

Planning for the future

Information for people who have an advancing neurological illness



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Introduction

This booklet is for people who have an advancing neurological illness, and who want to make plans for their future. It may also be useful for family members, friends, carers and healthcare professionals.

It is not for people who have recently been diagnosed with an advancing neurological illness. If you are newly diagnosed, contact an organisation that supports people living with your illness, such as those listed on pages 21 and 22.

Although many neurological illnesses progress in a similar way, your illness is individual and unique to you. Understanding the nature of your particular illness will help you as you read this booklet. It can also help you to understand and manage your symptoms, and help you to speak confidently with your healthcare team. You can get information from your doctor and other healthcare professionals, or from the organisations which support people living with your illness.

This booklet aims to help you to:

- understand why planning for the future can be helpful
- find out how you can plan for your care in advance
- sort out your legal affairs

- talk to your family and healthcare team about your plans
- understand the role of palliative care when you are living with an advancing neurological illness.

Not all the information in this booklet may apply to you. Feel free just to read the parts which seem most relevant.

The booklet was written by people and organisations with expertise in this area. See page 23 for a full list.



Advancing neurological illnesses

“Advancing neurological illnesses” is the name given to a group of illnesses that affect the brain and spinal cord. Many of these are progressive, chronic conditions. They can have a big impact on many aspects of people’s lives.

Living with an advancing neurological illness can be hard. At present they cannot be cured, but symptoms can be treated and managed to minimise their effect on your quality of life.

It is not possible to predict the exact way in which your advancing neurological illness will affect you. However, at some time you might experience some, none or all of these changes:

- heightened emotions
- changing communication needs
- changing personal relationships
- changing levels of independence
- falls
- infections
- changes in eating and drinking
- changing continence needs.

You may want to make plans in case these changes happen to you. The rest of this booklet explains what plans you can make, and how to do that.



Planning for the future with advancing neurological illnesses

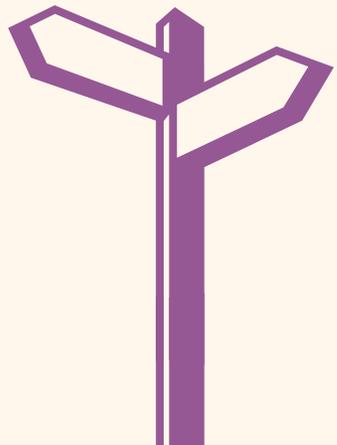


Why plan for the future?

“Now that I’ve talked to my doctor and family about what I want, it means I can focus on living.”

“It gives me great peace of mind knowing that everything is in order.”

Everyone should plan for the future, as anyone’s health can change suddenly. Planning helps people to prepare for and influence events that may happen. People plan for the future in different ways, such as by saving for a rainy day, contributing to a pension or making a will. When you have an advancing neurological illness, planning for the future may also include talking with your family and healthcare team about your wishes and preferences in case you become very unwell and are unable to communicate clearly.



Some people feel overwhelmed by the idea of planning for the future. When you are living day-to-day with an illness, it may feel like the last thing you want to do. Some family members also may not want to discuss future plans with you. This is a normal reaction. However, people who have planned ahead usually feel relieved that arrangements are in place. They feel able to focus on living their life, rather than worrying about the future.

Planning for the future can help you to:

- say important things to the people you care about
- be prepared for things that might arise
- make things easier for family and friends as your illness progresses
- deal with concerns and fears you and your loved ones may have
- know that your wishes will be followed if there is a crisis in your health, or if it gets much worse
- enjoy life knowing that important things have been discussed.

What is advance care planning?

ADVANCE CARE
PLANNING?



Advance care planning is the name given to the process of deciding what care you want in the future. You are the best judge of what matters to you, and what treatments you do and do not want. It is important that your doctor, healthcare team and family understand and respect your wishes for the care you would like to receive, especially towards the end of your life.

For example, you may want to be specific about which treatments you want or don't want. You have a right to refuse any medical or surgical treatment. You may wish to continue to receive treatments designed to keep you comfortable but not want some other treatments. If you write down the details of the type of care you want, it can help your loved ones to make sure that your wishes are respected as much as possible.

You can plan for your healthcare needs with your healthcare team. You can also include your family and friends in these discussions if you like. See page 15 for tips on how to start the conversation.

Your healthcare team can help you to understand how your illness may progress in the future and what treatments will be available to maximise your quality of life. If you wish, you can also put a formal advance healthcare directive in place (see page 11).

There are some other legal aspects to planning for the future which you may also want to consider, like making a will or setting up an enduring power of attorney. See page 13 for more about these.



