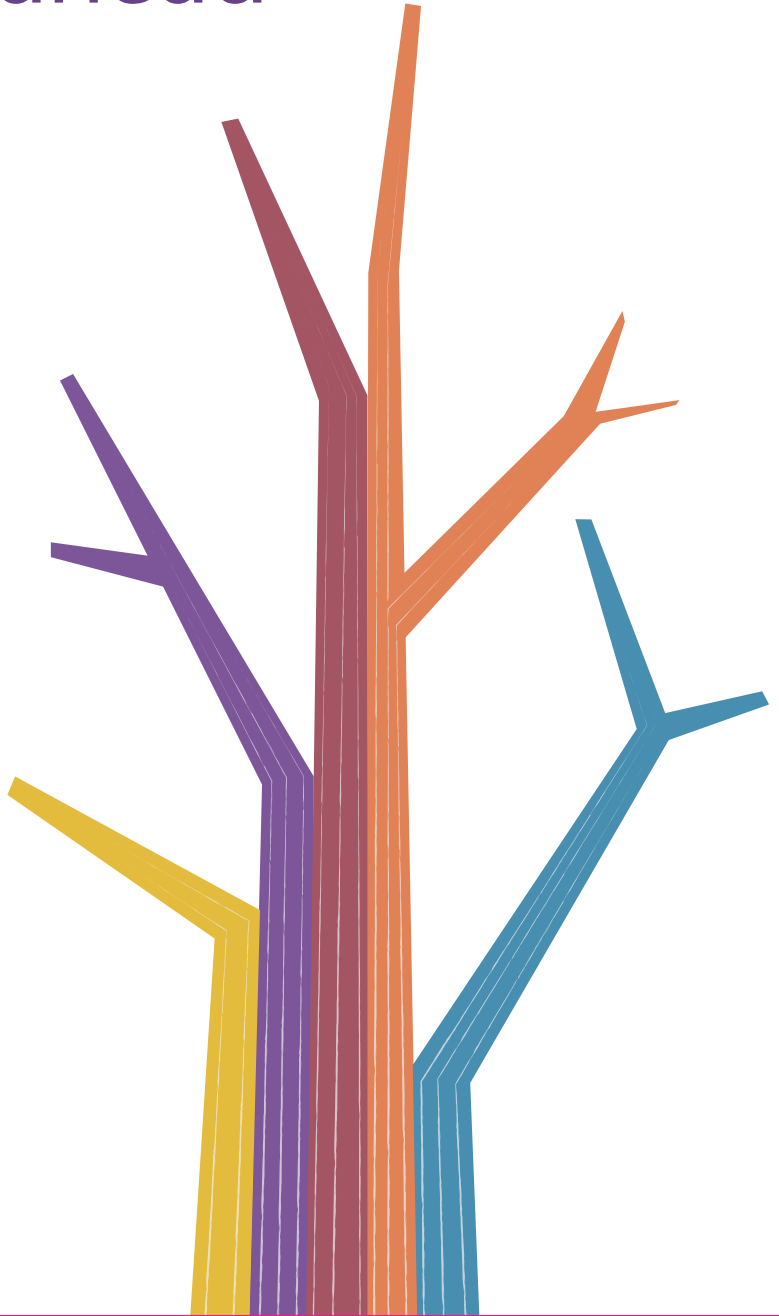


Your life and your choices:  
plan ahead



# 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 Northern Ireland. It is for anyone who wishes to plan ahead, whether they have a serious illness or not.**

This booklet was produced by the Public Health Agency and Macmillan Cancer Support. It tells you about some of the ways you can plan ahead, including information on:

- **Your wishes for your care** – these include how and where you would like to be cared for if you become seriously ill or you are reaching the end of your life (see pages 34–41).
- **Advance Decisions to Refuse Treatment** – these are your decisions about specific treatments that you don't want to have (see pages 44–58).
- **Enduring Power of Attorney** – this is when you give someone you trust the power to make decisions on your behalf about your property and finances (see pages 62–65).

This booklet also has information about making a will (see pages 26–31), organ and tissue donation (see pages 72–75), and funeral planning (see pages 78–81).

We hope this booklet will help you:

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

Changes in health can be gradual and expected, or very sudden and unexpected. Planning for your future care is important in case you ever become unable to make choices yourself. For example, this might be if your health were to change and you became unconscious or lost capacity (the ability) to make decisions about treatment.

Planning ahead is also called **advance care planning**.

## How to use this booklet

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

We can't advise you about the best ways to plan ahead. These decisions are very personal. You may find it helpful to discuss what's best for you with a health or social care professional, and someone close to you. This may be a partner, relative or close friend.

Remember that it is your choice, and you are the best person to decide if you want to plan ahead. If you do, you may want to use some of the ways we've suggested in this booklet.

Planning ahead can be emotionally difficult. But it is a good way to improve the chances of getting the care you would choose. Most people feel better knowing they have prepared for the future.

If you don't want to plan ahead or you need more time to think about it, that's fine too.

## Quotes

Throughout this booklet we've included quotes and case studies that you may find helpful. Some names have been changed. Some of these are from people planning their care and their relatives. Others are from health and social care professionals who have cared for people with cancer, chronic obstructive pulmonary disease (COPD) and motor neurone disease (MND). There is also a case study about Annie, who had Parkinson's disease (pages 40–41).

## Supporting documents

There are three documents at the back of this booklet. You can use them to help you think about and write down your wishes and decisions for your future care. The documents are:

- a **planning ahead checklist**
- a **Record of my wishes** document (see pages 34–38)
- an **Advance Decision to Refuse Treatment** document (see pages 44–58).

## Further information

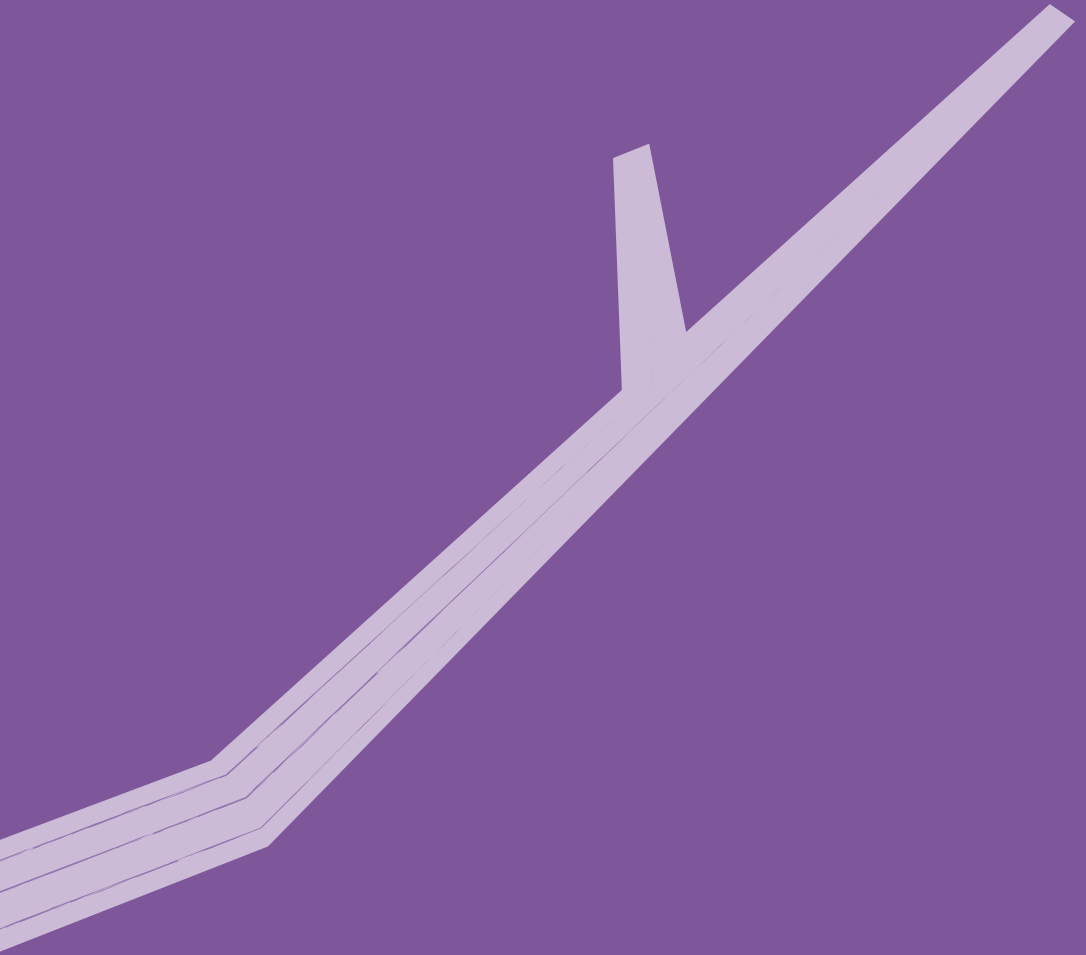
Pages 88–97 have the contact details of organisations that may be useful for you. There is also space for you to write down any notes or questions you may have for a health or social care professional (page 100).

