords with someone you trust. For example, so they can use your computer, phone or tablet. Or so they can manage some online or social media accounts for you. Remember to check that the person you ask has the technical skills to do what you want them to do.

Some people decide to write a 'social media' will. This is a way of saying what you would like to happen to your social media accounts after your death. digitallegacyassociation.org has more information about this type of planning.

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. This will help your family, friends and health or social care professionals know how you would like to be cared for. You can find an example of a form you can use at be.macmillan.org.uk. It is called **Record of my wishes**.

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

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 health and social care professionals looking after you. This includes your GP, district nurse, specialist doctor 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 health and social care 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 health and social care 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.

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 want healthcare professionals to talk to about your wishes if you become unable to make decisions about your healthcare.

- Who you would like to look after any pets. We have more information about planning pet care on our website. Visit macmillan.org.uk/pet-care
- Whether you would like someone to tell you how serious your condition is and what might happen in the future.
- Your thoughts about organ and tissue donation. If you do not want to donate your organs or tissue after your death, you must register your decision not to donate on the NHS Organ Donor Register.

Writing down your wishes for your care

You can use the **Record of my wishes** document at be.macmillan.org.uk to write down your wishes.

Once you have completed the document, share it with anyone who may be involved in your care. This may include:

- a family member
- a trusted friend
- a health or social care professional, such as your GP, nurse, social worker or hospital doctor.

The health or social care team looking after you may find the information helpful if they are completing an Advance Care Planning Summary or ReSPECT form with you.

Keep your **Record of my wishes** in a safe place at home. Tell people involved in your care where it is so they can find it quickly if they need to. If you have an emergency at home, they may want to show it to the emergency doctor or paramedic. This will help them follow your wishes too.

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, next of kin or other people you trust
- your community nurse
- your GP
- your hospital doctor.

Take your written plan with you, or ask someone to bring it, if you are admitted or transferred to a:

- hospital
- care home
- hospice.

Show it to the staff looking after you, so they know what your wishes and preferences are for your care.

An example of preferences and priorities in a Record of my wishes form

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.

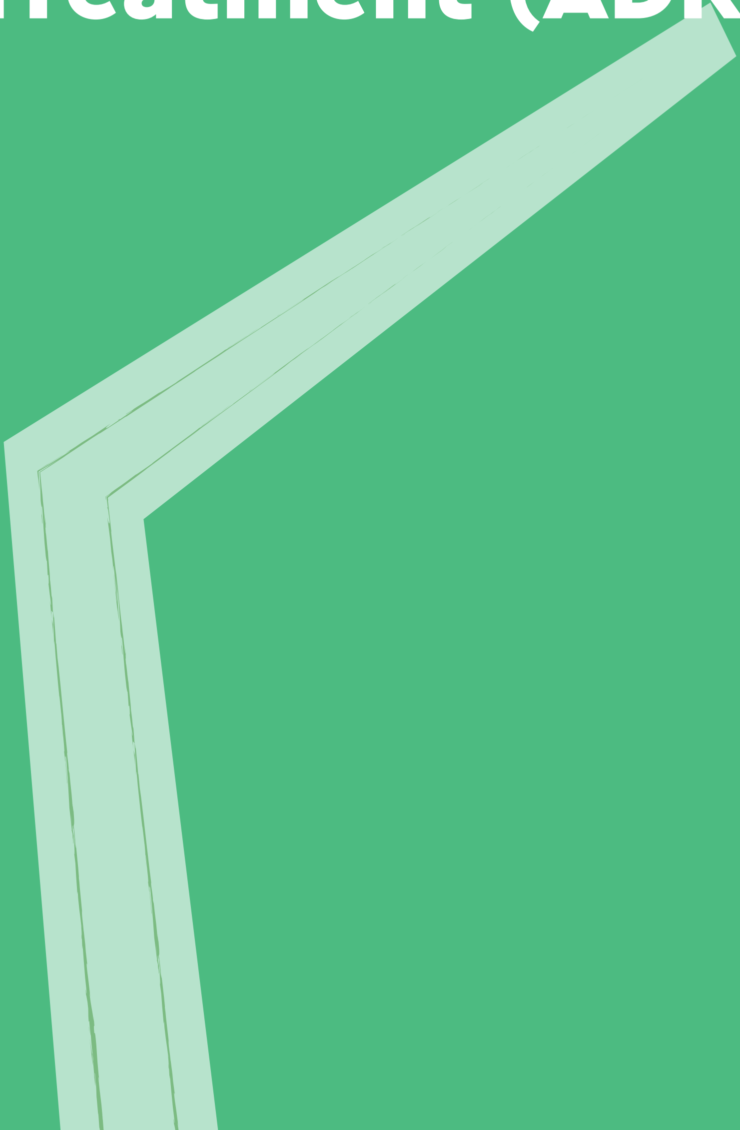
Signed *Johnny Finnegan*
Date 25.10.2023

