



I have dementia...
**How do I plan
for the future?**





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Other useful publications

The Alzheimer Society of Ireland has a range of publications including:

- ▶ I have dementia, I have rights
- ▶ I have dementia... First steps after diagnosis
- ▶ Practical tips for Living well with dementia

For free copies contact

The Alzheimer National Helpline at **1800 341 341**
or visit **www.alzheimer.ie**

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Foreword from Helen Rochford-Brennan

When I was first diagnosed with Alzheimer's, I realised there were so many difficult conversations that needed to happen with loved ones and friends. There was that first conversation when I had to tell them the news, and then the many difficult, sad and at times humorous conversations about adapting life to live well with your diagnosis, and then those harder conversations around planning for the future which can be difficult.

Following my initial conversation with my family the most valuable thing I have come to know on my journey with dementia is that it is a good idea to talk to someone about your diagnosis and life with dementia. There are people who you can talk to and who can help. My family and friends are so supportive however, the support I have received from The Alzheimer Society of Ireland has given me tremendous courage to talk and have a good quality of life. Lao Tzu once said;

'Do the difficult things while they are easy and do the great things while they are small. A journey of a thousand miles must begin with a single step.'

I hope this booklet will help you to take your next step.

Helen Rochford Brennan

How do I plan for the future?



About this booklet

This booklet is for people with dementia. It provides information to help you to plan for the future.

It will help you to plan:

- 👁️ your legal affairs;

- 👁️ your financial affairs;

- 👁️ how you would like to be cared for in the future;

- 👁️ who can help you to plan for the future;

- 👁️ how you can talk to your family about your plans.

What is dementia?

Dementia is the name for a range of conditions which cause damage to the brain. This damage can affect memory, thinking, language and the ability to carry out everyday tasks.

The most common form of dementia is Alzheimer's. Other forms of dementia include Vascular dementia, Lewy body dementia and Fronto-temporal dementia.

For more information about the type of dementia you have, you can:

- 👁️ speak with your doctor

- 👁️ contact our **National Helpline at 1800 341 341**

- 👁️ visit **www.alzheimer.ie**



Thinking about the future

At any time planning for the future can feel overwhelming. When you are dealing with your diagnosis of dementia, it may feel like the last thing you want to do. But planning for the future is important.

Why is this important?

Early planning is important because it lets you:

- 👁️ express your wishes and preferences;
- 👁️ put your affairs in order;
- 👁️ reduce some of the anxiety or uncertainty you may be feeling;
- 👁️ help your family to know your wishes and preferences; and
- 👁️ focus on living well.

What does planning for the future mean?

People plan for the future in different ways - by making a will, saving for a rainy day, contributing to a pension or taking out health insurance. We plan for the future so we can prepare for and influence events that may happen.

Planning for the future also includes talking with our family and doctors about our wishes and preferences should we become very unwell and unable to communicate.

Planning for the future is especially important when you have a diagnosis of dementia. Doing this at an early stage means there is a record of your preferences and wishes.

How do I plan for the future?

Planning for the future involves five steps.

1. Planning your financial affairs.
2. Planning your legal affairs.
3. Planning for your health and care needs.
4. Planning for what happens after you die.
5. Talking to your family about the plans you want to make.



Step 1:

Planning your financial affairs

Things you can do to put your financial affairs in order include:

1. Organise your financial details:

- Write a list with details of your bank accounts, savings, income, pension, trusts, properties, assets, loans and debts.
- Keep the list in a safe place.
- Tell at least one person you trust where the list is, this could be a family member, your solicitor or both.
- Take steps to make sure any savings or income will be accessible to pay for your future needs. This may include setting up an enduring power of attorney (EPA) – **see page 11 for more details about this.**
- If you have a joint bank account, ask the bank or credit union about changes you may need to make in light of your diagnosis.
- For information about how best to organise your financial affairs talk to your bank, financial institution or an independent financial advisor.