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# Planning ahead





## Why plan ahead?

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

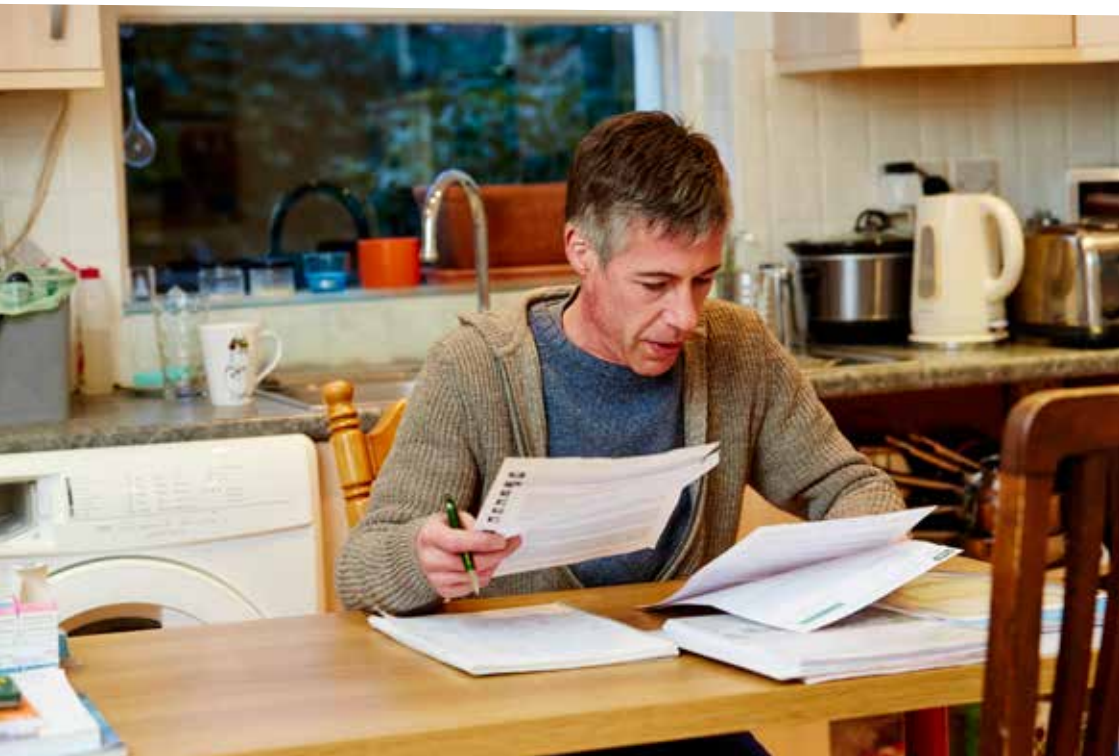
But planning ahead is important, whether you have an illness or not. This is because none of us can say for sure whether we will always be able to make our own decisions about our care. For example, you may suddenly become very ill and be unable to make decisions about your healthcare, or to make financial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

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

Remember that you're the expert on you and what you really want. Only you can know exactly how and where you would like to be cared for. If you haven't told them in advance, even your closest family and friends may not know. This might mean you aren't cared for in the place or way you would have chosen.

For example, if you had an illness that couldn't be cured and your condition suddenly got worse, you may want to be cared for at home. If your family or health or social care team didn't know this, and you are too ill to tell them, you may be admitted to hospital.

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 on.



## Ways to plan ahead

There are several ways you can plan in advance, which we have listed over the next few pages. It's important to remember that you don't have to use them all. Many people find it helpful to start with the ones that are most relevant to them.

### A will

Making a will is the best way to make sure that your wishes are carried out after you die. It can make sure your family and friends are provided for in the way you want. A will includes who you would like your property, personal things and money to go to after you die. It may also include who you would like to look after anyone dependent on you (your dependants) and any specific funeral arrangements you want. We have more information on making a will on pages 26–31.

### Your wishes for your care

You can tell people your wishes or write them down. These will be specific wishes about how you would like to be cared for if you ever become unwell. They can include your choice about where you would like to be cared for. This may be at home, or in a hospital, care home or hospice.

If you are ready to plan your wishes, it is important to tell your GP or healthcare professional. They can record them, so that any health and social care professionals involved in your care know what your wishes are. There is more information about your wishes for your care on pages 34–41.

## Advance Decisions to Refuse Treatment

You can write down your wishes about any treatment you don't want to have, in case you're not able to tell your doctors or family later. This is called an Advance Decision to Refuse Treatment or ADRT (see pages 44–58). An ADRT is legally binding.

## Enduring Power of Attorney

To create an Enduring Power of Attorney (EPA), you put the name of someone you trust to make decisions on your behalf in writing. These decisions might be about managing 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.

An Enduring Power of Attorney is a legal document and needs to be registered. You can find more information about Enduring Power of Attorney on pages 62–65.

## Mental capacity

Having mental capacity means that you are able to:

- understand the decision you are making
- understand what may happen as a result of the decision
- remember and process any information that is relevant to making the decision
- make the decision
- communicate the decision to your doctor or others caring for you.

When people are unwell, their mental capacity can change from time to time. Your health and social care team needs to make sure you have the mental capacity to make a decision about your treatment. If your doctor is concerned about your mental capacity, they may need to ask you questions to help them assess it. There is more information about mental capacity on page 69.

## Organ and tissue donation

Some people choose to write down any wishes they have for organ and tissue donation or whether they would like to donate their body for medical research and medical teaching. We have more information about organ and tissue donation on pages 72–75.

## Funeral planning

You may wish to be involved in planning your funeral. This can be helpful if you know how you would like your funeral to be carried out. It's also possible to pay for your funeral in advance. We have more information about funeral planning on pages 78–81.

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

Remember, it is your decision whether you use just one or two of these ways to plan ahead or all of them.



# Who can help you with planning ahead?

Planning ahead for our healthcare isn't something we usually think about. If we are well, we don't 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 this isn't always the case.

For many people with an illness, especially a long-term illness, planning ahead may feel particularly difficult. You may already be struggling to cope with fears and uncertainties about the future. It is important that you don't feel alone when planning ahead. Remember that there are many professionals who can help you, as well as your family and friends.

## Professionals

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

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

They will be able to tell you who the best person to speak to is. If you're thinking about making a will or creating an Enduring Power of Attorney, you can contact a solicitor.



Starting a conversation about your future plans may feel difficult. You may want to start the conversation with something like this:

'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 could you point me in the direction of someone who could help me explore what options I have and what I need to do?'

## Family and friends

Involving people close to you can be really helpful. You might want to talk to your family and friends. They may be able to help you think through some of the issues, so that you can plan ahead better. It will also mean that they know what your wishes are, so they can help make sure they are carried out.

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

## If they don't want to talk about it

Sometimes family and friends don't want to talk about planning ahead. They may appear to ignore the fact that you want to think about the future, perhaps by playing down your worries and changing the subject. If this upsets or hurts you, try telling them why it's important for you to plan ahead. You could explain that knowing you have planned the sort of care you want will help you feel less worried. Or you could ask them to read this booklet, so that you can talk about it together when you feel ready.

Perhaps start by reassuring them that this is something you want to do and it will help if you could talk to them about it. You could try saying something like this:

'I know it's difficult to talk about this, but I'd really like to talk about how I want to be cared for if my health was to suddenly get worse.'



# Coping with your emotions

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

There are many people who can help you cope with your emotions. Talking to close family or friends can help. Health and social care professionals can also give you support. This could be your GP, social worker, specialist nurse or hospital doctor. You may also find it helpful to join a support group or talk things through with one of the organisations on pages 88–97.

Some people may be offered counselling. This can be very helpful, particularly if you don't feel like talking about your feelings with people close to you.

