



An introduction for family members

Living with Dementia



THE ALZHEIMER
SOCIETY of IRELAND

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Other useful publications

The Alzheimer Society of Ireland has a range of publications for family carers including:

- The Carer Information Pack
- Practical Tips for coping with Memory Loss
- My Life Story Book

For further information and to order a copy contact The Alzheimer National Helpline at 1800 341 341 or visit www.alzheimer.ie

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

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Introduction

Living with Alzheimer's or a related dementia can be a challenging journey, not just for the person with the condition but also for their family and loved ones.

When a family member is diagnosed with dementia, each day can bring with it new demands; new highs and new lows. Sometimes you may feel somewhat overwhelmed and unable to cope with the changes you are facing.

At times like this it is important to know that you are not on this journey alone. Other family members, friends, healthcare professionals and The Alzheimer Society of Ireland can each in their different ways provide practical, emotional and social support that will enable you to care for yourself as well as your loved one. Don't be afraid to ask for or accept their help.

The more information and support you have, the better you can navigate the demanding road ahead. Start by learning about dementia, where to find support, and how to determine the care options that are best suited to you and your loved one.

This booklet has been designed to help you to:

- Begin to think about life with dementia and the changes this illness brings
- Understand more about dementia
- Know what services may be available and how to access them
- Think about and plan relevant legal & financial issues
- Find out where to go for more information.

first steps

When a diagnosis is made



Hearing the words dementia or Alzheimer's can leave us feeling shocked, no matter how much we may have expected the diagnosis. You face the task of trying to understand what dementia means and of adjusting to the life-changing impact of this condition.

Reading this booklet will help you and your family to begin to work out how to live with dementia. It is important to try to understand the range of emotions and reactions that you, your loved one with dementia, and your family may experience and to take steps to help to deal with them.

The range of emotions you, your loved one with dementia and your family may feel include:

Disbelief & Denial are very common and are often a way of coping, as they provide time to understand and accept what the diagnosis means. However they can also be a source of

frustration for other family members who do not experience disbelief or denial. It is very common for people within the same family to accept or understand a diagnosis at different times and in different ways.

Relief that there is an explanation for what has been happening.

Fear about what will happen next and how to cope.

Reluctance to become a carer or to become part of a support team.

Guilt can occur even though developing dementia is not anyone's fault. People can feel guilt for not being understanding or patient or for being angry and frustrated. Guilt that you don't want to be a carer.

Loss & sadness about the things a person may not be able to do in the future and for the changes in relationships and future plans.

Frustration and anger that dementia has happened, and that your lives are changing and you feel helpless to stop it.

Loneliness and isolation, as many people feel they are alone when a diagnosis is made, even when they are surrounded by people.

It is normal to feel different things at different times, and it can be hard to deal with these emotions. The following pages outline steps you and your family can take.

“My thoughts were racing, I had vaguely heard of Alzheimer's, when I heard the words I wanted to shout ‘what's Alzheimer's?’ but of course I didn't.... Our whole lives changed after that....”

First steps

Talk to someone about how you are feeling

Talk to someone you trust; a family member or friend. You can also talk to your doctor, a social worker, or a trusted person in your community. You can talk to different people about different emotions at different times, but talking to someone will help.

Call the **Alzheimer National Helpline** to speak in confidence to someone who will understand and be there to listen and support you. Freephone 1800 341 341 Monday to Friday 10 am to 5 pm and Saturday 10 am to 4 pm or email: **helpline@alzheimer.ie**

For some, speaking to a professional counsellor can help. You can speak to your doctor about this option. You can find out which counsellors operate in your area through a number of bodies such as the Counselling Directory, see page 41 for contact details.

“Getting involved (with a Support Group) was the best thing I ever did. Through the meetings I made many friends and the Society brought in different people to talk to the group”

Keep a journal or a diary

Write down how you are feeling day-to-day or week-to-week. This can help you to understand what you are feeling and why. It can also help if you feel overwhelmed; it can help you to talk to someone about how you are feeling.

