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.

This booklet, which was produced by the Public Health Agency and Macmillan Cancer Support, includes information on:

- Advance Care Plans – these are your wishes about how you would like to be cared for at the end of your life (see pages 27–33)

- 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 35–38)

- Advance Decisions to Refuse Treatment (Advance Directives) – these are your decisions about specific treatments that you don’t want to have (see pages 39–51).

It also has information about making a will, organ and tissue donation, and planning your funeral.

Planning for your future care is important in case you ever become unable to make choices yourself, for example if you were to become unconscious or lose capacity (the ability) to make decisions about treatment.

We hope this booklet answers some of your questions and helps you deal with some of the feelings you may have.
Getting the most out of this booklet

To get the most out of this booklet, you may want to read it all through first and then concentrate on the sections that are most helpful for you. We can’t advise you about the best ways to plan ahead for yourself. You may find it helpful to discuss what’s best for you with a health and social care professional, and someone close to you. You may also want to discuss this information with someone from one of the organisations listed on pages 63–71.

After reading this booklet, you may not want to plan ahead. Or you may need more time to think about it, or want to discuss it with someone else. That’s fine – it’s your decision.

At the end of this booklet there are some useful addresses and helpful websites (see pages 63–71). There’s also a page to fill in with any questions you might like to ask a health and social care professional (page 72).

There are also two documents at the back of this booklet that you can use to help you think about and write down some of your wishes and decisions for your future care:

- What’s important to me You can use this document to make notes about what’s important to you for your care at the end of your life. Your notes will provide helpful information for your Advance Care Plan (see pages 27–33).

- My Advance Decision to Refuse Treatment You can use this document to record your decision to refuse specific treatments (see pages 39–51).
Throughout the booklet we’ve included quotes and case studies that you may find helpful. Some names have been changed. Some of these are from people 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). On pages 32–33 there’s a case study about Dennis, who wrote an Advance Care Plan. Throughout this booklet we’ve included photos of Dennis’s family.
We hope our booklet supports you to plan ahead for your future care.

Adrienne, Macmillan Programme Manager and Dennis’s daughter-in-law
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Your life and your choices: plan ahead
Planning ahead

Planning ahead is important for anyone, regardless of whether they have an illness or not.

Many people think they don’t need to make decisions about their future care unless they reach a time when they know that an illness, such as advanced cancer or heart failure, can no longer be treated.

However, planning ahead is important for anyone, regardless of whether they have an illness or not. This is because none of us can say for sure whether we’ll always be able to make our own decisions about our care. For example, some people may become very ill unexpectedly. They may then be unable to make decisions about their health or social care, or make any financial plans for their close family or friends.

Living with cancer, motor neurone disease, chronic obstructive pulmonary disease, heart failure or any other long-term illness may start you thinking about your future care and what you’d want to happen if you were to become seriously ill. Even if you’ve been cured of an illness, it’s still helpful to think about the future.

You can talk through your wishes or other plans with a professional and a family member or friend you trust. Remember that you’re the expert on you, and only you can know exactly how you’d like to be cared for.
Ways to plan ahead

There are several ways people can make plans in advance. Although we list several ways here, 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 one way to make sure that your wishes are carried out after you die and that your family and friends are provided for in the way you want. A will includes who you would like your property, personal possessions and monies to go to after you die. It may also include who you’d like to look after any dependants you have and any specific funeral arrangements you want. Turn to pages 21–26 for further information about making a will.

Advance Care Plans
You can use a document known as an Advance Care Plan to write down your wishes for your care when you’re reaching the end of your life. It can include your choice about where you would like to be cared for, for example at home, in a hospital, care home or hospice. The document means those caring for you will know what you’d prefer, so they can plan your care according to your wishes, if this is possible. An Advance Care Plan is not legally binding, but it will be taken into account if you aren’t able to make decisions for yourself. There’s more information about Advance Care Plans on pages 27–33.
Enduring Power of Attorney
Creating an Enduring Power of Attorney means putting in writing the name of someone you trust to make decisions about or manage your property and financial affairs. The person you name can make decisions on your behalf if you become unable to do so because you lack mental capacity (see below). You may lose mental capacity because of an accident, injury or serious illness.