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

## How to plan ahead

- **Write your plans down.** You may want to use the Record of my wishes and My Advance Decision to Refuse Treatment documents at the back of this booklet.
- **Tell your GP or a health and social care professional what your wishes are.** They can record this on an Advance Care Planning Summary. This can be seen by other health and social care professionals involved in your care.
- **If you want to make a will (see pages 26–31) or create an Enduring Power of Attorney (see pages 62–65),** it is a good idea to speak to a solicitor, because these are important legal documents. A solicitor can also help you to write an Advance Decision to Refuse Treatment.
- **Keep your documents in a safe place.** Make sure they can easily be found by your family, friends and health and social care professionals. Your family should know where they are kept.

- **Review your documents regularly.** This is to make sure they still reflect your wishes. Your wishes can vary over time, especially if your circumstances change. For example, your health may get worse. You may wish to review your documents with your health and social care professionals. It is important to include the people close to you too.
- **You can change the plans you've made at any time.** This includes your will, a record of your wishes, Advance Decision to Refuse Treatment, Advance Care Planning Summary or your wishes for organ and tissue donation. If you do change any of your plans, you need to make sure that everyone involved in your care knows. You should also write down (document) your new wishes, even if this isn't a legal requirement for the plan you want to change. Writing down your wishes officially and sharing them makes sure that everyone who's involved in your care knows what they are.

You may find it helpful to use the planning ahead checklist at the back of this booklet. You can use it to keep a record of the ways you have planned ahead, important contacts and where you keep different documents. Make sure someone close to you knows where you keep this checklist.

## An example of planning ahead

'I first met George, an 88-year-old man, when I was asked by his GP to assess him at home. George lived with his daughter, Nicola. He had COPD and was getting more breathless, so I organised for him to have oxygen at home.

Over the next few months George's condition and breathing continued to get worse. He told me he had an important milestone that he was determined to make. His daughter Nicola was due to get married and George wanted to be at her wedding. When the day came, with a bit of forward planning, some help, and oxygen available at the wedding venue, George managed to get to Nicola's wedding and had a wonderful time.

I continued to see George regularly. He was aware that his condition was getting worse and that time was limited. George told me that he wanted to spend his remaining time at home rather than going into hospital. So with Nicola we discussed making a plan for George to be cared for at home. His bed was moved downstairs and carers were organised to come and help him with his personal care.

On one visit, George talked about making an Advance Decision to Refuse Treatment, as he didn't want to have his heart restarted (be resuscitated) if it were to stop beating. I made sure his GP was aware of this and that it was recorded in his medical and nursing records. This meant that if any out of-hours services were called to George's house, they would know that he didn't want to be resuscitated.

George agreed to go on the radio to discuss the importance of planning ahead and some of the plans he had made. This included his wish to remain at home and his wish not to have his heart restarted if it were to stop beating. The radio presenter asked him what he wanted to do before he died. To my surprise, George said that he really wanted to see his sweet pea grow in his garden. A little while later I received the most beautiful photo of George holding his sweet pea.

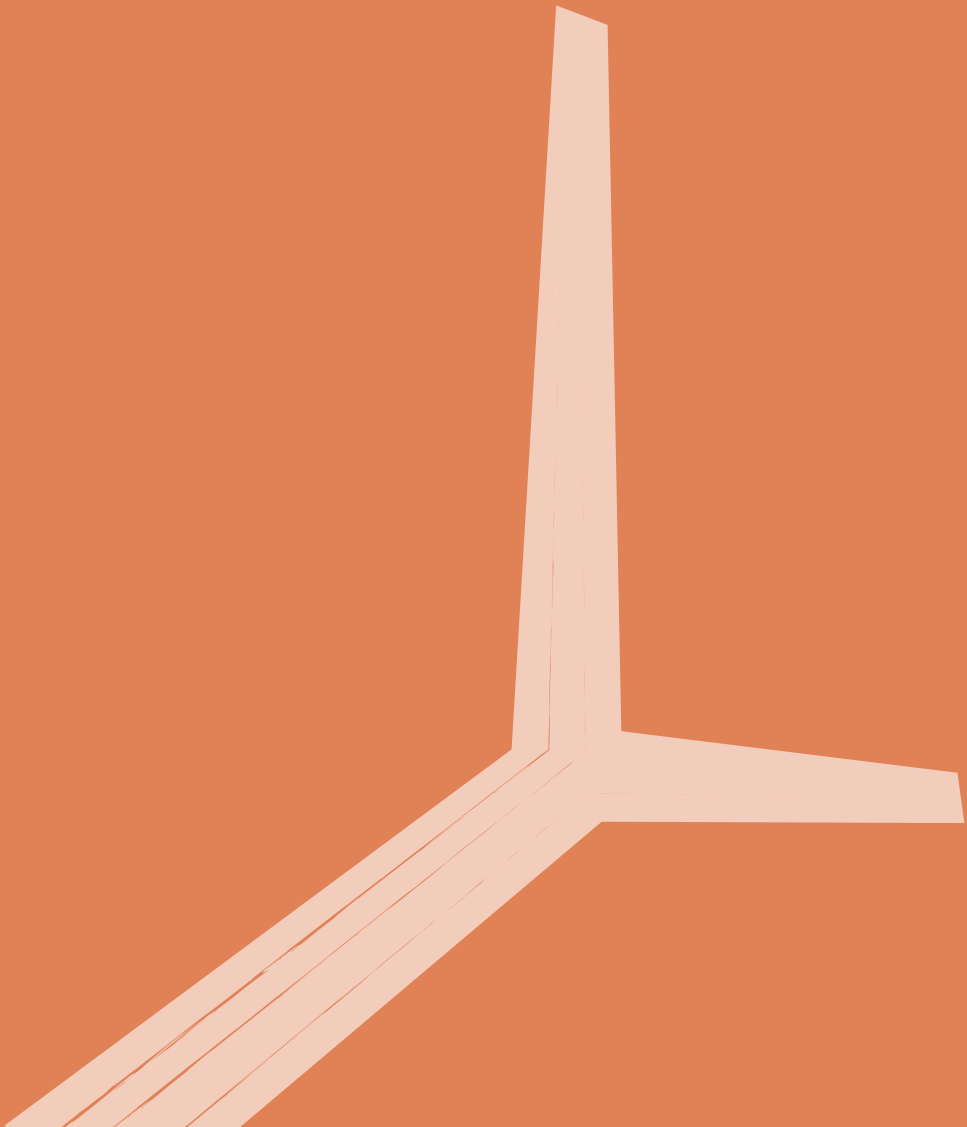
As the weeks went by, George became weaker and it was clear that he was dying. He was still able to chat and talk about his needs, so I asked him whether he wanted a nurse to come and care for him overnight. He agreed but said to leave it for another day. George died at about 6am the next morning, very peacefully in his sleep. This was just as he and his family had hoped.'

Annemarie, George's specialist nurse





# Making a will



## Why make a will?

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

If you die without a will, it is known as dying intestate. When someone dies intestate, it often takes much longer to deal with the estate and it can be complicated. There are strict rules known as intestacy rules, which say:

- who should deal with the affairs of the person who has died
- who should inherit the estate.

This may mean that the people who inherit the estate aren't 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. It is worth taking advice about this from a solicitor or from someone at Citizens Advice (see page 94).

## Involving a solicitor

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

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



# Things to think about when making your will

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

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

You may want to start by making a list of everything you own (your assets) and how much they are worth. 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 (your liabilities) and how much these add up to. This includes your outstanding mortgage balance and any overdrafts, credit card debts and bank loans.

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

## Who to include in your will

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

## Other important information

Other things you'll need to think about include:

- Who you want to be responsible for carrying out the instructions in your will. They are known as executors.
- Who you want to be the legal guardian or guardians of your children, if you have children under the age of 18.
- Who you want to look after anyone who relies on you for support. This could be financial support or giving day-to-day care. These people are known as your dependants.
- What funeral instructions you may have, if any.
- Who you would like to look after your pets, if you have any.

You can get more information about making a will from organisations such as Age NI (see page 88) and the Law Society of Northern Ireland (see page 94).

## Meeting with a solicitor

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

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

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

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

It's a good idea to leave your up-to-date will somewhere safe and easily found. For example, you can leave it with your solicitor. Keep a copy for yourself and make sure those responsible for carrying out the instructions in your will know where it is.

## An example of writing a will

'Writing a will was always something I'd thought about, especially now that I have two children aged 10 and 8. When I tried to discuss it with my husband, he never wanted to know. He always said, "Not now," or, "We'll do it sometime".