Join a support group

Meeting other people who also have a loved one who has been diagnosed with dementia can be a very positive experience. Support groups can provide a safe place to talk and to learn more about dementia and about ways to get help and support.

There are also a number of on-line forums and groups where you can connect with others in similar situations. For more information on support groups see page 28.

Talking to children or grandchildren

You may find it difficult to try to answer questions from children and teenagers about dementia, or to explain to them that their loved one is unwell. There is a range of information available to help you talk to children about



dementia. There are also publications about dementia written for children to read. Contact the Alzheimer National Helpline for more details.

Encourage your loved one to talk about how they are feeling

Let them know that you or a family member, relative or friend is there to listen. Let them know that they can also talk to their doctor or social worker or a trusted person in their community.

If you are concerned that your loved one is very low in mood, it is important that you mention this concern to their doctor or another health care professional.

Your loved one can also call the Alzheimer National Helpline or go on-line to a number of forums for people with dementia to share

and discuss their feelings. See page 40 for further details.

Include your loved one in decision-making

As much as possible, continue to involve your loved one with dementia in decision making and planning. Seek and consider their opinions, thoughts and feelings. People with dementia have highlighted this as being very important.

It may be necessary to adjust how you communicate with each other. Your loved one may need to deal with one single thing at a time, and they may need more time to understand or follow a topic or issue. For more tips on communicating speak with your doctor, contact the Alzheimer National Helpline, or log onto **www.alzheimer.ie**

Encourage your loved one to do things they enjoy

Many people with dementia continue to do lots of things they enjoy for some time. Your loved one may need some extra support – talk to them, listen to what they have to say and offer gentle encouragement around continuing with hobbies, interests or activities. Talk to your family, friends and health care professionals about ways to help your loved one to continue to do these things. Sometimes simple things like a gentle prompt or reminder about what to do next can make all the difference. Contact the Alzheimer National Helpline for more information.

“... you gotta keep doing things and if you keep doing things, you’re going to keep your brain churning over.”
- Person with dementia

Information about dementia

Some people with dementia want to know more about the condition, others do not. If your loved one wants to know more, or wants to connect with

other people with dementia, there are a range of ways to do this. The Alzheimer Society of Ireland have a range of supports such as Alzheimer Cafes and Social Clubs which provide a place to meet others in your community. Our National Helpline is available six days a week and we have Dementia Advisors in some areas who can meet with you to help you to access information and support. We also host the Irish National Working Group of People with Dementia, the group is made up of people with different forms of dementia and meets quarterly to discuss issues that matter to them. Our website also has dedicated sections for both people with dementia and their families and contains practical tips for living well with dementia.

For more information about our publications, services and supports see page 25.

It is important for everyone to be open with one another about how they are feeling, try to be patient with one another, and to accept that people will deal with the diagnosis in different ways.

Learning more about dementia can help, the next chapter explains about dementia and its impact.

About dementia and Alzheimer's

Learning more about dementia can help you to understand what the person with dementia is experiencing and this will help you to deal with the changes you see, and the emotions you are feeling. This chapter will explain more about dementia.



What is dementia?

Dementia is a physical illness that causes damage to brain cells. This damage means a person's ability to remember, think, speak and to do everyday things will change. As dementia progresses, the changes become greater, and the person will need more help.

Currently there is no cure for dementia, but there is a lot that can be done to help the person with dementia and to help you, as their loved one and caregiver.

Below is a brief outline of some of the more common types of dementia; this is followed by a general overview of how dementia can progress. Finally an overview of the treatment available is provided. In every section, you are provided with links to where you can go to get more information.

Types of dementia

There are many conditions which cause dementia. Different types of dementia can lead to different experiences and problems for the person with

“One of the first things I noticed, apart from her memory, was her ability to coordinate daily tasks was deteriorating. When she cooked a meal, she might cook the vegetables first and it could be hours afterwards that she would put the meat on.”

dementia and their loved ones. Not every person will experience all the symptoms and the problems linked to their type of dementia. Some people experience a mix of two types of dementia.

