



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
- Practical steps to support your independence; a guide on how assistive technology can help people with dementia and their families.
- Driving and 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.

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. Participating in advocacy and research has given me confidence and a sense of purpose.

It is a good idea to begin to make plans for your future. The new Assisted Decision Making (Capacity) Act has delegated the power and control back to me, the individual, to decide what I want to do with my life and what I believe is best for me, and not what others think is in my best interests. Martin Luther King once said:

"You don't have to see the whole staircase, just take the first 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.

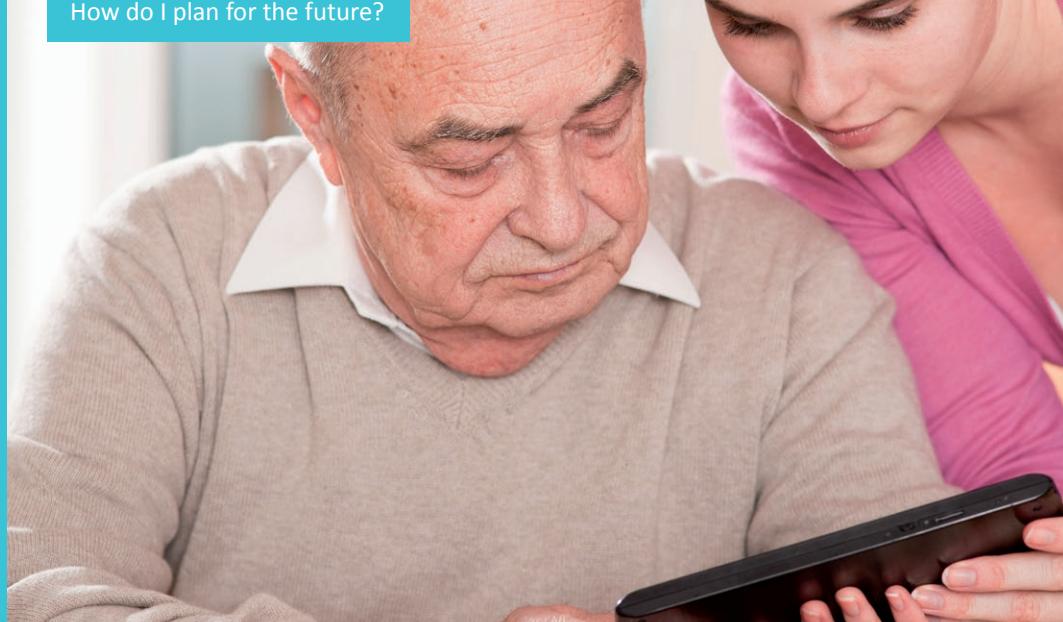
What is dementia?

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, preferences and decisions;
- put your affairs in order;
- reduce some of the anxiety or uncertainty you may be feeling;
- help your family to know your wishes, preferences and decisions; 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 decisions.

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. The Think Ahead Planning pack from Irish Hospice Foundation includes an area where you can record this information. For more information on the Think Ahead Planning Pack **see page 24**
- 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 15 for more details**.
- 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 adviser. There are dedicated vulnerable customer support lines in banks to help you with this.

2. Manage your money day-to-day

- Organise your wallet or purse, for example clear out any unnecessary cards or paper.
- Limit the amount of cash you carry with you each day, particularly if you find it hard to manage cash.
- 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 adviser.





You should get legal advice when making or updating your will.

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 that you own at the time of your death. It does not give anyone any entitlement while you are alive.

Dying without a will is called dying **intestate**. 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. This 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.

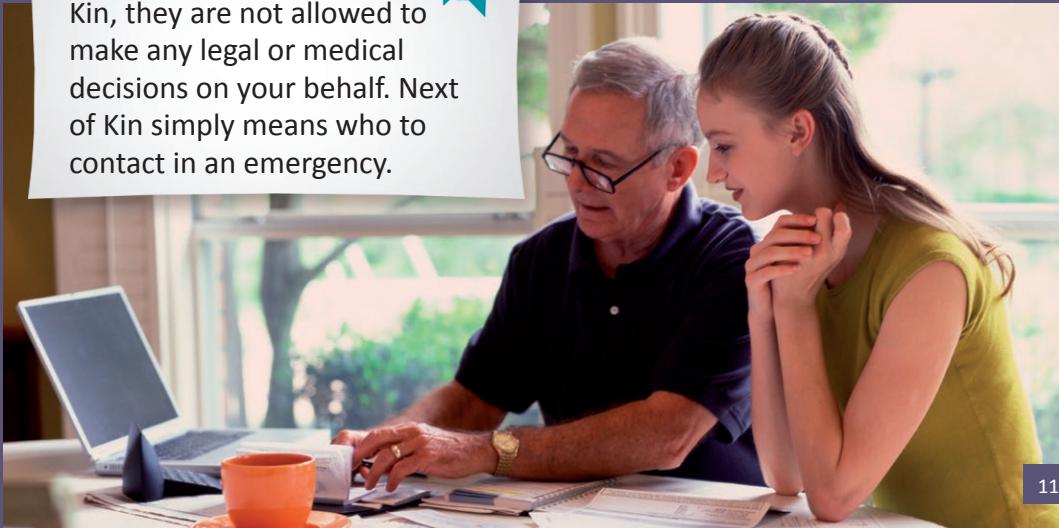
2. Create a decision support arrangement

Decision support arrangements are legally recognised arrangements for people who need support to make certain decisions. These arrangements have been made legal because of the Assisted Decision Making (Capacity) Act. This Act came into law on 26 April 2023. It makes a number of important changes to Irish law about what happens when people have difficulty making decisions.