Then one Sunday I got a phone call to say that my cousin, who was 43, was rushed to hospital as he felt very unwell. Within a matter of hours he was on a life support machine and within a few days he had died. It all started with a headache, but he was diagnosed with a rare blood disorder and this was the cause of his death. This event made me stop and think how quickly things change in our lives, which we have absolutely no control over. I thought of my own children and what I would want for them if something happened to me.

Following this, I made an appointment with one of our local solicitors and then told my husband he was coming along to make sure we had a will in place. This process was made so easy for us and the solicitor explained everything. We kept the will simple and straightforward. When it was drafted, we then went back to the solicitor's office to agree to the final will and sign it.

I'll always remember walking out of the office and the relief I felt. I am now assured that I know my children will be looked after, and this offers me great comfort.'

Maeve





Your wishes for  
your care



# Thinking about how you would like to be cared for

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

Writing down your wishes and preferences means that your family and health or social care professionals will know how you would like to be cared for. You can find an example of a form you can use at the back of this booklet. It is called **Record of my wishes**.

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

Before you write down your wishes and preferences, it may help to talk through your plans with your family or a close friend. This can be particularly helpful if you:

- want them to be involved in your care
- want them to make decisions on your behalf.

You should also talk through your plans with one or two of the health and social care professionals looking after you.

It is also important to discuss whether your wishes are realistic. You can talk about this with your health and social care professionals and the people close to you. If they aren't, try to think of some other options. For example, you may prefer to die at home, but not have any family members or close friends to support you there. So it may be more realistic for you to be cared for in a care home or hospice.

It may not always be possible for your wishes and preferences to be met at the time when you become less well. For example, you may want to be cared for at home by a family member, but if they become ill or overtired they may not be able to look after you. In this case, health or social care professionals may be able to arrange care for you so you can stay at home. If this isn't possible, they will plan for you to get the best possible care somewhere else. This may be in a hospital, care home or hospice.

# What to include in your wishes for your care

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

- Where you would like to be cared for when you can no longer look after yourself. For example, if you would like to be at home or in a care home.
- Where you'd like to be cared for when you are dying. For example, this could be at home or in a hospice.
- What kind of care and treatments you would like. Remember, you can't demand particular treatments.
- Information about specific spiritual or religious practices that you would like to be carried out or reflected in your care.
- Who you would like to be involved in your care. For example, family or close friends.
- Who you would like to be involved if decisions need to be made about your care and you are unable to make them yourself.
- Who you would like to look after any pets.
- Whether you would like someone to tell you how serious your condition is and what might happen in the future.

# Writing down your wishes for your care

You can use the **Record of my wishes** document at the back of this booklet to write down your wishes.

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

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

If you are admitted or transferred to a hospital or hospice, take your document with you. This will let the staff know your wishes and preferences for your care.

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

It's important to regularly review your wishes and keep them up to date. You can change your mind at any time. Remember, you will need to make sure you record your changes. You will also need to let your family, and health and social care professionals know, and give them an updated copy of the document.

## An example of some information that may be in a Record of my wishes form

### **Your preferences and priorities**

#### **In relation to your health, what has been happening to you?**

My doctors have told me that I'm now only receiving care to control my symptoms. Curing my illness is no longer possible.

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

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

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

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

**Signed Johnny Finnegan Date 24.04.16**

# Advance Care Planning Summary

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. They can record and communicate this information in a document called an Advance Care Planning Summary.

Over the next two pages, there is an example of how an Advance Care Planning Summary can be helpful.



## An example of an Advance Care Planning Summary in action

'Even though my Dad had been ill for several years we'd never discussed what would happen at the end of his life. Following his death, our family regretted not having those discussions and my Mum, Annie, was keen to ensure things were better planned and hopefully easier for my brother and I when her time came.

Mum had been diagnosed with Parkinson's disease several years previously and although her health was stable she wanted to be prepared for the future. Over the following weeks, we talked with each other, with her health and social care professionals and with our solicitor. We noted some of her preferences and things important to her in the Record of my wishes and Mum arranged with her solicitor for me to be her Enduring Power of Attorney.

Mum was clear that she didn't want us to give up our lives to care for her, she didn't want to be resuscitated, and if possible she would like to stay in her own bed. She also expressed a fear of being in pain at the end.

As her Parkinson's progressed and her health began to deteriorate Mum moved into a nursing home, where her GP visited her and together we recorded her wishes for her future care on an Advance Care Planning Summary.

Mum lived in the nursing home for just over two years, where I visited her every day. During that time, Mum was also diagnosed with dementia and was prone to infections and falls. The staff were great and always aimed to treat Mum in the nursing home to try and avoid admissions to hospital. That was because taking Mum away from the nursing home environment made her agitated and scared.

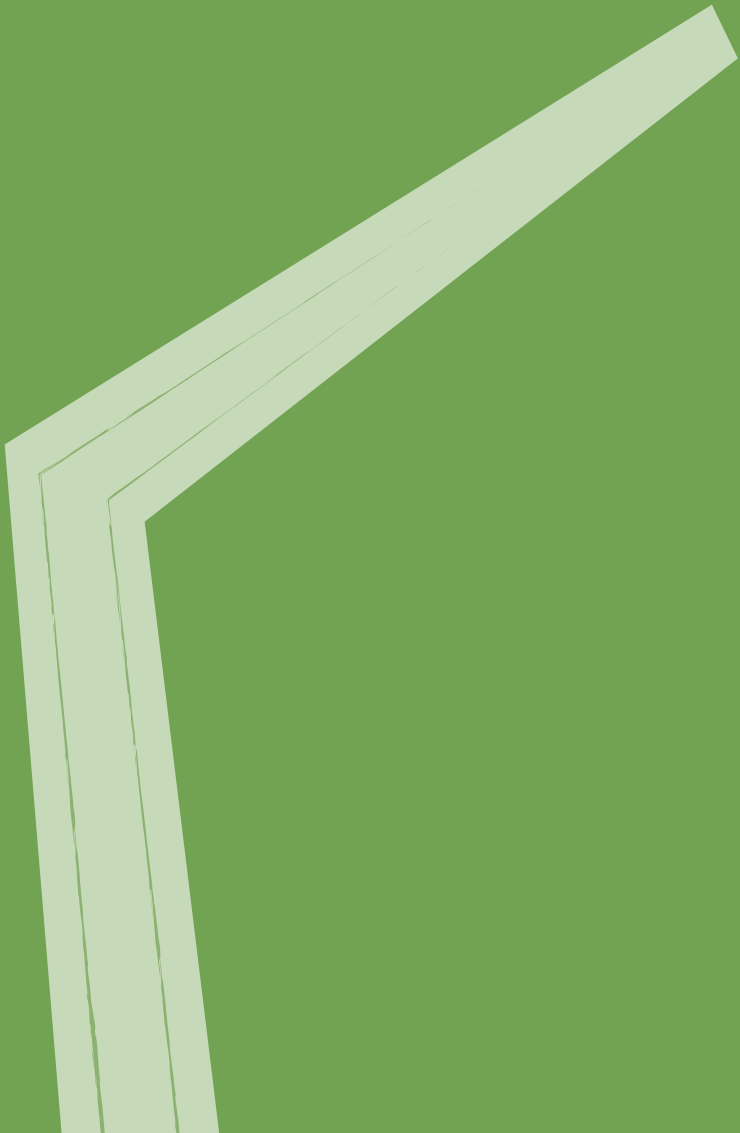
My Mum's final deterioration was quick, over the course of a weekend. On the Sunday afternoon it was apparent that she was in pain, so the out-of-hours GP was called. He initially suggested sending her to hospital. However, after reviewing her Advance Care Planning Summary he was able to arrange appropriate pain relief in the nursing home.

My Mum passed away peacefully several hours later in her own bed. I was holding her hand. Following her death, I've taken great comfort from knowing that we were able to care for mum how she had wanted in her final days.'

Diane, Annie's daughter.



# Advance Decisions to Refuse Treatment



# Advance Decisions to Refuse Treatment (ADRT)

An Advance Decision to Refuse Treatment (ADRT) is a written statement of your wishes to refuse a particular treatment. It's from you to your medical team. It may also set out the specific circumstances in which you would not want a particular treatment.

It is a way of making sure everyone knows what treatments you don't want to have if you're unable to make your own decisions in the future.

For example, you may decide that:

- If your illness couldn't be cured and you become very unwell after all possible treatment, you wouldn't want to be kept alive by being given fluids through a feeding tube or drip.
- If you are being fed or given fluids through a feeding tube or drip, you do not want this to continue if your condition were to get worse and it isn't improving your quality of life.
- You do not want to be given antibiotics for an infection if you are only expected to live for a few days,
- You do not want to be resuscitated if your heart stops (see pages 56–58).