2. Manage your money day-to-day

- If you find it hard to manage cash, limit the amount you carry with you daily.
- Organise your wallet or purse, for example clear out any unnecessary cards or paper.
- If you find it difficult to remember the pin number for your bank cards, talk to your bank about alternatives.
- Set up direct debits and standing orders to pay your bills.
- Make sure that household bills are not solely in your name so that someone else (perhaps a family member) can help to pay bills or address issues that may arise.
- It is a good idea to have an up-to-date form of identification, such as a passport.



For information about how best to organise your financial affairs talk to your bank, financial institution or an independent financial advisor.



When making or updating a will it is important to get legal advice.



Step 2:

Planning your legal affairs

Things you can do to plan your legal affairs include:

1. Make or update your will

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

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. These people are called your executors and they make sure your wishes are followed.

A will only takes effect after you die and applies to property which you own at the time of your death. It does not give anyone any entitlement while you are alive.

If you do not make a will then everything you own will be distributed in accordance with the law as set out in the Succession Act 1965.

Dying without a will is called dying intestate. 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, the State will inherit your estate.

Important points about making a will:

When making or updating a will it is important to:

- get legal advice; and
- get a written medical opinion from your doctor that confirms you understand the will and its implications at the time you sign it.

2. Set up an Enduring Power of Attorney, EPA

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 reach a point where you cannot make these decisions yourself.

This person is called your Attorney. You can choose family members or friends to become your Attorney. Setting up an EPA is a good idea. It means you can state who you want to manage this area for you when you can no longer do this.

You can choose family members or friends to become your Attorney.



Important points to know about creating an EPA include:

- You need to create this document while you are able to manage your legal and financial affairs. Once it is set up, nothing will happen, until you reach a point when you cannot manage your legal and financial affairs any more.
- You need a solicitor to create an EPA.
- You will need to get a medical opinion from your doctor and another healthcare professional that confirms you understand the EPA and what it means at the time you sign the document.
- It is a good idea to appoint two people to be your Attorney in case one person cannot take up the role when the time comes.
- Your Attorney will only begin to manage your legal and financial affairs for you when there is a medical report that confirms you can no longer manage your affairs yourself.
- When you die, your EPA ends. Your will or lack of will takes over.

Assisted Decision-Making (Capacity) Act 2015

The Assisted Decision-Making (Capacity) Act makes a number of important changes to Irish law about what happens when people have difficulty with decision-making.

In December 2015, the Act was put onto the Irish Statute books. The next step is for a Commencement Order to be signed, this is what will make it an active law in Ireland. It is not clear when exactly this will happen, it may happen in 2017.

Until the Commencement Order is signed, everyone must use the existing laws.

What does the new Act do?

The Assisted Decision-Making (Capacity) Act:

- recognises that a person may be able to make some decisions and not others and that their ability to make decisions may vary over time;
- introduces 3 new ways of supporting people who have difficulty making decisions, depending on how much support they need;
- introduces new guidelines which everyone must follow when making decisions on someone else's behalf. For example, the person's wishes and preferences must be respected as far as possible;
- creates a new Decision Support Service which will have responsibility for providing information and guidance and overseeing decision-making arrangements;
- abolishes the Ward of Court system and replaces it with the Decision Support Service;
- makes some changes to the Enduring Power of Attorney Act 1996;
- allows people to make Advance Healthcare Directives, **see page 21**.

When the Decision Support Services is set up, more information will be available on the new arrangements for decision-making.

What can you do to plan for your future?

Talk to your solicitor about how the new Act may affect you. The Act says that your wishes and preferences must be respected even if you cannot make decisions yourself any more. It is a good idea to make sure that people know what is important to you and what you value. You can:

- Talk to your family or to a trusted person.
- Write down your wishes and preferences and keep this in a safe place with your financial documents.
- The Think Ahead: Speak for Yourself form can help you write down, **see page 28** for information about how to get this form.