What is decision-making capacity?

One of the important things the Assisted Decision Making (Capacity) Act does is to define what **capacity** means.

If someone is your Next of Kin, they are not allowed to make any legal or medical decisions on your behalf. Next of Kin simply means who to contact in an emergency.



You have the capacity to make decisions if you can do four things:

1. Understand the information about the decision.
2. Remember the information long enough so you can think it over before making the decision. (Even if your short-term memory is poor, it does not necessarily mean that you cannot do this.)
3. Think about and understand what is likely to happen if you make a particular decision, or what is likely to happen if you choose not to make a decision.
4. Communicate your decision in any way that can be understood.

When we talk about assessing capacity, it means working out if someone can do these four things. If you need help to do those four things in relation to a particular decision, but you can do them when you have the right help, you have the capacity to make that decision. You cannot be assessed as not having capacity unless an effort has been made to help you.

What support can I get?

There are three different decision support agreements available for people who need support to make decisions and choices. A decision supporter is a person appointed by you or the court under a formal legal arrangement. This is called a **decision support agreement**.

The Decision Support Service (DSS) is a service that was established under the Assisted Decision Making (Capacity) Act. The DSS provides advice and support on how to create a decision-making agreement. You can find contact details for the DSS at the end of **page 30**.

The level of support you can get depends on your decision-making capacity, which we explained above. You will find a summary of the levels and what they offer below.

Lowest level of support: Decision-making assistance agreement

At this level of support:

- You still make decisions.
- Someone you know and trust will help you to make the decision. However, this person does not have any decision-making power. This person is called your decision-making assistant.
- You do not need a solicitor, but the decision-making agreement must be in writing using a form supplied by the decision support service (DSS). It must also be signed by you and your decision-making assistant and witnessed by two other people.

Middle level of support: Co-decision-making agreement

At this level of support:

- Someone you know and trust makes decisions jointly with you. This person is called your co-decision maker.
- Only decisions mentioned in the agreement are relevant.
- You do not need a solicitor, but the co-decision-making agreement must be in writing using a form supplied by the DSS. The form must be signed by you and your co-decision maker and witnessed by two other people.

Highest level of support: Decision-making representation order

- When you no longer have capacity, the court will choose someone to act on your behalf, considering your wishes.
- If there is nobody available who you know and trust, the court will appoint someone from a panel of professionals.
- You will need a solicitor for this. There may be one or more hearings in court.

More details about the process, costs and forms can be found by going to the Court website
www.courts.ie/assisted-decision-making-circuit-court.

How can I make these agreements?

If you have decided to make a decision-support agreement using the Decision-Support Service (DSS), you must first do three things.

1. Create an account called myDSS account

You need to create a myDSS account. The DSS is a digital first service. The quickest way to create an account is by going to the:

- ⦿ Decision Support Service website (www.decisionsupportservice.ie)

If you do not have access to the internet or a computer, you can still create an account by phoning the DSS on: (01)211 9750. The DSS will send out forms for you to fill in to create a my DSS account.

2. Fill in the application form you need

The applications form you need to make your decision support agreements are on the (DSS) website. You can access these after you have set up your myDSS account.

If you do not have access to the internet or a computer, the DSS can send you paper application forms. It takes longer to process paper applications.

3. Get the form signed

You will need to sign the form (and all forms) in front of a witness. After you sign any forms, you have five weeks to send them back to the DSS. Anyone else who must sign must also sign in front of a witness.

Sometimes, you may need to move from a lower level of support to a higher level of support. To do this, you need to contact the DSS and fill in new forms and register the new agreements with the DSS.

The exception to this is the highest level of support, the ‘decision-making representation order’. You must apply for this in the circuit court.

Covering the cost of using myDSS

Generally, you must pay to set up any agreements. You can contact the DSS for costs involved

However, the service is sometimes free. This depends on a person's financial situation. If you wish to find out if you qualify for the free service, you can contact the Legal Aid Board who will assess your needs.

- Legal Aid phone: 0818 615 200
- Legal Aid email: info@legalaidboard.ie

How does the new Act affect me?

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 anymore. It is a good idea to make sure that people know what is important to you and what you value. You can:

- Create an Enduring power of attorney (see below).
- Create an Advance Healthcare Directive. **See page 24.**

3. Set up an Enduring Power of Attorney, (EPA)

An Enduring Power of Attorney (EPA) is a legal document. It sets out who you would like to manage your legal and financial decisions for you. It also explains who will look after certain personal care decisions for you, if a time comes when you cannot make these decisions yourself.