See pages 52–53 for an example of how some of this information could be written in an ADRT document.

An ADRT can't include a request to have treatment or to have your life ended. You can request, but not insist on, treatment in your wishes for your care (see pages 34–38).

It is important to be as clear as possible about:

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

This is to make your wishes clear to anyone reading the document.

An ADRT can't be used to refuse any basic care you might need to keep you comfortable. This includes warmth, shelter, food and fluids by mouth, and pain control.

## ADRT and the law

In Northern Ireland, an ADRT is legally binding although it is governed by common law instead of an Act. 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 (see page 69)
- 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?

You can only make an ADRT if:

- you are aged 18 or over
- you are able to understand what it means for you – this means you have mental capacity (see page 69).

## Who else should be involved?

Before making an ADRT, it's important to discuss the decisions you would like to make with one of the health and social care professionals involved in your care. This may be your GP, or a doctor or specialist nurse looking after you at the hospital. They will be able to tell you what the likely effects of stopping a treatment are and what may happen if you have the treatment.

A solicitor can also discuss an ADRT with you, help you write one and make sure it meets legal requirements.



# What should be included in an ADRT?

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

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

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 particular situation, but not in another. It must also contain a statement such as:

**'I refuse this treatment even if my life is at risk as a result.'**

## ADRT checklist

There is nothing in law that says what must be included in an ADRT if it doesn't relate to treatment that will keep someone alive. However, it is advisable to include the following:

- Your name, date of birth, address and any particular distinguishing features (for example, a birth mark). This is in case you are unconscious or unable to communicate, and professionals need to 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 ever lack capacity to make decisions.
- A statement of which treatment or treatments are to be refused, and the circumstances when your decision would apply.
- The date your Advance Decision was created.
- Your signature and a dated signature of at least one witness. Two witnesses are usually preferred if it is a written statement. The witnesses should be over the age of 18.
- If it is an Advance Decision to Refuse Treatment that will keep you alive, it must also include the statement: **'I refuse this treatment even if my life is at risk as a result.'**

## If you refuse a treatment in all circumstances

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

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

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

Remember to review your ADRT regularly. It's important to do this so you know it is up-to-date and reflects your current wishes.

## Questioning an ADRT

Sometimes there may be situations when a doctor does not act on, or questions whether it's right to act on an ADRT. For example, this might happen if:

- What you say you want in your Advance Decision 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 Advance Decision. For example, a recent development in treatment may have become available that strongly improves your outlook (prognosis). This may have led you to make a different decision, if had you known about it.

Your ADRT may also be questioned or overturned if:

- you made your Advance Decision when you didn't have the required mental capacity
- it is believed that you were influenced by others to make the Advance Decision.

## An example of an Advance Decision to Refuse Treatment from someone with cancer

### My Advance Decision to Refuse Treatment

<b>I wish to refuse the following specific treatments</b>	<b>In these circumstances</b>
<p>I refuse cardiopulmonary resuscitation if my heart and lungs stop functioning, even if my life is at risk as a result.</p>	<p>If I have terminal cancer and my heart and lungs stop functioning in a way that allows me to breathe spontaneously.</p>
<p>I refuse artificial feeding or hydration, even if my life is at risk as a result.</p>	<p>If I have terminal cancer, become unconscious and am unable to swallow food or fluids unaided.</p>

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

### My Advance Decision to Refuse Treatment

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

## An example of an ADRT

'My dad William wrote an Advance Decision to Refuse Treatment. It helped inform the doctor's decision making when Dad couldn't communicate his wishes, locked in his body as he was. It was hard discussing Dad's Advance Decision to Refuse Treatment. But it meant that when the time came, his wishes were followed just as he wanted.'

Catriona, William's daughter



'I first met William when he was diagnosed with motor neurone disease. He had symptoms of weakness in both his arms and shortness of breath. To help William's breathing, he was started on a special machine to help inflate and deflate his lungs (known as non invasive ventilation).

Over the next few months, William's condition continued to get worse. I talked with him about planning for his future care in case he lost capacity or became unable to consent to or refuse treatment. After discussion with William and his family, he decided to write an Advance Decision to Refuse Treatment. A copy of William's Advance Decision to Refuse Treatment was sent to his GP, his neurologist and the Northern Ireland Ambulance Service. His family also kept a copy, which they were advised to take with them if William needed to be admitted to hospital.

A few months later William became less well and was admitted to hospital. The hospital team discussed transferring him to the intensive care unit for treatment.

At this point William's family showed them his Advance Decision to Refuse Treatment. It stated that he did not want the treatment being offered in the intensive care unit. Knowing what William's wishes were meant the hospital team did not transfer him to the intensive care unit for treatment. Instead, William was given care to keep him comfortable and manage his symptoms on the ward. He died peacefully the next day.'

Brian, William's specialist nurse



# Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

You may hear doctors or nurses talk about a DNACPR decision. This may also be referred to as a DNAR or NFCPR. A DNACPR is a written record of a decision to not treat someone with cardiopulmonary resuscitation (CPR) if they have a cardiac arrest.

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

You may have already made a decision about not wanting to be resuscitated in a specific situation and included this in your ADRT (see pages 44–55). However, if you haven't made a decision about CPR and you want to, you should discuss this with your medical team or specialist nurse. You may also want to talk this through with your family, a close friend or a spiritual carer, such as a chaplain.

Your medical team will be able to tell you how successful CPR is likely to be in different situations. They will take into account any other health problems you have.

A senior healthcare professional will ask if you want CPR to be attempted if they believe you may have a cardiac arrest and that resuscitation could be successful. For example, you may have a cancer that can't be cured but you are expected to live with the condition for a long time, sometimes years. In this situation, the doctor will make sure that you have all the information you need to make an informed decision. They will tell you:

- what is likely to happen if you have CPR
- how this might extend your life
- what your quality of life might be.

If a senior healthcare professional believes that CPR will not be successful and so not be appropriate for you, a decision will be made not to attempt CPR in the event that you have a cardiac arrest. The doctor will discuss this decision with you. They should also let your family know what they recommend, unless you have asked them not to.

Your healthcare team will take your wishes about CPR into account. But you cannot insist a doctor attempts CPR if their clinical judgement is that it is not appropriate. If you don't agree with this decision, you can ask for a second opinion from another senior doctor.

## After a decision has been made

After discussing the DNACPR decision with you, a senior doctor who is responsible for your care will make, write and sign the DNACPR. This might be a hospital consultant, a palliative care doctor or your GP. The decision will be clearly written in your medical and nursing notes.

If you are at home, you will be asked to keep a written record of your DNACPR where it can easily be found. This is so that emergency services, such as out-of-hours ambulance services and doctors, will know about it.

Your decision about CPR won't affect any other care or treatment you have. You can change your mind at any time. If you do change your mind, it is important to discuss this with a member of your healthcare team. If you wish to change your decision after talking with your healthcare team, they will make sure this is recorded in your medical notes.

Remember to also tell your family or the person looking after you, as this will help to avoid any confusion.

Macmillan Cancer Support has more information about cardiopulmonary resuscitation for people with cancer – call the support line on **0808 808 00 00** to request it.





# Enduring Power of Attorney



# What is an Enduring Power of Attorney (EPA)?

An Enduring Power of Attorney (EPA) is a legal document. It allows you to choose other people to make decisions on your behalf about your property and financial affairs. This might include paying your bills, dealing with the bank or even selling your house.

The people chosen to make decisions on your behalf are known as attorneys. You can have more than one attorney.

Having an EPA allows you to plan ahead in case:

- you lose the mental capacity (see page 69) to make your own decisions about your finances and property
- you aren't physically able to carry out tasks, such as visiting your bank.

These changes could happen if you unexpectedly have an accident or you develop a serious illness.

## An example of an EPA

'My mother Orla created an Enduring Power of Attorney when she updated her will. This meant that when she developed dementia, we were able to pay her bills and manage her finances. We made sure she was cared for at home and her home was kept as she liked it. Because we could do this, my mother was able to die peacefully in her own home, just as she wanted.'

Steve, Orla's son

## Who can make an EPA?

You can only make an EPA if you're aged 18 or over and have mental capacity (see page 69).

## Who can help you make an EPA?

A solicitor will help guide you through the process of making an EPA. When choosing a solicitor, it's best to ask a few to give you an estimate of their costs for drawing up an EPA.