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 35–38.

Mental capacity
Having mental capacity means that you’re able to understand the decision you’re making. You need to be able to remember and process any information that’s relevant to making the decision. You also need to be able to weigh up this information, make a decision and communicate it 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 be 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 some questions to help them assess it.

There’s more information about mental capacity and how it’s assessed on pages 61–62.
Advance Decisions to Refuse Treatment
You can also prepare a document that records your decisions for any treatment you don’t want to have, should you ever become unable to let your doctors or family know yourself. This is known as an Advance Decision to Refuse Treatment (see pages 39–51), but it may also be called an Advance Directive. An Advance Decision to Refuse Treatment is legally binding.

Organ and tissue donation
Some people choose to write down any wishes they have for organ and tissue donation or donating their body for medical research. You can read more on pages 53–54.

Your plans for after you die
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. You can also pay for your funeral in advance. We have more information about this on pages 55–57.

Why is planning ahead important?
Planning ahead is important because it’s not always possible for health and social care professionals to know exactly how you would like to be cared for in certain situations. This could be if you were unwell and unable to talk to them, or if you were unable to make decisions about your care, for example if you were unconscious.

If you haven’t planned ahead and you lose the capacity to make decisions and can’t tell your health professionals what you want, they will act in your best interests. This means
they will plan care for you based on their experience and understanding of your situation, and through discussion with your family and friends. They will take account of other things too, such as your circumstances. This is known as a best interests decision (see pages 59–60). Although a best interests decision takes all this into account, it won’t necessarily be the same as the decision you would have made yourself.

Who can help you with planning ahead?

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

For many people with 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’s important that you don’t feel alone when planning ahead. Remember that health and social care professionals can help you, as well as your family and friends.

Professionals
There are many professionals who can help you with planning ahead. You can ask your GP, district nurse, specialist nurse, social worker or your hospital doctor who is the best person to speak to about planning ahead.

It’s fine for you to raise the subject with one of these professionals. However, it might feel difficult to know how
to begin. 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?’

If you’re thinking about making a will, you should contact a solicitor.
Family and friends
Involving people who are close to you, such as your family and friends, can be really helpful. They may be able to help you think through some of the issues, so that you can plan ahead better. It’ll also be good for them to know what your wishes are, so they can help make sure they’re carried out.

If your plans involve your family or friends taking on more responsibility for your care – for example if you want to die at home and need them to look after you – it’s important to discuss this with them. 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 support that might be available to help them, and about other care options.

Sometimes family and friends don’t want to talk about planning ahead. They may appear to ignore the fact that you want to think about the future, perhaps by playing down your anxieties and changing the subject. If this upsets or hurts you, try telling them. Perhaps start by reassuring them that this is something you want to do and that it will help if you could talk to them about it. You could try saying something like this:

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

Planning ahead can stir up emotions, particularly if you’re already coping with an illness. These feelings can include sadness, anxiety and fear. These are normal reactions that people often have when coping with uncertainty about their future. Even if you’re feeling well, thinking about how you’d like to be cared for if you were to become seriously ill can stir up all sorts of feelings.

There are many people who can help you cope with your emotions. Talking to a close family member or trusted friend can help. Health and social care professionals can also give you support – this includes your GP, social worker, specialist nurse and hospital doctor. They can also tell you what support is available locally.

Some people may be offered counselling. This can be very helpful, particularly if you don’t feel able to discuss your feelings and emotions with people close to you.

Although planning ahead can be hard, it can help relieve anxiety and fear by giving you a greater sense of control over your life and your future.

How to plan ahead

Planning ahead can be carried out in simple steps. Don’t feel you need to follow all these steps in order – just do what feels right for you and take your time:
• Find out about the different ways you can plan ahead. You can find more information in this booklet, or you may want to contact one of the organisations listed on pages 63–71. The professionals involved in your care can also help.

• Identify the ways you’d like to plan ahead. You may want to:
  • make a will
  • write an Advance Care Plan
  • create an Enduring Power of Attorney
  • document an Advance Decision to Refuse Treatment (Advance Directive)
  • register your wishes for organ and tissue donation
  • make a plan for after you die (a funeral plan).