Alzheimer's is the most common and well-known cause of dementia. It is thought to cause over half of all cases. It is recognised by the build up of protein on the brain which forms plaques and tangles that stop the brain working as it should. In general, with Alzheimer's changes are gradual over time and the illness may last several years. At first, changes may be slight and as the illness goes on, the changes become greater. Memory loss is often one of the first symptoms of this disease; however there are a range of early signs and symptoms including getting stuck for words, misplacing things regularly, losing track of time, changes in mood and behaviour and difficulty in finding the way, even in familiar places.

Vascular dementia is the second most common type of dementia and it occurs when the blood supply to the brain is damaged. There are two



main types of vascular dementia; one caused by stroke and the other by small vessel disease.

Multi-infarct dementia is a type of vascular dementia that is caused by small strokes. The strokes can be so tiny that no-one notices them happening, but the person may get worse quite suddenly and then not change again until the next stroke happens. As a result, the progression of this dementia is often described as happening in steps rather than steady gradual changes, such as in Alzheimer's. People with vascular dementia will often have difficulty concentrating and communicating. They may have memory problems, but this may not be the first symptom. Depression is also common in people with this type of dementia.

Lewy body dementia is a type of dementia that shares characteristics with both Alzheimer's and Parkinson's disease. Like Alzheimer's symptoms progress gradually over several years. The person will experience many of the signs and symptoms of Alzheimer's and may also experience muscle stiffness, trembling of the limbs and a tendency

to shuffle when walking. They may also experience hallucinations (seeing things that are not there) and fall asleep during the day and then not sleep at night.

Fronto-Temporal Dementia, including **Picks Disease** is a rare type of dementia. During the early stages, a person's memory may be fine but their personality, behaviour and language skills can change. This dementia often causes a loss of insight and so the person may say and do things at the wrong time and in the wrong place. This can be embarrassing for family members and it is important to know that there is a physical cause for these changes. The progression of this dementia is unpredictable and in the later stages symptoms are similar to those of Alzheimer's.

Other forms of dementia include **alcohol-related dementia** such as Korsakoff's Syndrome and **Creutzfeldt-Jacob Dementia**. Some people with Down's syndrome also develop dementia in middle age. The above provides you with a brief outline of some types of dementia.

For more information about the type of dementia that your loved one has, and the symptoms associated with it, you can speak to your doctor or contact the Alzheimer National Helpline at 1800 341 341 or log onto www.alzheimer.ie.

How does dementia progress?

Each person's experience with dementia is unique. Not every person will experience all the signs and symptoms of their type of dementia. Other illness or health care issues can occur.

“In the early years of her illness mum recognised me as her daughter and she recognised her home and we lived reasonably well with Alzheimer's.....it was still possible for her to enjoy life”

As a result, how the disease will progress varies from one person to another. Dementia may

last many years, sometimes progressing faster, sometimes more slowly. This means that it is not possible for anyone to tell you exactly how the disease of your loved one will progress and how long they will live with dementia. Many people find it stressful that they do not have answers to these questions and that is normal. Understanding as much as you can about dementia will help.

In the early stages of dementia changes are slight - the person with dementia may forget things easily or repeat things frequently. The person may behave in ways that seem odd or different. They may have some problems with language, and may appear to be stuck for words or lose track of what they have been saying, and they may find new situations or places confusing. The person usually looks well and continues to do lots of things they usually did. They may be aware that something is wrong or different, and may be anxious, frustrated and even angry as a result. They may become withdrawn and can become depressed. Some people lose interest in their appearance or in



things they once enjoyed. Others continue to engage in activities they enjoy but may find it hard at times.

Changes noticed. As dementia progresses, changes become greater and the person will need more help. The person's memory generally gets worse and changes in behaviour may be more difficult to understand and to live with. The person can look well and at times appear well, but more and more they find everyday activities harder to complete. They can be withdrawn, seem self-centred and become frustrated. This can be hard for family members and friends to understand and to cope with. There are ways of coping and this book will guide you to where you can go to get practical and emotional support.