Advance Care Planning summary and ReSPECT form

If you would like your wishes for future care to be available to all health and social care professionals involved, it is important to tell your GP. With your consent they can record and communicate this information. They may do this using documents such as:

- an Advance Care Planning summary
- a Recommended Summary Plan for Emergency Care and Treatment (ReSPECT form) when this becomes available.

Advance Decisions to Refuse Treatment (ADRT)



What is an Advance Decision to Refuse Treatment (ADRT)?

An Advance Decision to Refuse Treatment (ADRT) is a 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 lose the mental capacity to make and 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 by having fluids through a drip.
- If your condition and quality of life are not improving and are 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.
- You do not want to be resuscitated if your heart stops.

Although you can make most ADRT orally (spoken), it is better to write them down. This helps avoid confusion later. We have examples of how some of this information could be written in an ADRT document.

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.

An ADRT cannot:

- be used to refuse any basic care you might need to keep you comfortable – this includes warmth, shelter, food and fluids by mouth
- include a request to be given specific treatments, or to have your life ended – you can request, but not insist on, specific treatments in your wishes for your care.

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

ADRT and the law

In Northern Ireland, an ADRT is legally binding. This means it must be followed by your health and social care team, as long as they know about it.

An ADRT must meet certain criteria. For example:

- you must be able to make the decision in the first place – this is called having mental capacity
- the treatment being refused must apply to the decision that has to be made at the time.

Your health and social care team will be able to tell you more about this.

Who can make an ADRT and who should be involved?

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

Before making an ADRT, it is important to talk with one of the health or social care professionals involved in your care. 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. A solicitor can also discuss an ADRT with you, help you write it and make sure it 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.

Writing an ADRT

If possible, it is best to have an Advance Decision to Refuse Treatment (ADRT) in writing. And there are certain situations where it is always better to have an ADRT in writing. For example, if the ADRT states that you:

- refuse treatment to keep you alive
- do not want to have your heart restarted – this is called cardiopulmonary resuscitation
- do not want to be put on a breathing machine – this is called a ventilator.

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. There is more information in the forms at the back of this booklet.

What should be included in an ADRT?

It is always advisable to include the following in an Advance Decision to Refuse Treatment (ADRT):

- Your name, date of birth, address and any obvious distinguishing features – for example, a birthmark. This is in case you are unconscious or unable to communicate. It will help 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 1 situation, but not in another.
- The date your ADRT was created.
- Your signature and a dated signature of at least 1 witness. But 2 witnesses are usually preferred if it is a written statement.
- If it is a decision to refuse treatment that would keep you alive, your ADRT should 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 1 specific situation.

For example, some people may want to refuse a specific medication in all circumstances 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 can answer any questions you have and help you understand the possible effects of refusing a treatment. They will make sure that your ADRT is clear for any healthcare professional who may need to use it in the future.

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 change or cancel your ADRT, tell your healthcare team and the people you trust.

Questioning an ADRT

Sometimes there may be a situation where a doctor does not act on, or questions whether it is right to act on an ADRT. For example, this might happen if:

- What you say you want in your ADRT is inconsistent with your lifestyle. For example, you may have changed your religion since you wrote it.
- Medical circumstances have changed since you made your ADRT. For example, a recent development in treatment may have become available that strongly improves your outlook (prognosis). You may have made a different decision if you had known about it.

Your ADRT may also be questioned or overturned if:

- you made your ADRT when you did not have the required mental capacity
- it is believed that you were influenced by others to make the ADRT.

Refusing treatment that is life-sustaining

If you wish to refuse a treatment that is, or may be, life-sustaining, you should state in the box: 'I am refusing this treatment even if my life is at risk as a result.' Life-sustaining means a treatment that is necessary to keep you alive.