Advance healthcare directives

An advance healthcare directive is a formal way of saying what you want. Part of it is about saying which medical and care treatments you do not want to have. For example, you may or may not want to:

- have CPR (cardiopulmonary resuscitation) if your heart stops
- be put on a machine to breathe for you or to support your breathing (artificial invasive ventilation)
- be tube-fed if you can no longer swallow (artificial nutrition).

Another part of an advance healthcare directive allows you to say who you want to represent you if a time comes when you can no longer speak for yourself. They could then say, on your behalf, what you would and would not like to happen.

The part of an advance healthcare directive which deals with treatments that you **do not want** in the future is legally binding. You can also say which treatments you **would like** in the future, but this is NOT legally binding. Your healthcare team will take your views into account, but doctors do not have to provide a treatment that they don't believe is appropriate or helpful. You can find out more about this by visiting www.hospicefoundation.ie.

How do I create an advance healthcare directive?

You can make an advance healthcare directive on your own, or you can get someone else, such as your doctor, to help you. The Irish Hospice Foundation has a form, called **Think Ahead: Speak for Yourself**, which can help you to make an advance healthcare directive. The form can help you to discuss and record your preferences. There is space for details about your emergency contacts, health information, legal information, financial affairs and wishes for care after death. You can get **Think Ahead** from your local Citizens Information Centre or from the Irish Hospice Foundation at www.thinkahead.ie.



You should check your advance healthcare directive regularly to make sure that it is up to date and reflects your current wishes and preferences. You can change it at any time.

Advance healthcare directives come into force only when you are no longer able to communicate your wishes. Make sure your family and healthcare providers are aware that you have an advance healthcare directive, and where you keep it. You may want to give a copy to your GP, solicitor or a trusted family member or friend.



Planning legal affairs

“As much as I can, I want to avoid any legal or financial problems.”

Planning for the future when you have an advancing neurological illness is not just about healthcare. There are legal matters which you may want to think about, too.

Setting up an Enduring Power of Attorney

An Enduring Power of Attorney (EPA) is a legal document that sets out who you would like to manage legal, financial and certain personal care decisions for you if you cannot make these decisions yourself. The person or people you choose are called your Attorney(s). You can choose family members or friends to become Attorneys.

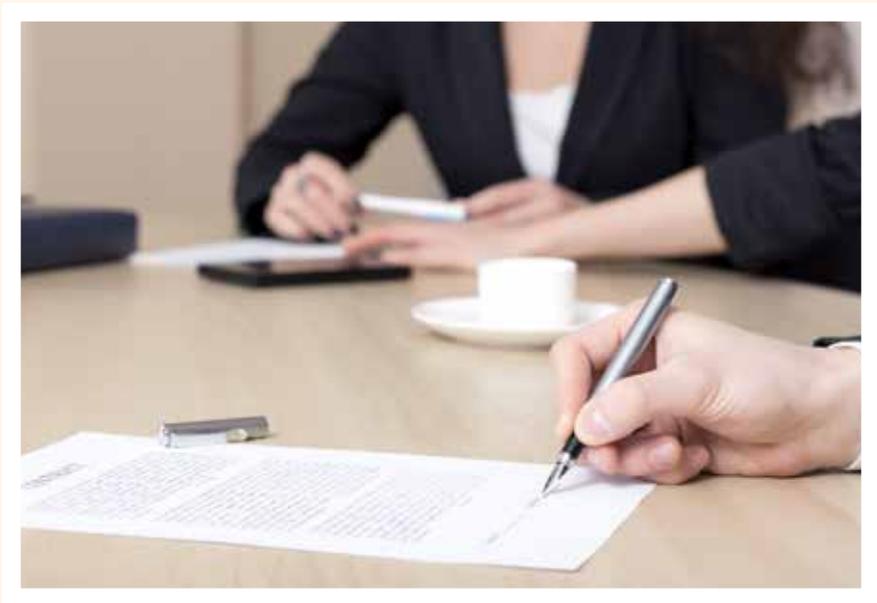
Making a will

A will is a legal document that sets out who you want to inherit your possessions, property and money when you die. Together, your possessions, property and money are called your estate.



The people you want to receive or inherit your estate are called your beneficiaries. As part of making your will you appoint one or two people to manage your estate and to make sure that your wishes are followed. These people are called your executors.

If you do not make a will everything you own will be distributed in accordance with the law (Succession Act, 1965). If you die without a will, the law sets out who may inherit from you and in what order they may inherit. If you have no living relatives, and have not made a will, the State will inherit your estate.



Talking to others about your plans

Talking to other people, such as a trusted family member or friend can be helpful when you are planning for your future. Talking openly and honestly gives everyone a shared understanding about what matters most to you at the end of life. Your mind may rest easy if you have made plans, and spoken about them.



The amount of detail you want to share is up to you. Be honest about what your diagnosis means to you and why you have taken any steps that you have.