It is also important to know that some symptoms occur for a period of time and then go away. For example a person who becomes very upset or very angry easily may, after some time, become calm. Many people with mild and moderate dementia can engage in lots of different activities, with support.

Later stages. In the later stages of dementia, a person is no longer able to do things on their own. They may not be able to use words, recognise close family members and move independently. They will need constant care. During this stage the person's ability to fight even simple infections is low and so, sadly, the illness may eventually be fatal. However, many people with dementia are older when they develop the illness and because it is, in the main, a gradual, progressive illness, many people die of completely unconnected causes.

A person with dementia may:

Confuse time & day and familiar people

Get lost in familiar places

Not recognise everyday objects

Find cooking and shopping increasingly difficult

Find managing money or decisions about finances difficult

Become upset or angry very quickly

Repeat themselves, ask the same question frequently and seem to get stuck for a word or phrase during a conversation

Find conversations hard to follow or understand, particularly when talking about new events

Find following a television programme or reading a book or newspaper difficult or confusing

Find bathing and dressing difficult or confusing

Be more comfortable talking about events in the past and remembering things from childhood or early adulthood

Not recognise some family & friends

Become confused easily and believe things to be real when they are not

Not eat regularly or eat too much

See or hear things that are not there (hallucinations)

Be up and about at night

Have continence problems

These are some of the things a person with dementia may experience - your loved one probably won't experience all of these things. However as their dementia progresses they will need more and more help. That means you will need support to help you to care for them.

Treatments for dementia

Sadly there is no cure for dementia at the moment. However there are treatments that can help. Drug treatments can be effective for some people and there are a range of medications that can help with some of the symptoms.

Drug treatments

People with dementia can be prescribed a range of medications during the course of the illness. Some are specifically for Alzheimer's and others are for symptoms that may emerge as part of the dementia.

Alzheimer drugs

There is a range of Alzheimer drug treatments that can help some people. They do not cure dementia. For some people they can help to slow down the progression of the dementia for a period of time. These treatments are not successful for everyone and they may not be suitable for others.

The main drug treatments for Alzheimer's are donepezil, rivastigmine, galantamine and memantine. In general donepezil, rivastigmine and galantamine are used for people with mild to moderate Alzheimer's. Memantine is usually prescribed to people in the middle to later stages of the disease. These are the chemical names for these drugs, the prescription may have a trade name also on the script. Ask the doctor if you are unsure.

These drugs may also be used for people with Lewy body dementia and in some cases for people with vascular dementia.

Vascular dementia

People with vascular dementia often need to take medications for underlying conditions such as stroke, high blood pressure, diabetes, high cholesterol or heart problems. Controlling these conditions and adopting a healthy lifestyle by not smoking, drinking only in moderation, taking regular exercise and eating a balanced diet may help to delay the progression of this dementia.

Drugs for behavioural symptoms and depression

People with dementia may be prescribed a range of medications to help relieve behavioural symptoms and depression. These medications can include sleeping tablets, tranquillisers, anti-anxiety drugs, anti-psychotic drugs and anti-depressants. Not every person with dementia will need these medications and there are other methods to help manage these symptoms. Some people may need medication for a short period of time.

A decision to prescribe these medications should involve a full assessment of the person with dementia, their physical health and well being. A Psychiatrist of Later Life may be introduced in order to carry out this assessment and help manage the symptoms. Areas such as unrecognised pain, eyesight, hearing and dental health should be explored to see if there are any other causes for the behaviour. It may be possible that a behaviour is a result of something in the environment triggering a response. Talk to the doctor about daily routines, likes and dislikes so they can build a full picture and help to identify what is triggering a behaviour. There are lots of ways to manage symptoms and behaviours that

may emerge, medication is one option which may or may not be suitable for your loved one.

Working with medications

With all medication, it is important to understand what drugs are being prescribed, why they are being prescribed, what benefits they are supposed to bring, and what side-effects may emerge. Where possible, it is important for both your loved one and you to discuss this with the prescribing doctor.