An ADRT refusing life-sustaining treatment should be signed by you, or by another person in your presence and by your direction.

It should also be witnessed by at least 1 other person. The witness should sign the ADRT in your presence, or in the presence of the nominated person directed by you to sign.

An example of an ADRT from someone with cancer

My Advance Decision to Refuse Treatment

I wish to refuse the following specific treatments	In these circumstances
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 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 food or fluids unaided.

An example of an ADRT from someone with motor neurone disease (MND)

My Advance Decision to Refuse Treatment

I wish to refuse the following specific treatments	In these circumstances
I refuse assisted ventilation (breathing using a machine), even if my life is at risk as a result.	If my motor neurone disease progresses so that I can no longer breathe by myself.
I refuse artificial feeding or hydration, even if my life is at risk as a result.	If my motor neurone disease has deteriorated so that I cannot swallow safely without the help of others.

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 the breathing stops, this is called a respiratory arrest. Usually, both happen at the same time. This is called a cardiopulmonary arrest. 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 or illness is very advanced, giving CPR is very unlikely to restart the heart.

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, you may want to talk to your GP, hospital doctor or specialist nurse. You may also want to talk to your family, a close friend, or a spiritual or religious leader.

Your healthcare professional can tell you how successful CPR is likely to be in different situations. This information may help you if you are trying to make a decision. They will consider any other health problems you have. Sometimes other health problems mean CPR may be unlikely to be successful.

If a senior healthcare 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 a 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.

We have more information about getting a second opinion on our website. Visit macmillan.org.uk/second-opinion

Your healthcare team will take your wishes about CPR into account. However, you cannot insist on CPR being given by the healthcare 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 decision with you and those close to you. Then a senior doctor who is responsible for your care will record the decision in writing. This person might be:

- a hospital consultant
- a palliative care doctor
- your GP.

There are different ways of recording a CPR decision in writing. They will write your decision clearly in your medical and nursing notes. They may also record the decision using one of the following forms:

- A 'Do not attempt CPR' (DNACPR) form is currently used.
- A ReSPECT form will replace DNACPR in the future.

Your healthcare team will share these with anyone involved in your care in hospital or at home. They should give you a copy to keep at home. You need to keep this safe and somewhere it can be found in an emergency.

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 on our website. Visit macmillan.org.uk/cpr

Enduring Power of Attorney (EPA)

What is an Enduring Power of Attorney (EPA)?

An Enduring Power of Attorney (EPA) is a legal document. It lets you choose other people to:

- share control of your financial affairs and property
- make decisions about your financial affairs and property on your behalf, if needed.

This might include paying your bills, dealing with your bank or even selling your house.

The people chosen to make decisions on your behalf are known as attorneys. You can have more than 1 attorney. Having an EPA allows you to plan ahead in case:

- you lose the mental capacity to make your own decisions about your finances and property
- you are not physically able to carry out tasks, such as visiting your bank.

These changes might happen if you were to have an accident or develop a serious illness.

Who can make an EPA?

You can make an EPA if you are aged 18 or over and have mental capacity.

Who can help you make an EPA?

A solicitor can help you through the process of making an EPA. You can find a solicitor through the Law Society of Northern Ireland. When choosing a solicitor, it is best to ask a few to give you a quote for the cost of drawing up an EPA.

You can also complete your own EPA. The Office of Care and Protection can give you advice on how to do this.

The power of your attorney

You can restrict the power of your attorney in your Enduring Power of Attorney (EPA). For example, you can stop them selling your house. If you have no restrictions, your attorney has power to act on your behalf over any matters relating to your property, income and finances.

You can find out more about restricting the power of your attorney from a solicitor.

An EPA does not give your attorney power to make any decisions about your health and social care. For example, it does not allow them to make decisions about treatment and end of life care.

At the moment the law says that no one can consent to treatment on behalf of another person in Northern Ireland. When an adult does not have the mental capacity to make a specific decision themselves, a best interests decision is made by a senior healthcare professional.

Choosing when your EPA becomes effective

An Enduring Power of Attorney (EPA) becomes effective as soon as the attorney has signed it as long as there are no restrictions stated. This means you will share control of your financial affairs and property with your attorney.

But if you wish, you can state in your EPA that it can only become effective if you lose the mental capacity to make your own decisions. Some people do not do this because, even though they have mental capacity, they may not be physically able to manage their finances.