If you wish, you can complete your own EPA. The Office of Care and Protection (see page 94) can give you advice on how to do this.



## Choosing when your EPA becomes effective

When you make an EPA, you share control of your financial affairs and property with your attorney. 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 prefer not to do this, because they may still have mental capacity but not be physically able to manage their banking.

## The power of your attorney

You can restrict the power of your attorney in your 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 personal welfare or medical treatment, or to access your medical records.

## Registering an Enduring Power of Attorney

Before an EPA can be used, it needs to be registered with the Office of Care and Protection. This will need to be done by your attorney when they believe you are no longer able to manage your affairs.

There is a fee to register an EPA.

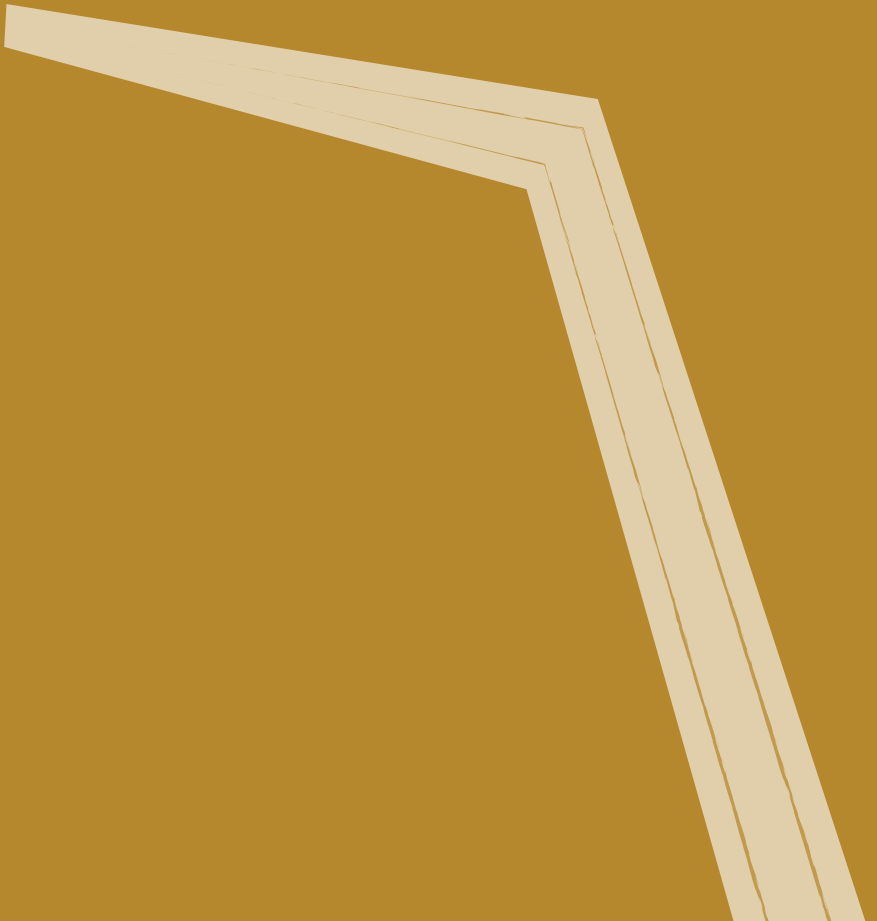
## Cancelling an Enduring Power of Attorney

Sometimes, a person may need to cancel their EPA. For example, you may need to do this if your attorney is no longer able to act on your behalf. You can cancel your EPA at any time, as long as you still have capacity. 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 (see page 94).



# Mental capacity





# Mental capacity

In 2007, the Mental Capacity Act 2005 came into force in England and Wales. The Act does not apply in Northern Ireland, but many of the principles set out in the Act do. These include the principles for assessing a person's capacity to make decisions.

The Act aims to protect people who can't make a decision for themselves. It means that a person can plan ahead for a time when that might happen. It clarifies who can make decisions, in which situations, and how they should go about it.

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

A person will lack capacity if they can't to do any one of the following:

- Understand the information relevant to the decision.
- Retain that information.
- Use or weigh up that information as part of the process of making the decision.
- Communicate their decision – whether by talking, using sign language or in any other way.



# Organ and tissue donation





# Donating your organs and tissue

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

If you have a medical condition such as cancer, a healthcare professional will review your medical history after you have died. Then they will decide if one or more of your organs or tissues are suitable for donation. This means that while you're alive, you won't know whether your organs or tissues will be suitable. Only your family will know this after you have died.

## Corneal transplants

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

The cornea is the clear tissue at the front of each eye. It lets light into the eye and focuses it on the retina so we can see. If the cornea becomes damaged, it may mean you are no longer be able to see.

Corneal transplants 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

You can find out more about organ and tissue donation by visiting the NHS Blood and Transplant website – **organdonation.nhs.uk** They keep a register of people who wish to donate their organs or tissue or both after their death. You can join the register online, by phone or by texting (see page 95).

It's important to discuss donation with the people closest to you. This means that when the time comes, they will find it easier to carry out your wishes.



# Donating your body for medical research and education

Some people want to donate their body for medical research and education. If you're thinking about donating your body, it's important to talk about it with your GP, hospital or community care team. You can also talk about it with your family or close friends.

As part of the donation process, you will be asked to sign a consent form. A copy should be kept with your will.

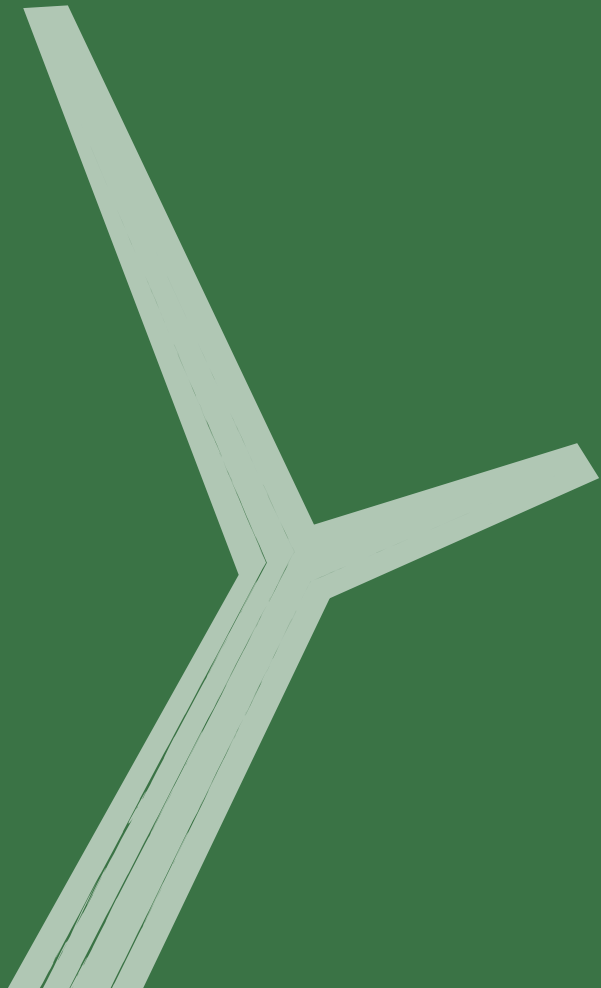
If you want your body tissue to be used for a specific type of research, you need to tell the health and social care professional who is dealing with the consent form. Your wishes need to be written on the consent form.

Not everyone who wishes to donate their body will be able to do so. This may be for medical reasons.

In Northern Ireland, Queens University Medical School is the only medical school that accepts body donations. See page 95 for contact details.



# Funeral planning



## Why plan your funeral?

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

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

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

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

**'I have been thinking about planning my funeral for a long time. I'm well now, but want everything organised and paid for so my family will have no financial worries if anything happened to me.'**

**Eileen**





# Things to think about including in a funeral plan

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

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

- Whether you want to be buried or cremated. A burial is usually in a churchyard or other designated burial place. Cremation takes place in the Belfast Crematorium (see page 88). 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.
- Whether you want to have a spiritual or religious service or not. People who have a spiritual or religious faith often have a clear idea of who they want to conduct the funeral. However, you don't have to have a religious service or a religious leader to conduct a funeral or memorial service. You could choose to have a family member, friend or lay speaker take the service instead.

- Whether you want specific music, songs or readings.
- Whether you want flowers.
- Whether you want donations to be given to specific charities.
- What clothes you want to wear. For some people this can be important. For example, a person may want to wear clothes that have been significant to them during their lives, such as military uniform.