This person is called your **Attorney**. You can choose family members or friends to become your Attorney.

Important points to know about creating an EPA include:

○ Create an EPA when you are well

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 anymore.

○ Contact your GP/ consultant

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. When the time comes that you can no longer manage your affairs yourself, a medical report is then needed from the doctor. Your Attorney will send this to the DSS to register the EPA.

○ Use a solicitor

You need a solicitor to help you with some sections of the EPA. These include asking you some questions to make sure you understand what it means to create an EPA and they will fill in a form called a Legal Practitioner Statement.

○ Appoint two attorneys

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.

○ EPA works while you are alive

Your EPA is only in place while you are alive. When you die, your will comes into effect, if you have made a will.

Setting up an EPA is a good idea. It means you can say who you want to look after your affairs for you when you can no longer do it yourself. To create an EPA, you must create an account with the DSS (**see page 14**) and then you can access the necessary forms and documentation to create your EPA.

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 30 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 30** for contact details.

Some important points when working with your solicitor include:

 **Get a written cost estimate**

When a solicitor agrees to do some work for you, the law says they must give you a written estimate of costs.

 **Prepare a list**

Prepare and bring a list of your valuable possessions and your income, pension, savings, property, assets, insurance, debts and loans with you to the meeting with your solicitor.

 **Go with a friend – or go alone**

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.

 **Ask your solicitor to write key points for you**

You can ask your solicitor to write down important information for you, particularly if you need to do anything following the meeting.

 **Tell your solicitor about issues**

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.



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 28 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.

Palliative Care

What is palliative care?

Palliative care is holistic care that focuses on relieving pain and other symptoms when you have a serious illness, regardless of your age, diagnosis, or stage of illness. Palliative care is often offered alongside of other treatments. Receiving palliative care does not necessarily mean you are dying. Palliative care includes looking after your physical, psychological, emotional, and spiritual wellbeing.

Palliative care also supports your family or significant people in your life by facilitating open and honest communication to ensure that treatment options and care decisions align with your preferences and values.



How do I get palliative care?

If you have been diagnosed with dementia, you can access palliative care in Ireland. You can arrange palliative care by speaking to your GP or through the hospital. There is **no cost** for palliative care. Providing palliative care is the responsibility of an entire healthcare team. This team may include General Practitioners (GPs), Public Health Nurses (PHNs), Registered General Nurses (RGNs), Carers, Hospital-Based Healthcare Professionals, Pharmacists, Counsellors and many other allied health professionals; this is your Primary Palliative Care Team. Palliative care is available in hospices, hospitals, residential centres, nursing homes and/or at home.

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;
- create an Advance Healthcare Directive, there are forms to help

How do I plan for the future?

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 21**. 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 make or express your medical decisions. This person is called your designated healthcare representative.
- State what you would like to happen – and what you do not want to happen – regarding certain care treatments.

If you have an Advance Healthcare Directive and cannot speak for yourself at the time a decision has to be made, doctors must refer to it:

- If you have chosen to refuse a particular treatment, they must not give you that treatment.
- If you have asked for a particular treatment, they must consider your wishes. However, there may be a valid reason why you cannot have that particular treatment. For example, if you have asked for a certain type of medication which could cause serious side effects, the medical team may go against your Advance Healthcare Directive.



You can change your Advance Healthcare Directive.

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 resources that can help you to write your Advance Healthcare Directive.

- you can get the Think Ahead Planning Pack at www.thinkahead.ie or by phoning Irish Hospice Foundation on 01 679 3188
- You can find the **Decision Support Service Guidance** on making an Advance Healthcare Directive at www.decisionsupportservice.ie/resources/guidance-materials

You can change your Advance Healthcare Directive.

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

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. They will do this in line 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
- Learn more on the Think Ahead resource hub at www.thinkahead.ie and in the Irish Hospice Foundation's Think Ahead Planning Pack
- www.decisionsupportservice.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.
- The Think Ahead Planning Pack provides space to record your decisions, wishes and preferences.





The Think Ahead Planning Pack and online hub can help you set out your wishes.



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.

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 need not 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 Planning Pack
- The DSS website www.decisionsupportservice.ie

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.

Decision Support Service (DSS)

Call: 01 211 9750 **Website:** www.decisionsupportservice.ie

Email: queries@decisionsuppptservice.ie

Irish Hospice Foundation

Think Ahead Planning Pack & Palliative Care booklet

Website: www.hospicefoundation.ie

Call: (01) 679 3188 **Email:** info@hospicefoundation.ie

Citizens Information Service

Call: 0818 074 000 **Website:** www.citizensinformation.ie

Legal Aid Board

Call: 0818 615 200

Website: www.legalaidboard.ie **Email:** info@legalaidboard.ie

FLAC: Free Legal Advice Centre

Information and referral line: 01 906 1010

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, Head of Dementia Advisory services 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