If your loved one is unable to participate in a discussion about medication, it is important you understand what is being prescribed and why. Talk to the doctors and ask questions. Ask them to provide information about the medications and to write out dosages and times to take them. You may also need to give the doctors feedback on any changes in your loved one when they are taking the medication, both positive and negative.

You can talk to your doctor or pharmacist about issues that may arise. Your pharmacist may be able to provide the medications in a blister pack or a medication box which arrange medication



by day and time. Building a relationship with one pharmacist can be helpful.

It may also be helpful for another family member or friend to be aware of the medication routine and the name of the doctor and pharmacist you and your loved one work with.

There are a range of fact sheets available on the above medications and behaviours associated with dementia; call the Alzheimer National Helpline for further information.

Who to talk to about symptoms and behaviours

There can be a number of health care professionals involved in managing symptoms once dementia is diagnosed.

General Practitioner: In many cases, the General Practitioner, GP is a key person in the everyday management of the condition. It is important to keep in contact with the GP and to update them of any changes as they arise.

Dementia Specialist: The GP can refer a person to a Psychiatrist of Later Life, Geriatrician or Neurologist (if under 65) to obtain specialist support during the course of the condition.

Supports in your Community: Help and support may be available through a public health nurse and your local HSE office. See page 25 for further details. Your pharmacist can also be a support and it may be helpful to build a relationship with one particular pharmacist.





caring

Looking after yourself

Becoming a carer for a family member who has dementia is a life changing experience. Many people find themselves becoming carers slowly, over time, as the person with dementia's needs change and increase. For others, changes happen more quickly.

Looking after a loved one with dementia can be both rewarding and stressful. If you are to be a family carer or if you are supporting a person who is the main family carer, it is important to understand the impact becoming a carer can have and to understand, from the beginning, the importance of looking after your needs too.

Why is it important to look after yourself?

It is very common for people who are looking after a loved one with dementia to put their own needs to one side. Becoming a carer has an emotional, physical, and sometimes, financial impact. As your loved one with dementia needs more support, you will too.

If you don't look after yourself, you may experience high levels of stress, anxiety, exhaustion and depression. You may also be more likely to develop other illnesses.

Looking after yourself is not selfish. When you take care of yourself, everyone benefits. You feel better. You are able to be there for your loved one with dementia. You are able to be part of the lives of other family members and friends. You and your loved ones can live with dementia.

How do I look after myself as a carer?

Make a conscious decision

You are the only person who can decide to look after yourself. Other people can help you and support you, but you are the only one who can make this decision. Caring for a loved one is hard work. The earlier you make a conscious decision to look after yourself as a carer, the better for you and your family.

Acknowledge your emotions

Your feelings about caring have a big part to play in your care-giving experience. You may be feeling sad, angry, resentful, frightened and alone. On the other hand you may find caring a very rewarding and fulfilling role. For most carers, it is both rewarding and stressful.

There are a number of things that can affect how you are feeling including your relationship with the person with dementia, your reasons for caring, changes in your lifestyle and how much support you have.

It is normal to feel a range of different and conflicting emotions. It is important to recognise how you are feeling and to talk to someone - a family member, friend or your doctor. See page 26 for tips on people you can talk to.

Be nice to yourself

No one is perfect. There will be days when you lose patience or it feels like everything you do is wrong. Try to give yourself positive messages, remind yourself of all the things you are doing well. It is okay to focus on one day at a time, or an hour at a time if you are finding a particular day very hard.

Build a support network

Looking for and accepting help is a positive step that will benefit you, your loved one with dementia and your family.

“We lived in total isolation. Cracks began to appear in my health. I was constantly exhausted. I was stressed. I was living in fear for both our futures. I contacted the Alzheimer Society of Ireland and the HSE to try to get some help and allow us to carry on at home for longer.”



You and your loved one will need different types of help at different times over the course of your living with dementia. That means that your support network will change over time. The next chapter outlines a range of approaches to building your support network.

“How I lived for those hours when mum was looked after... I could go for a walk, I could sit in the hairdressers.. I could relax and unwind.”