Remember that it’s up to you whether you use one or two of these ways to plan ahead or all of them.

• Talk to your family and friends. They’ll be able to help you clarify your plans, and it may also help them feel involved.

• Arrange to speak to a health and social care professional to discuss the ways you’d like to plan ahead. It may take some time to discuss your plans and talk it all through. The professional won’t expect you to rush into making any plans unless you’re sure about them. Some people take many months before they feel happy to make plans for their future care or treatment.
• When you’ve decided what plans you’d like to make, it’s best if you write them down. You can use the documents at the back of this booklet: What’s important to me and My Advance Decision to Refuse Treatment. What’s important to me will help you think about your wishes for your care if you were to become seriously ill. You may want to fill this in before you speak to a health and social care professional about completing an Advance Care Plan.

• If you want to make a will or create an Enduring Power of Attorney, it’s a good idea to see a solicitor, as these are important legal documents. A solicitor will also help you with writing an Advance Decision to Refuse Treatment.

• Keep all your documents in a safe place and make sure your family, friends and health and social care team can find them easily. Your health and social care team may ask you for permission to share your written plans with other professionals who may need to be involved in your care.

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

• Remember that you can change the plans you’ve made at any time. If you do change them, make sure everyone involved in your care knows. You should also document your new wishes, even if this isn’t a legal requirement for the particular plan you want to change. Documenting your wishes makes sure everyone involved in your care knows what they are.
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 (property, personal possessions and money) to can’t be guaranteed.

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

Involving a solicitor

Having a professionally written will can help reduce any problems or disputes in the future. It’s best to use a solicitor when making or updating your will to make sure all legal procedures are followed. The process doesn’t have to be lengthy or expensive. It’s worth shopping around or asking for a quote before committing yourself to a specific solicitor.

If you need help to find a local solicitor you can contact the Law Society of Northern Ireland (see page 69).
Things to think about when making your will

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

The value of your estate and what you have to leave in your will
You may want to start by making a list of everything you own (your assets) and how much they’re worth. This might include your house, car, jewellery, bank and building society accounts, savings accounts and life insurance policies.

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

Add together your total assets and subtract the amount of your total liabilities to find the value of your estate.

Who to include in your will
Make a list of the family and friends you want to remember in your will and consider what you want to leave them. For example, you might want to give a particular person a specific amount of money, or an item with real or sentimental value, such as a piece of jewellery. You may also want to consider leaving money to a charity.
Other important information to include in your will
You can also include who you want to appoint as your executors (people responsible for settling your affairs) and who you want to look after your dependants. If your dependants are children under the age of 18, you can include in your will who you want to take care of them. The person or people you choose to do this are known as their legal guardian(s). Sometimes guardianship arrangements for children can be complicated if you’re a parent who’s separated or divorced from your spouse or you’re unmarried. In this situation, it’s best to take advice from a solicitor.

If you have pets, you can give details of who you want to look after them.

Your will can also include any specific funeral instructions you have.

You can get more information about making a will from organisations such as Age NI (see page 63) and the Law Society of Northern Ireland (see page 69).
Meeting with a solicitor

When you meet with your solicitor it will help to take your completed lists of what you have to leave and who you want to include in your will, and the names of your executors and any guardians for your children.

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

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

Leave your up-to-date will somewhere it will be secure and easily found, for example with your solicitor. Keep a copy for yourself and make sure your executors know where it is.
‘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
Advance Care Plans

An Advance Care Plan is a document where you can record your wishes and preferences for your health and social care.

Documenting your wishes means that health and social care professionals know how you’d like to be cared for if you ever become seriously ill and unable to tell others what you want to happen. Although this record of your wishes isn’t legally binding, it will be very helpful for health and social care professionals when they make decisions about your care.

Before you write down your wishes and preferences, it can help to talk through your plans with your family or a close friend. This can be particularly helpful if you want them to be involved in your care or make decisions on your behalf. You should also talk through your plans with one or two of the professionals looking after you, such as your GP or specialist nurse.