You may find that some people are open about your illness and are there for you to talk to. Others may seem withdrawn or even uninterested. People cope with things in different ways.

Here are some phrases that may help you start the conversation:

“This illness means that at some point in the future making legal and financial decisions could become difficult for me....”

“I know this is hard for everyone, but it is important to me that we do this now.”

“I want to make sure that nobody has to face these decisions later without knowing what I want.”

Talking about your wishes with your healthcare team

“I want to let the doctors know about my wishes so that they can do their job with my input.”

After you have had the conversation with your family or friends, it is a good idea to talk to your doctor or healthcare team about your wishes. Even if you are in good health, it's still good to make sure that your healthcare team knows your wishes and care preferences, since anyone's health can change suddenly.

Remember, you are the expert about what matters most to you. Your doctor and healthcare team's role is to listen to you carefully, and then help you to make the most appropriate decisions about your care.



You do not have to decide everything at once. Every conversation with your healthcare team will be a little different, and will help them to understand what matters to you.

Here are a few things that might help:

- **Decide who you want to speak with:** It could be your GP, practice nurse, neurologist or another healthcare professional.
- **When is a good time to have this conversation?**
You can have this conversation at a routine healthcare visit, if you are worried about anything or after a hospital stay. Ideally, let the person know in advance that you want to talk about your future care plans, so they can be prepared and make time for it.

Write down your questions in advance. For example:

- What can I expect from this illness?
- What can I do to maintain my independence for longer?
- What are some possible big changes in my health that my family and I should be prepared for?

Make sure that you are clear about what the other person is saying. Be sure to tell them if you don't understand. For example, you could say, "I don't understand - can you explain it in a different way?"

You don't have to decide about anything right away, and you can change your mind at any time. It is good to have follow-up conversations to revisit the issues, as your preferences may change as time passes. Your healthcare team may ask you to consider treatment options that you need to think about for a bit.

More information about starting a conversation with your loved ones and your healthcare provider is available from the Conversation Project (see page 22).

REMEMBER:
It's never too early to plan ahead!

Palliative care

At some stage your healthcare team may suggest that you get palliative care. Many people find the words “palliative care” difficult and think that it is only for the end of life. In fact, palliative care is all about keeping you as well as possible and maintaining the best possible quality of life. It makes sense at any stage of a neurological illness. Palliative care can:

- provide relief from symptoms such as pain, breathlessness or fatigue
- help you and your family to cope with the progress of your illness
- help you to prepare and plan for the future.



Who provides palliative care?

All healthcare professionals deliver a palliative care approach. However, if your symptoms are more complex, your GP or healthcare team may put you in contact with a Specialist Palliative Care team. Specialist palliative care is available in many settings, such as in your own home, in hospitals, in community settings, nursing homes and hospices. If you need more information about palliative care, speak with your GP or healthcare team and/or see the Resources section at the end of this booklet.



Resources:

Below is a list of websites that host further information that you might find useful:

1. AllHPC Palliative hub: www.thepalliativehub.com hosts information about palliative care as well as a section, “Caring for Carers”, that offers advice for family carers.
2. Brain Tumour Ireland: www.braintumourireland.com hosts information and resources for those living with brain tumours.
3. Citizens Information: www.citizensinformation.ie contains information about making a will and accessing information in relation to health, including accessing medical cards and accessing community supports.
4. Free Legal Advice Centres www.flac.ie offers advice and information to help people to understand and access their legal rights.
5. Huntington’s Disease Association of Ireland: www.huntingtons.ie hosts information and resources for those living with Huntington’s Disease.
6. Irish Hospice Foundation: www.hospicefoundation.ie has information about palliative care in Ireland.

7. Irish Motor Neurone Disease Association: www.imnda.ie hosts information and resources for those living with Motor Neurone Disease.
8. National Advocacy Service for People with Disabilities is an advocacy service for people with disabilities.
9. Neurological Alliance of Ireland: www.nai.ie hosts information and resources for people living with all types of neurological illnesses and conditions.
10. Parkinson's Association of Ireland: www.parkinsons.ie hosts information and resources for those living with Parkinson's Disease.
11. PSPA Ireland: www.pspaireland.ie hosts information and resources for those living with Progressive Supranuclear Palsy and Corticobasal Degeneration.
12. The Institute for Health Care Improvements (2013) *The Conversation Project*: <http://www.ihc.org/Engage/Initiatives/ConversationProject/Pages/default.aspx>
13. The Multiple Sclerosis Society of Ireland: www.ms-society.ie hosts information and resources for people with multiple sclerosis.
14. Think Ahead: www.thinkahead.ie is where you can access the Think Ahead form.

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This booklet is available to download from www.nai.ie and www.hospicefoundation.ie