## Recording your funeral plans

You can write your wishes in your will (see pages 26–29). Or you can keep a record of them and leave them in a safe place that your family or friends know about.

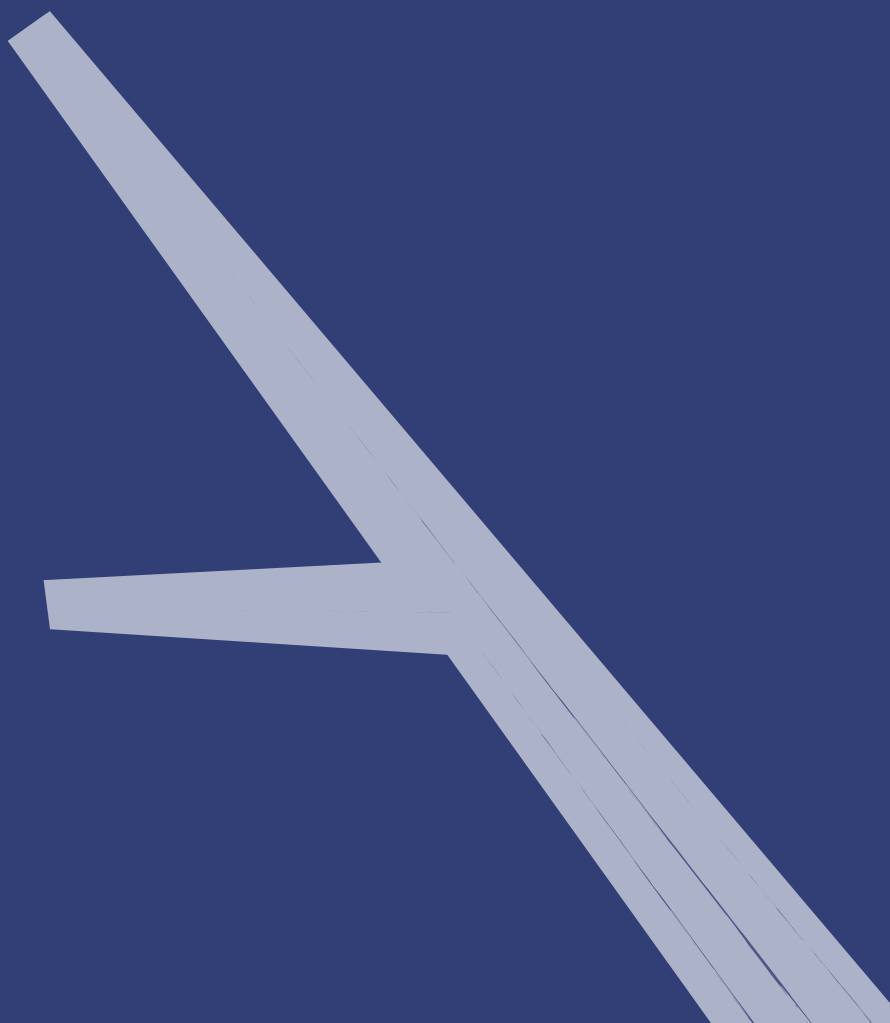
If you don't want to write down your plans, you can simply tell your family members or friends what your wishes are.

## Paying for a funeral

Funerals can be expensive, so you may want to pay for your funeral in advance by taking out a funeral pre-payment plan. You can find out more from your local funeral director or the National Association of Funeral Directors (see page 90). It's best to look into prices first. Make sure you know what services are included in the price, as these can vary.



Managing your  
care if you haven't  
planned ahead



## Best interests decisions

If you haven't planned ahead and something happens, it means you can't make decisions yourself. Instead, other people will need to make decisions for you.

Sometimes a decision may need to be made about your medical care or treatment. No one has the legal authority to consent to medical care or treatment on your behalf. In this situation, a senior healthcare professional will make the decision based on their experience and understanding of your circumstances. They will discuss the decision with your family, friends and anyone else who might be involved in your care.

These decisions are known as best interests decisions. There are several things a healthcare professional should consider when making a best interests decision. These include:

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

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

A best interests decision makes sure all the relevant circumstances about your care are taken into account. It also makes sure that the motives of the person making the decision are proper and in your best interests.

The views of your family and friends will be taken into consideration in any best interests decision. But the final responsibility for the decision remains with the decision maker. Sometimes this means the views of family members are not followed. In this situation, the healthcare professional should explain to the family the law about best interests decisions and the reason for the decision.



# Further information and support





## Further information and support

### **Advice NI**

1 Rushfield Avenue,  
Belfast BT7 3FP

**Tel** 0800 917 4607

**Email** [info@adviceni.net](mailto:info@adviceni.net)

**[www.adviceni.net](http://www.adviceni.net)**

An independent  
advice network.

### **Age NI**

3 Lower Crescent,  
Belfast BT7 1NR

**Tel** 0808 808 7575  
(daily, 8am–7pm)

**[www.ageni.org](http://www.ageni.org)**

Provides information and  
advice for older people  
via the website and  
advice line. Also publishes  
impartial and informative  
fact sheets and advice  
guides.

### **City of Belfast Crematorium**

129 Ballygowan Road,  
Belfast BT5 7TZ

**Tel** 028 9044 8342

**[www.belfastcity.](http://www.belfastcity.gov.uk/crematorium)**

**[gov.uk/crematorium](http://www.belfastcity.gov.uk/crematorium)**

Provides cremation  
services for people living  
in Northern Ireland.

### **Disability Action Belfast**

Portside Business Park,  
189 Airport Road West,  
Belfast BT3 9ED

**Tel** 028 9029 7880

**Email**

[hq@disabilityaction.org](mailto:hq@disabilityaction.org)

**[www.disabilityaction.org](http://www.disabilityaction.org)**

Works to ensure that  
people with disabilities  
attain their full rights as  
citizens, by supporting  
inclusion, influencing  
government policy,  
and changing attitudes  
in partnership with  
disabled people.

## **Dying Matters**

**Tel** 0800 021 4466

**www.dyingmatters.org**

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

## **General Medical Council (GMC)**

9th Floor,  
Bedford House,  
16–22 Bedford Street,  
Belfast BT2 7FD

**Tel** 028 9031 9945

### **Email**

gmcnorthernireland@  
gmc-uk.org

**www.gmc-uk.org**

Registers doctors to practise medicine in the UK. Protects, promotes and monitors the public's health and safety by ensuring proper standards in the practice of medicine.

## **Health and Social Care in Northern Ireland**

**www.hscni.net**

The official gateway to health and social care services in Northern Ireland.

## **Healthtalk**

**www.healthtalk.org**

**www.youthhealthtalk.org**

Both websites have video and audio clips of people talking about their experiences of illnesses and health conditions and their treatments.

## **Humanist**

**Email** info@humanistni.org

**www.humanistni.org**

Humanist Association of Northern Ireland.

Represents non-religious people and supports those who wish to live humanist lives, including providing humanist ceremonies.

Promotes equal treatment in law and policy, regardless of religion and belief.

### **National Association of Funeral Directors**

618 Warwick Road,  
Solihull,  
West Midlands B91 1AA  
**Tel** 0845 230 1343

**www.nafd.org.uk**

Monitors standards of funeral directors in the UK and gives help and advice on what to do in the event of a death. Also advises on arranging funerals and has information on what you should expect from a funeral director.

### **The Natural Death Centre**

In The Hill House,  
Watley Lane,  
Twyford,  
Winchester SO21 1QX  
**Tel** 01962 712690

#### **Email**

contact@naturaldeath.org.uk

**www.naturaldeath.org.uk**

Aims to support those dying at home and their carers. Aims to help people arrange inexpensive, family-organised and environmentally friendly funerals.

### **Patient Client Council**

1st Floor,  
Ormeau Baths,  
18 Ormeau Avenue,  
Belfast BT2 8HS

**Tel** 0800 917 0222

**Email** info.pcc@hscni.net

**www.patientclientcouncil.hscni.net**

Provides an independent voice for people on health and social care issues.

### **Patient UK**

**www.patient.co.uk**

Provides people in the UK with information about health and disease.

## **Public Health Agency**

Linenhall Street Unit,  
12–22 Linenhall Street,  
Belfast BT2 8BS

**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 individuals, communities and others to achieve this.

## **Think Ahead**

**www.thinkahead.ie**

Aims to guide people to discuss and record their preferences in the event of an emergency, serious illness or death.