It’s important to talk to your health and social care professionals and the people close to you about whether your wishes are realistic. If they aren’t, try to think of some alternatives. For example, if you would prefer to die at home but don’t have a family member or close friend who’d be able to support you at home, 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 over-tired they may be unable to care for you. In this situation, health and social care professionals may be able to arrange care for you so that you can stay at home. However, if this isn’t possible they’ll plan for you to receive the best possible care somewhere else, for example in a care home or hospice.

What to include in your Advance Care Plan

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

For example, you could include the following:

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

• What kind of care you would like. However, bear in mind that you can’t demand particular treatments.

• Where you’d like to be cared for when you’re dying, for example at home, or in a hospital, care home or hospice.

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

• Which family members or close friends you would like to be involved in your care.
• Who you would like to act on your behalf if decisions need to be made about your care.

• Who you would like to look after any pets.

• Whether you would like someone to tell you how serious your condition is and the likely prognosis.
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: *23.09.13*
Who can give you an Advance Care Plan?

Ask one of your health and social care professionals to give you an Advance Care Plan document. They will give you the specific document that’s used in the area where you live.

If you like, you can use the What’s important to me document at the back of this booklet to make notes about your wishes for your care. These notes will be helpful when you come to record your wishes in your Advance Care Plan.

Keeping your Advance Care Plan

Always keep your written Advance Care Plan in a safe place so it can be easily found by those involved in your care. Remember to regularly review your choices and keep them up to date.

Sharing your Advance Care Plan

Share your Advance Care Plan with anyone who is, or is likely to be, involved in your care, such as a family member, close friend, GP, nurse or hospital doctor.

If you’re admitted or transferred to a hospital or hospice, take your Advance Care Plan with you so the staff know what your wishes and preferences are for your care.

Changing your mind about your Advance Care Plan

You can change your mind about your Advance Care Plan at any time, but remember to record your changes. You’ll need to let your family and your health and social care professionals know and give them an updated copy of the document.
'In February my father-in-law Dennis was diagnosed with small cell lung cancer. Unfortunately the treatment didn’t work, and in August the doctors told him that he wouldn’t benefit from any further active treatment. Although disappointed, Dennis was relieved to stop as it was exhausting him.

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

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

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

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

Adrienne, Dennis’s daughter-in-law
Your life and your choices: plan ahead
Enduring Power of Attorney

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.

Having an EPA allows you to plan ahead in case:

• you lose the mental capacity (see page 9) 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.

The people chosen to make decisions on your behalf are known as attorneys. You can have more than one attorney.
An example of an Enduring Power of Attorney

‘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 Enduring Power of Attorney?

You can only create an EPA if you’re aged 18 or over and have mental capacity (see page 9).

Who can help you make an Enduring Power of Attorney?

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 69) can give you advice on how to do this.
Choosing when your Enduring Power of Attorney becomes effective

When you create 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’re no longer able to manage your affairs. There is a fee to register an EPA.
Cancelling an Enduring Power of Attorney

Occasionally 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, providing 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 69).
Advance Decisions to Refuse Treatment (Advance Directives)

An Advance Decision to Refuse Treatment is a set of instructions from you to your medical team. It sets out the specific circumstances in which you would:

- not want certain treatments
- want a particular treatment to be stopped.

It’s a way of making sure everyone knows what treatments you don’t want or what treatments you want stopped, in case there’s ever a time when you can’t make decisions for yourself.

If you have an illness that may get worse, it’s not unusual to think about your future and the care you may need, if and when your condition changes. Usually you’ll be able to talk to your health and social care professionals about the care you want. However, there may come a time when you’re unable to make decisions about your treatment or care, or to tell others what you want. For example, this may happen if you were to become unconscious. An Advance Decision only comes into effect if you aren’t able to make decisions for yourself.
There are a number of benefits to making an Advance Decision:

- It can help you feel more in control of your circumstances and future care.
- It can help you avoid taxing treatments that may not always be helpful anyway.
- It means your family and health and social care team will know what you want and can respect your wishes.
- It can help avoid disagreements about your care and treatment within your family or health and social care team.

**What an Advance Decision to Refuse Treatment can’t do**

An Advance Decision 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.