Registering an EPA

If your attorney believes you are, or soon will be, unable to manage your financial affairs, they will need to register the Enduring Power of Attorney (EPA) with the Office of Care and Protection. This needs to be done for the EPA to become effective.

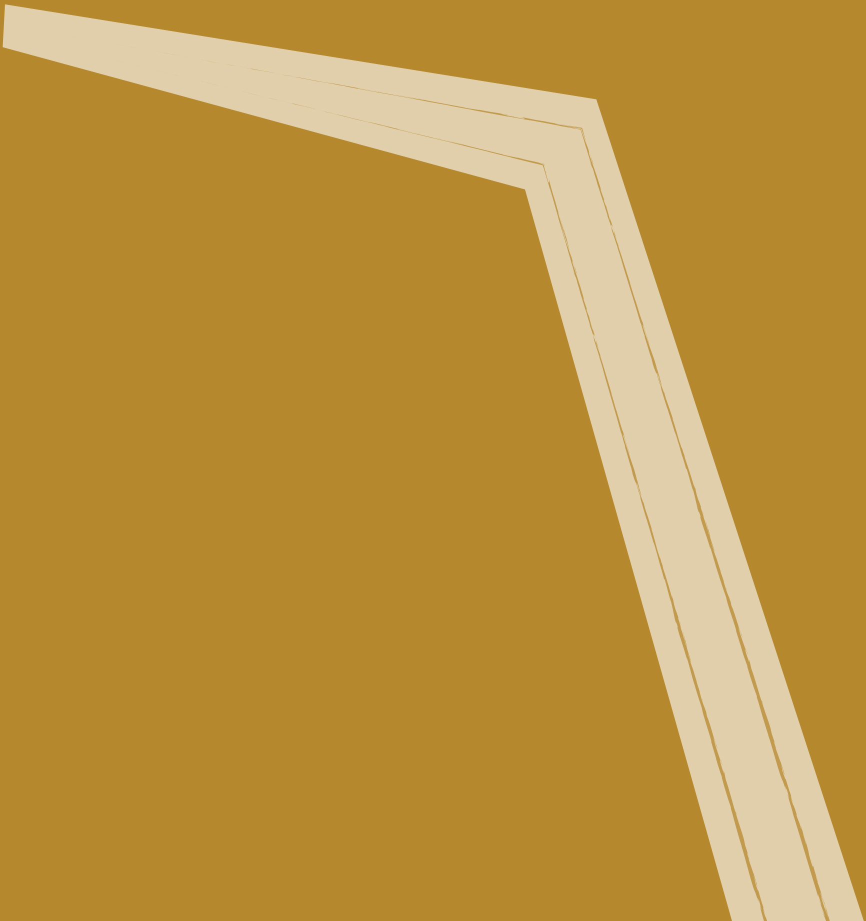
There is a fee to register an EPA.

Cancelling an EPA

You can cancel your Enduring Power of Attorney (EPA) at any time, as long as you have mental capacity. For example, you may need to do this if your attorney is no longer able to act on your behalf. A solicitor can help you with this.

You can get more information about EPAs from your solicitor or from the Office of Care and Protection.

Mental capacity



The Mental Capacity Act in Northern Ireland

In 2016, the Mental Capacity Act (Northern Ireland) became law.

At the time of printing, the Act was not fully in force yet. But many of the principles set out in the Act are already followed. These include the principles for assessing a person's capacity to make decisions.

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. It explains:

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

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.

Health and social care professionals usually assume a person is able to understand information and make decisions. A person lacks capacity if they cannot do 1 or more 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.

Organ and tissue donation

Donating organs and tissue

Organ and tissue donation means giving part of your body to someone else who needs it.

If you do not want to be considered as a possible donor after your death, you need to opt-out. The best way to do this is to register your decision on the NHS Organ Donor Register and to tell your family members and loved ones.

Most adults will usually be considered as a possible donor, unless they have opted out. There are also a small number of people who will not be considered because they are in a group that is excluded. You can find out more about organ and tissue donation and how to opt out on the Organ Donation Northern Ireland website. Visit organdonationni.info

You should tell your family members and loved ones whether you do or do not want to donate. Whatever you decide, it is important that they know your wishes. This will help them support your decision. After your death, they will be asked about whether you wanted to be an organ donor or not. Organ donation will not go ahead if they object.