## **Counselling and emotional support**

### **British Association for Counselling and Psychotherapy (BACP)**

BACP House,  
15 St John's Business Park,  
Lutterworth,  
Leicestershire LE17 4HB

**Tel** 01455 883 300

**Email** [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

**www.bacp.co.uk**

Promotes awareness and availability of counselling, and advises people about appropriate services.

You can search for a counsellor on the website.

## Support for specific health conditions

### British Heart Foundation

Admail 3987,

Belfast BT1 1TG

**Tel** 0300 330 3322

**Email** ni@bhf.org.uk

**www.bhf.org.uk**

Supports people affected by heart conditions.

### British Lung Foundation

#### Email

northernireland@blf.org.uk

**www.blf.org**

**Helpline** 03000 030 555

#### Helpline email

helpline@blf.org.uk

Supports people affected by any type of lung disease.

### Cancer Focus

#### Northern Ireland

40–44 Eglantine Avenue,

Belfast BT9 6DX

**Tel** 028 9066 3281

#### Email

hello@cancerfocusni.org

**www.cancerfocusni.org**

Offers a variety of services, including a free helpline, counselling and links to local support groups.

### Macmillan

#### Cancer Support

89 Albert Embankment,

London SE1 7UQ

#### Support line

0808 808 00 00

(Mon–Fri, 9am–8pm)

**www.macmillan.org.uk**

Improves the lives of people affected by cancer. Provides support through practical, medical, emotional and financial help. A force for change, listening to people affected by cancer and working with them to improve cancer locally and nationally. Provides information about different cancer types, tests and treatments and living with cancer.

Has an online community where you can share your experiences, ask questions, get and give support to others at **macmillan.org.uk**

**uk/community**

**Marie Curie  
Northern Ireland  
Marie Curie Support Line**

0800 090 2309  
(Mon-Fri, 8am-6pm,  
Sat 11am-5pm)

**[www.mariecurie.org.uk/  
help](http://www.mariecurie.org.uk/help)**

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.

**Motor Neurone Disease  
Association (NI)**

5 Brooklands Drive,  
Newtownards BT23 4YX

**Tel** 028 9181 9101

**[www.mndani.com](http://www.mndani.com)**

Supports people with motor neurone disease and those caring for them.

**Northern Ireland Chest,  
Heart and Stroke**

21 Dublin Road,  
Belfast BT2 7HB

**Tel** 028 9032 0184

**Email** [mail@nichs.org.uk](mailto:mail@nichs.org.uk)

**[www.nichs.org.uk](http://www.nichs.org.uk)**

Provides support for people living with chest, heart or stroke conditions. Also provides support groups and programmes to promote health.

**Support for carers**

**Carers Northern Ireland**

58 Howard Street,  
Belfast BT1 6JP

**Tel** 02890 439 843

**[www.carersuk.org/  
northernireland](http://www.carersuk.org/northernireland)**

Offers information and support to carers.

## Money or legal advice and information

### Benefit Enquiry Line Northern Ireland

**Tel** 0800 220 674

(Mon–Wed and Fri,  
9am–5pm, Thu, 10am–5pm)

**Textphone** 0800 243 787

**[www.nidirect.gov.uk/  
money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)**

Provides advice and information for disabled people and carers on the range of benefits available.

### Citizens Advice

46 Donegall Pass,  
Belfast BT7 1BS

**www.**

**[citizensadvice.co.uk](http://citizensadvice.co.uk)**

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

### The Law Society of Northern Ireland

96 Victoria Street,  
Belfast BT1 3GN

**Tel** 028 9023 1614

**[www.lawsoc-ni.org](http://www.lawsoc-ni.org)**

Represents and can provide details of solicitors in Northern Ireland.

### nidirect Government Services

**[www.nidirect.gov.uk](http://www.nidirect.gov.uk)**

The official government website for Northern Ireland citizens.

### The Office of Care and Protection (OCP)

Room 2.2A,

2nd Floor,

Royal Courts of Justice,  
Chichester Street,

Belfast BT1 3JF

**Tel** 030 0200 7812

**[www.courtsni.gov.uk](http://www.courtsni.gov.uk)**

Helps people without mental capacity manage their property and financial affairs, under Part VIII of the Mental Health (Northern Ireland) Order 1986.

## Organ, tissue and body donation

### Human Tissue Authority

151 Buckingham  
Palace Road,  
London SW1W 9SZ

**Tel** 020 7269 1900

#### **Email**

[enquiries@hta.gov.uk](mailto:enquiries@hta.gov.uk)

**[www.hta.gov.uk](http://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.

### NHS Blood and Transplant

Fox Den Road,  
Stoke Gifford,  
Bristol BS34 8RR

**Tel** 0300 123 2323

**[www.organdonation.nhs.uk](http://www.organdonation.nhs.uk)**

**[nhs.uk](http://nhs.uk)**

Manages the organ donor register.

### Northern Ireland Organ Donation Services Team

**Tel** 0300123 1208

**www.**

**[organdonationni.info](http://organdonationni.info)**

### Queens University Medical School Centre for Biomedical Sciences Education (Anatomy Office)

**Tel** (028) 9097 2131

**Email** [anatomy@qub.ac.uk](mailto:anatomy@qub.ac.uk)

**[www.qub.ac.uk/schools/mdbs/bms/AboutUs/](http://www.qub.ac.uk/schools/mdbs/bms/AboutUs/)**

#### **BodyBequest**

Accepts body donations for research and medical teaching.



## Hospices

### Foyle Hospice

61 Culmore Road,  
Londonderry,  
Northern Ireland BT48 8JE  
**Tel** 028 7135 1010

#### **Email**

care@foylehospice.com  
**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.

### Macmillan Specialist Palliative Care Unit

Antrim Area Hospital,  
Bush Road,  
Antrim BT41 2RL

**Tel** 028 9442 4394

**www.northerntrust.hscni.net/services/1616**

A specialist palliative care inpatient unit in the grounds of Antrim Area Hospital.

### Marie Curie

#### **Hospice Belfast**

Kensington Road,  
Belfast BT5 6NF

**Tel** 028 9088 2000

#### **Email**

belfast.centre@mariecurie.org.uk

**www.hospicebelfast.mariecurie.org.uk**

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.

### Northern Ireland Hospice

**www.nihospice.org**

Provides specialist palliative care to adults and children with life-limiting and life-threatening illnesses.

#### **Adult services**

Whiteabbey Hospital  
Grounds,  
Doagh Road,  
Newtownabbey  
BT37 9RH

**Tel** 028 9078 1836

### **Children's hospice**

Horizon House,  
18 O'Neill Road,  
Newtownabbey  
BT36 6WB

**Tel** 028 9077 7635

### **Southern Area Hospice Services**

St John's House,  
Courtney Hill,  
Newry,  
Co Down BT34 2EB

**Tel** 028 3026 7711

**[www.northernareas  
hospiceservices.org](http://www.northernareas<br/>hospiceservices.org)**

Provides comprehensive  
specialist palliative care  
to patients with terminal  
illnesses.

## 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's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr Sara Booth, Macmillan Consultant in Palliative Care.

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This booklet has also been reviewed by Alphy Maginness, a legal adviser from Northern Ireland.

## Sources

We've listed a sample of the sources used in the publication below. If you'd like further information about the sources we use, please contact us at **[bookletfeedback@macmillan.org.uk](mailto:bookletfeedback@macmillan.org.uk)**

Alzheimer's society. Northern Ireland factsheet: Financial and legal tips. [www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2290](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2290) (accessed November 2015)

Mental Capacity Act 2005. [www.legislation.gov.uk](http://www.legislation.gov.uk) (accessed November 2015).

NHS Improving Quality. Capacity, care planning and advance care planning in life limiting illness: A Guide for Health and Social Care Staff. <http://www.nhs.uk/qualityimprovement/publications/eolc-ccp-and-acp.aspx>

NI Direct. Arranging a funeral. [www.nidirect.gov.uk/arranging-a-funeral](http://www.nidirect.gov.uk/arranging-a-funeral)

NI Direct.gov.uk. Managing your affairs and enduring power of attorney. [www.nidirect.gov.uk/managing-your-affairs-and-enduring-power-of-attorney](http://www.nidirect.gov.uk/managing-your-affairs-and-enduring-power-of-attorney)

Organ donation Northern Ireland. [www.organdonationni.info/homepage](http://www.organdonationni.info/homepage) (accessed December 2015)

# Your notes and questions

**You could use this page to write down any questions you want to ask your doctor or nurse, and then to write down the answers you receive.**

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