It also can’t be used to request that your life be brought to an end.
Advance Decisions to Refuse Treatment and the law

In Northern Ireland an Advance Decision is legally binding, although it’s governed by common law instead of an Act. This means it must be followed by your health and social care team, provided they know about it.

It 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 9), and 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 Advance Decision to Refuse Treatment?

An Advance Decision to Refuse Treatment can be made by anyone over 18 years old who has the capacity to do so (see page 9).
Who should be involved?

Before making an Advance Decision to Refuse Treatment, it’s important to discuss the decisions you’d 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 who’s looking after you at the hospital. They will be able to tell you what the likely effects of stopping a treatment are and will make sure your Advance Decision meets the requirements of the law.

A solicitor can also discuss Advance Decisions to Refuse Treatment with you and help you write one.

Preparing an Advance Decision to Refuse Treatment

Although an Advance Decision to Refuse Treatment can be made verbally (spoken), it’s better if you write it down. This helps avoid confusion later on. There are certain situations where it must be in writing, for example if it refuses a treatment that will keep you alive, such as having your heart restarted (resuscitation) or being put on a breathing machine (ventilator).

It’s always important to carefully weigh up any decision you make to refuse treatment. Always talk it over and discuss your wishes and preferences with your doctor or nurse and family beforehand. Your health and social care team will be able to tell you about the benefits and any potential risks associated with the advance decisions you wish to make. They can help you take your time so that you’re sure about the decisions you make.
You’ll also need to be clear about the circumstances in which you would want the Advance Decision to be acted on. For example, you may want it acted on if you were to become unconscious and unlikely to recover from your illness. The discussion you have with your doctor or nurse will help you identify these circumstances.

Here are some examples of treatments that you may want to refuse if you were to become unconscious and unlikely to recover from your illness:

- Being given antibiotics for an infection if you were only expected to live for a few days.

- Being fed or given fluids artificially (through feeding tubes and drips) if you were unable to swallow food and drink in the normal way.

- Having your heart restarted if it stopped beating.

- Being put on a breathing machine if your breathing failed.

You or your family may find it distressing to think about these things. So get as much support as you need from your health and social care team, family and friends.
What to include in an Advance Decision to Refuse Treatment

It’s best to include the information below when writing an Advance Decision. Any Advance Decision that refuses life-sustaining treatment must contain all the information below:

- Your name, date of birth, address and any distinguishing features. This is in case you’re 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 Advance Decision to Refuse Treatment document.

- A statement saying that the document should be used if you ever lack capacity to make decisions.

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

- The date your Advance Decision was created.

- Your signature (if it’s a written statement).

- A dated signature of at least one witness. Two witness signatures are usually preferred if it’s a written statement. The witness(es) should be over the age of 18.

- If it’s 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’. See the examples on the next pages.
An example of an Advance Decision to Refuse Treatment from someone with cancer

My Advance Decision to Refuse Treatment

<table>
<thead>
<tr>
<th>I wish to refuse the following specific treatments</th>
<th>In these circumstances</th>
</tr>
</thead>
<tbody>
<tr>
<td>I refuse cardiopulmonary resuscitation if my heart and lungs stop functioning, even if my life is at risk as a result.</td>
<td>If I have terminal cancer and my heart and lungs stop functioning in a way that allows me to breathe spontaneously.</td>
</tr>
<tr>
<td>I refuse artificial feeding or hydration, even if my life is at risk as a result.</td>
<td>If I have terminal cancer, become unconscious and am unable to swallow food or fluids unaided.</td>
</tr>
</tbody>
</table>
An example of an Advance Decision to Refuse Treatment from someone with motor neurone disease

<table>
<thead>
<tr>
<th>My Advance Decision to Refuse Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>I wish to refuse the following specific treatments</td>
</tr>
<tr>
<td><em>I refuse assisted ventilation (breathing using a machine), even if my life is at risk as a result.</em></td>
</tr>
<tr>
<td><em>I refuse artificial feeding or hydration, even if my life is at risk as a result.</em></td>
</tr>
</tbody>
</table>
Writing an Advanced Decision to Refuse Treatment

You can use the Advance Decision to Refuse Treatment document at the back of this booklet to write your ADRT. This form has been adapted from the National End of Life Care Programme’s Advance Decision to Refuse Treatment form. The document sets out all the information you need to include in your Advance Decision.