To be able to donate organs after death, a person needs to die in hospital in specific circumstances. After the death, specialist doctors decide whether a person's organs and tissue can be donated.

Having an illness or medical condition sometimes means you cannot become a donor. But not always. Someone with a current active cancer cannot become an organ donor. But it may be possible for people with certain types of cancers to donate after 3 years of treatment. It may also be possible to donate body tissue such as the corneas – the clear tissue at the front of each eye.

The opt out system for organ donation started in June 2023 and is also known as Dáithí's Law. It does not apply if:

- you are under 18
- you do not have the mental capacity to understand the opt out system
- you are a visitor to Northern Ireland
- you are a temporary resident in Northern Ireland.

If you need information about organ donation for someone in one of these groups visit organdonationni.info

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.

In Northern Ireland, Queens University Medical School is the only medical school that accepts body donations.

As part of the donation process, you will be asked to sign a consent form. You can get this from Queens University 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 the healthcare professional who is dealing with the consent form
- write your wishes down on the consent form.

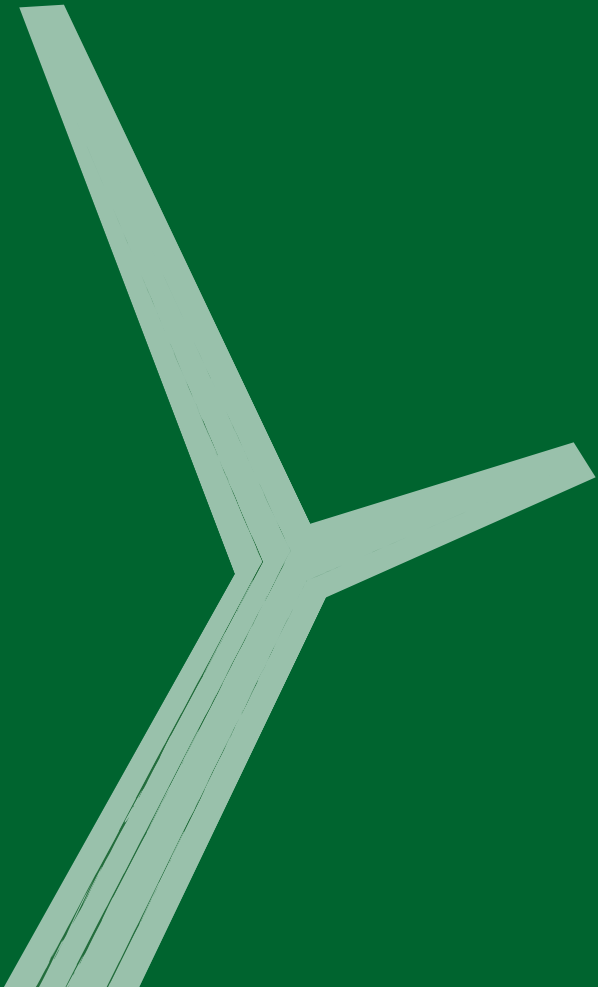
Not everyone who wishes to donate their body for teaching or research will be able to. This may be due to medical reasons. You should still make other funeral plans.

The Human Tissue Authority can give you more information about donating your body for medical research.

Your body cannot be used for both medical research and for organ donation after death. But you can be considered for either. You may be able to donate organs, or your body may be used for medical research.

If only the corneas are removed for donation, your body can still be considered for medical research.

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 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.

What you might include in a funeral plan

Although it can be hard to talk about, discussing your funeral plans with trusted family and friends can be helpful. They may have suggestions for ways to 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. A cremation takes place in a crematorium. It has a chapel 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.

You can find details for the Antrim and Newtownabbey Crematorium and the City of Belfast Crematorium on pages 100 to 101.

A religious or non-religious service

If you have a spiritual or religious faith, you may know 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. Northern Ireland Humanists can give you more information about humanist funerals and memorials.

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 be wearing certain clothes that are significant to you, such as military uniform.

Recording your funeral plans

You can write your wishes for your funeral in your will. Or you can write them down and leave them in a safe place that your family or friends know about. The organisations Dying Matters and the National Association of Funeral Directors have a form called My Funeral Wishes, which you can use to record your wishes.