Take care of your health

It is easy to neglect your own health when caring for a loved one, but your health is just as important. When building your support network consider what support you need to be able to:

- See your GP regularly, particularly if you are feeling low, stressed, anxious or are not sleeping
- Eat a well-balanced diet
- Take regular exercise

Take time out for you

As an individual, it is important that you continue to have some time set aside for you, to do things you enjoy, to relax and have time away from your care-giving role. When planning your support network include help which allows you to take time for you, what you do is entirely up to you.

Establish a routine

It can be a great help to have a sense of how your day and week is going to go. Having a routine allows you to build time for you into your schedule. It allows you to know what you are doing next, and to look forward to things that you, and your loved ones will enjoy. It also allows your family, friends and the health care professionals working with you to plan with you how and when they can support you both.

Keep up social contact

Caring for a loved one with dementia can be isolating. It is important to build time into your daily and weekly routine to meet other people.



Plan visits so you have something to look forward to. You and your loved one may be able to continue to do some of the things you enjoyed together with some extra supports. Meet friends and keep in contact by phone. Join a support group to meet other people who are caring for a loved one with dementia.

Focus on what is possible

You will both experience great changes over the course of this illness. These changes mean you and your loved one have to approach things differently. Your loved one still has many abilities. Try to focus on the things you can both do. Invite your loved one to participate on whatever level is possible, and this way you will be able to enjoy time together.

Contact the Alzheimer National Helpline for more information and ideas on activities.

The Alzheimer Society of Ireland

Contact the Alzheimer National Helpline
Monday to Friday 10 am to 5 pm
and Saturday 10 am to 4 pm.
Freephone 1800 341 341.
Email: helpline@alzheimer.ie
Visit www.alzheimer.ie





help

Supports and services that may help

“The difference to our life has been enormous since Maeve (specialist dementia home care worker) came.... You can plan something on a Tuesday, meet friends or do what ever you want...As well as that (mum) is in great form, all the family notice it.... she is just so happy”

Where do I start?

Many people find it difficult to look for help; knowing where to start, who to talk to and how to get help can feel overwhelming and frightening. Others find it hard to ask for help; some feel disloyal, and some have had a hurtful experience and feel let down.

Most people experience these feelings and situations. It is important to know that looking for and accepting help is a positive step which will benefit you, your loved one, and your family.

There are many ways to build a support network around you. What you and your loved one need today may be different to what you need in a year or two year's time. Your network will change as your needs change. Your support network may include health care professionals, dementia-specific service providers, general services and supports, financial supports, and family members and friends. Each may have a role to play.

The following sections outline:

1. Where to go for information and support in coping with your caring role.
2. Who provides community-based services and how to find your local services.
3. What financial supports may be available to you and where to go for more information.
4. Suggestions on including family and friends in your support network, including tips on asking for help.

1. Information and support

The Alzheimer Society of Ireland provides a range of information services and supports throughout the country. Our staff and volunteers will work with you and your family throughout the course of the condition. Our information and support services include:

The Alzheimer National Helpline

Our free and confidential Helpline service is for people with dementia and their families, carers and anyone concerned about dementia.

Our dedicated team of Helpline Advisors and trained Helpline Volunteers listen and provide information and support on:

- all types of dementia
- how to get help locally
- practical day-to-day tips for living well with dementia
- legal and financial matters,
- accessing care & support and much more.

We post our information free of charge to people with dementia and their families.

The Alzheimer Society of Ireland

Alzheimer National Helpline
Talk to someone who understands

Freephone 1800 341 341
Email: helpline@alzheimer.ie

Monday to Friday, 10 am – 5 pm
Saturday, 10 am – 4 pm

Visit www.alzheimer.ie

“It’s great to know I can pick up the phone whenever things are getting too much.” Family member

“Going to my first support group meeting was like a light going on in my life...I had felt so alone, so powerless,...suddenly I knew there were people I could talk to, and I began to feel I could plan..”