Occasionally a person may wish to refuse a specific treatment in all circumstances, rather than identifying specific circumstances. For example, you may want to refuse a specific medication 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 must talk this through with a healthcare professional first. In some situations, refusing a treatment in all circumstances may cause more suffering and distress.

Who should know about my Advance Decision to Refuse Treatment?

When you’ve made your Advance Decision to Refuse Treatment, it’s important to let the people caring for you know about it. This will usually include your health and social care professionals, family and friends. This can help avoid any confusion if there’s a change in your condition. People often keep copies at home, and with their GP or a specialist nurse. Your health and social care professional can advise you about who else should know about it.
Reviewing your Advance Decision to Refuse Treatment

Remember to review your Advance Decision regularly so you can be sure it’s up-to-date and reflects your current wishes. This is important as your wishes may change if your circumstances change.

If you decide to cancel your Advance Decision, let your health and social care professionals and the people close to you know.

Questioning an Advance Decision to Refuse Treatment

Occasionally there may be situations when a doctor does not act on, or questions whether it’s right to act on, an Advance Decision to Refuse Treatment. For example, this might happen if:

• what you say you want in your Advance Decision is inconsistent with your current lifestyle – for instance, you may have changed your religion since you wrote the Advance Decision

• medical circumstances have changed since you made your Advance Decision – for instance, a recent development in treatment becomes available that strongly improves your outlook (prognosis), and may have led you to make a different decision, had you known about it.
Your Advance Decision to Refuse Treatment may also be questioned or overturned if:

- you made your Advance Decision at a time when you didn’t have the required mental capacity
- it’s believed that you were influenced by others to make the Advance Decision.

An example of an Advance Decision to Refuse Treatment

‘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 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
Organ and tissue donation

Many people think that if they have a serious medical condition, then they can’t donate their organs (such as a kidney) or tissue (such as the corneas of the eyes) to another person when they die. But having a serious medical condition doesn’t necessarily exclude you from being an organ donor. You can also usually donate tissue or your body for medical research (see below and on the next page).

To find out more about organ and tissue donation and whether it’s possible for you to be a donor, speak to your health and social care professionals. You can also visit the NHS Blood and Transplant website – organdonation.nhs.uk They keep a register of people who wish to donate their organs and/or tissue after their death. You can join the register online or by phoning NHS Blood and Transplant (see page 70).

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

Corneal transplants

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. The cornea is usually suitable for donation if a person dies with a medical condition such as cancer, heart failure or COPD.
When the cornea becomes diseased or injured, vision can be lost. In this situation corneal transplants, which replace the diseased or injured tissue with a disc of healthy tissue from a donor’s eye(s), can successfully restore a person’s sight.

Donating your body for medical research

Some people want to donate their body for medical research. If you’re thinking about donating your body, it’s important to discuss this with your GP, hospital or community care team, and with your family or friends closest to you. As part of the donation process, you and your next of kin will be asked to sign a consent form. You can get this form from your local medical school. A copy should be kept with your will.

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

Not everyone who wishes to donate their body will be able to. The Human Tissue Authority (see page 70) can give you more information about donating your body for medical research.
Your plans for after you die

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 someone’s death
- celebrate their life
- say goodbye.

Why plan your funeral?

Many people die without making any plans for their funeral. For family or close friends who are left behind, arranging a funeral can be stressful if they don’t know exactly what type of funeral a person wanted or how they wanted it carried out.

If you tell your family or friends what you want, your funeral is much more likely to reflect 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
Your life and your choices: plan ahead

Things to consider

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

Here are some suggestions of what you may want to include in your plans:

• Whether you want a burial or cremation. Burial is usually in a churchyard or other designated burial place. Cremation takes place in the Belfast Crematorium (see page 63). It has a chapel where a service can be held. After a cremation, your ashes are given in a container to your next of kin. You can discuss with your family what you want to be done with your ashes. For example, you may choose to have them scattered in a favourite place.

• Whether you want to have a 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 a military uniform.