If you do not want to write down your plans, you can tell your family members 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)
- the National Society of Allied and Independent Funeral Directors (SAIF).

You should try to find out how much the funeral will cost 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 used for a family member's funeral in the past. Try 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.

Further information and support

Macmillan Cancer Support Information

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

Our information is also available online at macmillan.org.uk/information-and-support

You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

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

Find out more at macmillan.org.uk/otherformats

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

Macmillan Support Line

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

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

Our trained cancer information advisers can listen and signpost you to further support.

Call us on **0808 808 00 00**. We are open 7 days a week, 8am to 8pm.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person.

Click on the 'Chat to us' button, which appears on pages across the website. Or go to macmillan.org.uk/talktous

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call **0808 808 00 00** and say, in English, the language you want to use.

Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Useful organisations

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

Advice NI

Helpline 0800 915 4604

Provides advice on a variety of issues including financial, legal, housing and employment issues.

Age NI

Helpline 0808 808 7575

www.ageni.org

Information and advice for older people. Publishes impartial, informative fact sheets and advice guides.

Antrim and Newtownabbey Crematorium

Tel 0300 123 4568

www.antrimandnewtownabbey.gov.uk/residents/births-deaths-marriages-civil-partnerships/crematorium/

Cremation services for people living in Northern Ireland.

Benefit Enquiry Line Northern Ireland

Helpline 0800 232 1271

Textphone 028 9031 1092

www.nidirect.gov.uk/money-tax-and-benefits

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Black Women Rising

www.blackwomenrisinguk.org

Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

British Association for Counselling and Psychotherapy (BACP)

Tel 0145 588 3300

www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

Cancer Black Care

Tel 0208 961 4151

www.cancerblackcare.org.uk

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

Cancer Care Map

www.cancercaremap.org

An online directory that helps people find cancer care and support services in their local area. It uses stories and videos to show how the services have benefited other people living with cancer and sign-posts services across the country.

Carers NI

Helpline 0289 043 9843

www.carersuk.org/ni

An advice and information service for carers and professionals, dealing with a range of issues such as carers' benefits, community care and services for carers.

City of Belfast Crematorium

Tel 0289 044 8342

www.belfastcity. gov.uk/crematorium

Cremation services for people living in Northern Ireland.

Digital Legacy Association

digitallegacyassociation.org

Information about social media wills and planning what you would like to happen to your digital assets after your death.

Disability Action

Tel 0289 029 7880

www.disabilityaction.org

Works to ensure that people with disabilities attain their full rights as citizens.

Dying Matters

Tel 0207 520 8200

www.dyingmatters.org

A national organisation that promotes public awareness of death, dying and bereavement and provides information on preparing for death, dying, and caring for someone who is dying.

Equality Commission

Tel 0289 0500 600

www.equalityni.org/home

Established by the Northern Ireland Act 1998 to provide protection against discrimination and provide advice and assistance for people who feel they have been discriminated against on the grounds of age, disability, race, religion and political opinion, sex and sexual orientation.

Foyle Hospice

Tel 0287 135 1010

www.foylehospice.com

Provides specialist palliative care to patients and their families in the northwest of Ireland, including home care, inpatient care, day therapy, bereavement support and 24-hour advice.

Health and Social Care in Northern Ireland

Tel 0300 555 0115

www.hscni.net

Provides information about health and social care services in Northern Ireland.

Hourglass NI

Tel 0808 808 8141

www.wearehourglass.org/ni

Hourglass NI listen, advise and support vulnerable older people and all those affected by abuse and neglect.

Human Tissue Authority

www.hta.gov.uk

Provides information about tissue, organ and body donation.

The Law Society of Northern Ireland

Tel 0289 023 1614
www.lawsoc-ni.org
Represents and can provide details of solicitors in Northern Ireland.

LGBT Foundation

Tel 0345 330 3030
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Macmillan Information and Support Services Northern Ireland

www.nican.hscni.net/info-for-patients-public/local-macmillan-cancer-information-and-support-services/

There is a Macmillan Information and Support Service in every Trust area, linked to your local cancer unit. They provide free information and confidential support to people living with cancer, as well as their carers, friends and family. They can offer benefits advice, counselling and complementary therapies, as well as practical help such as transport to hospital, help at home and questions about work or travel insurance.