Working with a solicitor

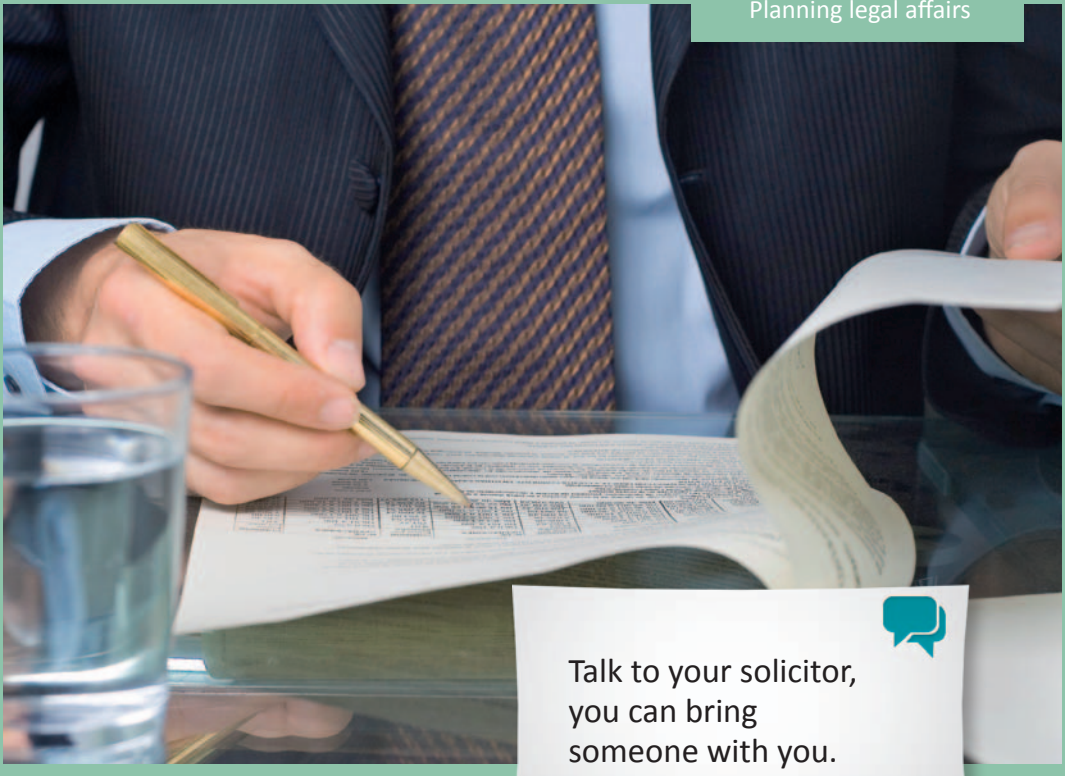
You may already have a solicitor whom you know and can talk to about these areas.

If you don't have a solicitor, you can contact the Law Society and ask for a list of solicitors working in your area. **See page 28 for contact details.**

There is also an association of solicitors and barristers called Solicitors for the Elderly which gives specialist legal advice to older people, their families and carers. **See page 28 for contact details.**

Some important points when working with your solicitor include:

- When a solicitor agrees to do some work for you, the law says they must give you a written estimate of costs.
- You can bring someone with you when you meet your solicitor, if you wish. Your solicitor may ask for some time alone with you to make sure that you are not being pressured by anyone and that you fully understand your decisions and their consequences.
- If you go alone, bring a list of questions you would like to ask and bring a pen and paper so you can write down key points from the meeting.
- You can ask your solicitor to write down important information for you, particularly if you need to do anything following the meeting.
- Bring a list of your valuable possessions and your income, pension, savings, property, assets, insurance, debts and loans with you to the meeting.
- If there are any disputes or issues that may cause someone to challenge your will or EPA, (Enduring Power of Attorney) tell your solicitor about this.



Talk to your solicitor,
you can bring
someone with you.

What if I cannot afford a solicitor?

You may qualify for legal aid if your income and savings are below a certain level. If this is the case, a solicitor in your local law centre may be able to help you write your will.

For more information and to arrange a means test contact your local Law Centre.