Recording your funeral plans

You can document your wishes in your will (see pages 21–26), or you can keep a record of them and leave them in a safe place known to your family or friends. Alternatively, if you don’t want to write them down, 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 65). 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 that means you’re unable to make decisions yourself, other people will need to make decisions for you. Sometimes a decision may need to be made about your medical care or treatment. No person has the legal authority to provide consent to medical care or treatment on your behalf. So, in this situation, a senior health professional would make the decision based on their experience and understanding of your circumstances. They would 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 health professional should take into consideration when making a best interests decision. They include:

- all the relevant circumstances
- your past and present wishes and your values and beliefs, if these are known or can be found out
- 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 ensures 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.

While the views of family members and friends will be taken into consideration in any best interests decision, the final responsibility for the decision remains with the decision maker – a senior health professional. Occasionally, this will mean the views of family members are not followed. In this situation, the health professional should explain to the family the law regarding best interests decisions and the reason for the decision.
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, for example 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 they may not be able to make decisions themselves. It clarifies who can make decisions, in which situations, and how they should go about it.
The Act states that a person lacks capacity if they are unable to make a decision for themselves – in relation to a specific matter – because of an impairment of, or a disturbance in, the functioning of the mind or brain.

A person will lack capacity if they’re unable 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 any other means).

The British Medical Association and the General Medical Council (see page 64) provide guidance for doctors on assessing mental capacity.
Further information and support

Advice NI
1 Rushfield Avenue,
Belfast BT7 3FP
Tel 028 9064 5919
Email info@adviceni.net
www.adviceni.net
An independent advice network.

Age NI
3 Lower Crescent,
Belfast BT7 1NR
Tel 0808 808 7575
(daily, 8am–7pm)
www.ageuk.org.uk/northern-ireland
Provides information and advice for older people via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

British Humanist Association
1 Gower Street,
London WC1E 6HD
Tel 020 7324 3060
www.humanism.org.uk
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.

City of Belfast Crematorium
129 Ballygowan Road,
Belfast BT5 7TZ
Tel 028 9044 8342
www.belfastcity.gov.uk/crematorium
Provides cremation services for people living in Belfast and elsewhere in Northern Ireland.
Disability Action Belfast
Portside Business Park,
189 Airport Road,
Belfast BT3 9ED
Tel 028 9029 7880
Email
hq@disabilityaction.org
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.
Healthtalkonline
www.healthtalkonline.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.

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, Lesley House,
25–27 Wellington Place,
Belfast BT1 6GD
Tel 0800 917 0222
Email info.pcc@hscni.net
www.patientclient
council.hscni.net
Provides an independent
voice for people on health
and social care issues.

Patient UK
www.patient.co.uk
Provides non-medical people
in the UK with information
about health and disease.
Public Health Agency
Linenhall Street Unit,
12–22 Linenhall Street,
Belfast BT2 8BS
Tel 028 9032 1313
www.publichealth.hscni.net
Protects public health and improves the health and social well-being of people in Northern Ireland. Reduces inequalities in health and social well-being through targeted, effective action. Builds strong partnerships with individuals, communities and other key stakeholders to achieve tangible improvements in health and social well-being.

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
www.bacp.co.uk
Promotes awareness and availability of counselling, and signposts people to 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**
7 Rickett Street,
Belfast BT9 6XS
Email
northernireland@blf.org.uk
www.blf.org
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/community
Motor Neurone Disease Association
5 Brooklands Drive, Newtownards BT23 4YX
Tel 028 9181 9101
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
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
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
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
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
Represents and can provide details of solicitors in Northern Ireland.

nidirect
government services
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 028 9072 4733
www.courtsni.gov.uk
The department of the court with responsibility for the administrative work associated with 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
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
Manages the organ donor register.

Foyle Hospice
61 Culmore Road, 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, in-patient 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 in-patient unit in the grounds of Antrim Area Hospital.

Northern Ireland Organ Donation Services Team
12A Clarendon Road, Belfast BT1 3BG
Tel 028 9051 8917
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 in-patient 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.northernareaeshospiceservices.org
Provides comprehensive specialist palliative care to patients with terminal illnesses.
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.
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.

Thanks

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Sources