Belfast HSC Trust
0289 615 0077
cancer.info@belfasttrust.hscni.net

Northern HSC Trust
0289 442 4000
ext 333079/334046
cancerinformation@northerntrust.hscni.net

South Eastern HSC Trust
0289 055 3246
macmillan.informationandsupport@setrust.hscni.net

Southern HSC Trust
0283 756 1001
macmillaninfo&support@southerntrust.hscni.net

Western HSC Trust
0734 207 5636
or 028 7132 0105
macmillan.information@westerntrust.hscni.net

Make the call

Tel 0800 232 1271
www.nidirect.gov.uk/contacts/make-call-service
Provides advice and information for Northern Ireland residents about benefits, supports and services available.

Marie Curie

Helpline 0800 090 2309
www.mariecurie.org.uk
Marie Curie nurses provide free end of life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

Marie Curie Hospice Belfast

Helpline 0800 090 2309
www.mariecurie.org.uk/help/hospice-care/belfast
Offers specialist care for people with cancer and other life-limiting illnesses and support for families. Has an inpatient unit and a day services department.

NI Direct

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

Northern Ireland Humanists

www.humanists.uk/northern-ireland/
Work on behalf of the non-religious in Northern Ireland to promote Humanism and equal treatment of everyone regardless of religion or belief. They have celebrants who carry out humanist ceremonies.

National Association of Funeral Directors (NAFD)

Tel 0121 711 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 and what you should expect from a funeral director.

The Natural Death Centre

Helpline 0196 271 2690
www.naturaldeath.org.uk
Offers independent advice on aspects of dying, funeral planning and bereavement.

Northern Ireland Hospice

Adult services
Tel 0289 078 1836
Children's hospice
Tel 0289 077 7635
www.nihospice.org
Provides specialist palliative care to adults and children with life-limiting and life-threatening illnesses.

The Office of Care and Protection (OCP)

Tel 0289 076 3000
www.justice-ni.gov.uk/articles/information-about-office-care-and-protection
Helps people without mental capacity manage their property and financial affairs, under Part VIII of the Mental Health Order NI 1986.

Organ Donation Northern Ireland

Tel 0300 123 2323
www.organdonationni.info
Information about organ donation in Northern Ireland.

OUTpatients

www.outpatients.org.uk
Supports and advocates for LGBTIQ+ cancer patients in the UK, inclusive of all genders or types of cancer. Also produces information, and runs a peer support group with Maggie's Barts.

Patient & Client Council

Tel 0800 917 0222
www.pcc-ni.net
Provides an independent voice for people on health and social care issues.

Public Health Agency

Tel 0300 555 0114
www.publichealth.hscni.net
Improves the health and social well-being of people in Northern Ireland by reducing inequalities. Works with communities and other organisations to achieve this.

Queens University Medical School Body Donation Programme

Tel 0289 097 2131
www.qub.ac.uk/schools/mdbs/Workwithus/BodyBequest/

Society of Allied and Independent Funeral Directors (SAIF)

Tel 0345 230 6777
www.saif.org.uk
Represents independent funeral homes and promotes best practice. Aims to protect the interests of their members and communities across the UK.

Southern Area Hospice Services

Tel 0283 026 7711
www.southernareahospiceservices.org
Provides comprehensive specialist palliative care to patients with terminal illnesses.

Turn2us

www.turn2us.org.uk
Turn2us helps people in financial need gain access to welfare benefits, charitable grants and other financial help – online, by phone and face to face through our partner organisations.

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 and the Public Health Agency do 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 Ollie Minton, Consultant Palliative Medicine.

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We welcome feedback on our information.

If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

Below is a sample of the sources used in our advance care planning information. If you would like further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Department of Health. For Now and For The Future: an Advance Care Planning policy for adults in Northern Ireland. October 2022. Available from www.health-ni.gov.uk/advance-care-planning-now-and-future [accessed June 2023].

Mental Capacity Act (Northern Ireland) 2016. Available from www.legislation.gov.uk [accessed June 2023].

Public Health Agency. Organ Donation Northern Ireland. Changes to the law. Available from www.organdonationni.info [accessed June 2023].

Your notes and questions

You could use the following pages to write down any questions you want to ask your doctor or nurse, and to write down their answers.

MACMILLAN CANCER SUPPORT

Palliative Care
in partnership

Trusted
Information
Creator

Patient Information Forum

HSC Public Health Agency

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