You can find your local Law Centre by calling The Legal Aid Board at 1890 615 200 or online at www.legallaidboard.ie



Step 3:

Planning for your health and care needs

It can be hard to think about what might happen as your dementia progresses and about what your future care needs may be.

At some point, in the future, your dementia may prevent you from being involved in discussions about your care. This is due to the way dementia progresses.

Taking early steps to plan your care means that your family and your health care team can be made aware of your wishes and preferences.

Here are some questions and points to think about.

- Who would you like included in discussions about your medical condition and discussions about your health and medical care?
- Are there cultural or religious preferences that you would like health care staff to know about when taking care of you?
- Where you would most like to be cared for as your dementia progresses and at the end of your life?
- Who would you like to visit you, or not visit you, as your dementia progresses?
- Who would you like to be present, if that is possible, when you are dying?
- If you have a partner and you are not married to each other, it is particularly important that you express your wishes about their involvement and presence as your dementia progresses and during the final days of your life.

How do I start planning my health and care needs?

The first step is to talk about it. Talk to your family and friends. Tell them what is important to you and what you value.

Page 25 gives you some practical tips to help you start this conversation.

Talk to your doctor or nurse about your dementia and what may happen as your dementia progresses.

Your doctor and nurse can explain some of the care treatments that can arise with advanced dementia such as:

- the use of a ventilator (a machine to breathe for you if you stop breathing);

- the use of artificial nutrition (tubes which feed you if you can no longer eat or swallow); and

- the use of Cardiopulmonary Resuscitation, CPR if your heart stops.





It is a good idea to talk to your doctor when making these plans. Your medical team will have ultimate responsibility for your health care decisions.

You can say what you would like to happen in relation to the use of certain care treatments. You can state the circumstances where you would not like them to be used.

To do this you can do any or all of the following:

- talk to your family;
- talk to your doctor;
- write down your wishes and preferences, there are forms to help you to do this, **see page 28**; and
- create an Advance Healthcare Directive, there are forms to help you to do this, **see page 21**.



You can change your
Advance Healthcare
Directive.

What is an Advance Healthcare Directive?

An Advance Healthcare Directive is where you write down what you would like to happen in relation to the use of certain medical care treatments, such as those mentioned on page 18. This can sometimes be called a 'living will'.

If you create an Advance Healthcare Directive you can:

- select someone to speak for you if you can no longer speak for yourself; and or
- state what you would like to happen – and what you do not want to happen – regarding certain care treatments.

How do I create an Advance Healthcare Directive?

Your doctor can help you to create your Advance Healthcare Directive and answer questions you may have.

There are forms that can help you to write your Advance Healthcare Directive.

- You can get the Think Ahead: Speak for Yourself form at www.thinkahead.ie or from your local Citizen Information Centre (developed by the Irish Hospice Foundation).
- You can order **Let me Decide**, a book about health and personal care directives by Prof. D William Molloy, at www.letmedecide.ie

You can change your Advance Healthcare Directive.

It is important that you regularly, perhaps once a year, check you are sure it still reflects your wishes and preferences.

Advance Healthcare Directives and the law in Ireland

Currently, the courts will generally recognise Advance Healthcare Directives as valid so they are a good way to express your wishes and preferences. Your doctor can help you to create your directive and answer any questions you may have about it.

When the Assisted Decision-Making (Capacity) Act 2015 is commenced it will legislate for Advance Healthcare Directives. It is expected this will happen sometime in 2017.

What happens if I don't discuss my wishes?

You can decide not to discuss your care preferences. It is your decision. Many people in Ireland today do not plan for their health and care needs.

However it is important for you to know that:

1. Your family, including your spouse or adult child, do not have the authority to make healthcare decisions on your behalf.
2. Your doctor and health care team can ask your family about what they know about your preferences and wishes as part of their overall decision.
3. Your doctor will make the medical care decisions, in accordance with their professional guidelines and taking account of what they know about your preferences and wishes.

Where can I get more information:

- 👁️ Talk to your doctor.
- 👁️ Read the Think Ahead: Speak for Yourself form at www.thinkahead.ie (developed by the Irish Hospice Foundation)
- 👁️ Read Let me Decide, a book about health and personal care directives by Prof. D William Molloy, which you can buy from www.letmedecide.ie

Where can I get more information:



- your doctor
- www.thinkahead.ie
- www.letmedecide.ie



Step 4:

Planning what happens after you die

You may want to make some decisions now about what will happen after you die. Of course, you do not have to make any decisions at all. But here are some things you might like to think about.

- Are there special funeral and burial arrangements that are important to you?
- Would you like to donate your organs?
- Would you like to donate your body for research, this can include donating your brain to help scientists understand more about dementia?



Step 5:

Talking to your family about your plans

A diagnosis of dementia can come as a great shock, even when it is expected. You and your family will experience a range of emotions as you come to understand the dementia you have and the changes it brings.

You may find some members of your family are open about your diagnosis and are there for you to talk to, however difficult the conversation may be. Other members of your family may seem withdrawn or even uninterested. People cope with this difficult news in different ways.

The amount of detail you want to share is up to you.

If you decide to plan for your future, it can be helpful to talk to members of your family about your wishes and decisions you have made. The amount of detail you want to share is up to you.

Your family may find it easier to know you have made plans. Be honest about what your diagnosis means and why you have taken these steps. The next page suggests some phrases that may help you to talk with your family.



The Think Ahead: Speak for Yourself form and online guide can help you set out your wishes.

Here are some phrases that may help you to talk with your family:

“My dementia means that at some point in the future I will not be able to make legal and financial decisions and I will not be able to tell the doctors what I want to happen.”

“Because I have dementia, I have made some decisions now, about what I want to happen in the future.”

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

“I want to make sure you don’t have to face these decisions later without knowing what I want.”

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

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

“We should all plan ahead, even if we don’t have dementia. We shouldn’t be afraid of planning. It makes life much easier in the end.”



Resources for your family:

Your family can get information and support from:

- 👉 their doctor

- 👉 The Alzheimer Society of Ireland

- 👉 The **Think Ahead: Speak for Yourself** form

- 👉 The **Let Me Decide** book.

Useful contacts and sources of information

The Alzheimer Society of Ireland 1800 341 341

National helpline: 1800 341 341

Email: helpline@alzheimer.ie

Website: www.alzheimer.ie

We have offices and supports throughout Ireland. Our Helpline can connect you to people and supports in your community.

Think Ahead: Speak for Yourself

Phone: 0761 074 000

Website: www.thinkahead.ie

Contact your local Citizen's Information Centre for a free copy. Think Ahead was developed by the Irish Hospice Foundation.

Let me Decide: by Professor D William Molloy

2011, Newgrange Press, ISBN 978-1-906642-33-4

Order this book and form online at **www.letmedecide.ie**

The Irish Hospice Foundation

Phone: 01 679 3188

Website: www.hospicefoundation.ie

Citizens Information Service

LoCall: 0761 074 000

Website: www.citizensinformation.ie

FLAC: Free Legal Advice Centre

Information and referral line: 1890 350 250

Website: www.flac.ie

There are local centres throughout the country, to find the one nearest to you call or visit the website.

The Law Society of Ireland

Call: 01 672 4800

Website: www.lawsociety.ie

Solicitors for the Elderly

Website: www.solicitorsfortheelderly.ie



Disclaimer

This booklet is not a legal document. It is a simple guide in plain English to help you plan for your future.

The Alzheimer Society of Ireland has taken great care to ensure the accuracy of the information contained in this booklet. We are not liable for any inaccuracies, errors, omissions or misleading information.

If you would like to comment on this booklet, please contact Samantha Taylor, Information and Helpline Manager at **01 207 3800** and **staylor@alzheimer.ie**

If you would like more information about the information contained in the booklet please contact our free and confidential Helpline at **1800 341 341**.

The photographs featured in this booklet are models.

The Alzheimer Society of Ireland

National Helpline: 1800 341 341

Email: helpline@alzheimer.ie

Website: www.alzheimer.ie