Dementia Advisor Service

The Alzheimer Society of Ireland has a number of Dementia Advisors who work with people with dementia and their families to provide an individualised and responsive information, sign-posting and emotional support service. Our Advisors can meet with you and help you to navigate your journey with dementia.

To find out more about this service call 1800 341 341 or visit www.alzheimer.ie.

Family Carer Support Groups

Meeting others whose loved one has dementia can be really important. It gives you an opportunity to meet people who understand dementia and who are living with similar challenges.

The Alzheimer Society runs support groups around the country. They usually meet monthly and in the evening time. It is an informal meeting and a wonderful way to share experiences and meet others. To find out where your nearest group meets call 1800 341 341 or visit www.alzheimer.ie

Support groups may also be run by other organisations in your community, speak with your doctor, public health nurse or social worker to see what may be available. On-line forums can also be a great source of support and practical information. See Useful Contacts for details.

Courses for Families

Family Carer Education Programmes can provide information and practical skills as well as an opportunity to share ideas and learnings with other families. The Alzheimer Society of Ireland runs education programmes during the year, call 1800 341341 or visit www.alzheimer.ie to find out more. Other organisations who run courses include The Carer’s Association and your local HSE office. See Useful Contacts for details.



Alzheimer Cafes

Alzheimer Cafes provide a warm and welcoming space for people with dementia, their families, friends and health and social care professionals to meet and exchange ideas. The cafe is based on an international model and usually meets in the early evening, although some cafes meet during the day. Contact our helpline at 1800 341 341 or visit www.alzheimer.ie to find your nearest cafe.

2. Services in your community

There may be a number of organisations in your community offering services which you need. The list below outlines the main national service providers; talk to your doctor and your public health nurse about other local providers in your area.

The Alzheimer Society of Ireland, ASI.

The Alzheimer Society of Ireland is the leading dementia-specific national voluntary organisation in Ireland and a registered charity. The Society provides a comprehensive range of services - designed exclusively for people living with dementia, their families and their carers.

Our services and supports strive to provide person-centered care which reflects the needs, wishes and views of people with dementia, including their personality, biography, achievements and life stories. Our trained staff and volunteers work with people with dementia and their families to maximise quality of life.



ASI supports and services include:

- Social Clubs
- Alzheimer Cafés
- Support Groups
- Family Carer Education Programmes
- Day Centres
- Home Care Services
- Respite Centres and Services
- Information and Support Services including our National Helpline and Dementia Advisor Service.

For more information call 1800 341 341 or visit www.alzheimer.ie

The Health Service Executive (HSE)

The Health Service Executive, HSE, is the body charged with providing both community and hospital-based health services to the citizens of Ireland. Your local health office will be able to provide you with the details of the services that

may be available to you and your loved one (See page 41 for contact details). Services can vary from county to county so it is important to contact your local health office or to speak to your doctor about the services that may be available.

In general, the Public Health Nurse or PHN is a key person within the HSE to talk to about community-based services in your area. The Public Health Nurse is often the person who will begin the process to help you access services such as home help, home care and home care packages. They can also help to source local respite services, provide referral to day-care services and provide advice and assistance with continence care management and advice on practical care techniques.

Public Health Nursing services are free to medical card holders, although the service is not exclusive to medical card holders. The HSE states that public health nursing services are free to all people aged over 65 and to those with a long term illness.

Day care, or her club as she calls it, gave her a whole new level of social interaction...and it brought back one of her greatest pleasures in life, singing. She always loved to sing.”

However, availability of public health nursing services can vary considerably from one area to another. You can contact your PHN through your local health office.

There may also be a Primary Care Team operating in your area. This team usually includes a Doctor, Public Health Nurse, Community Nurse, Occupational Therapist, Dietician and Speech and Language Therapist. These teams are not yet operating everywhere. Your local health office or your doctor will be able to tell you if there is a team operating in your area.

Other HSE services include physiotherapy services, occupational therapy, chiropody and social services. See page 41 for contact details.

The Carer’s Association

The Carer’s Association is a national voluntary organisation which provides a home respite service, family carer training, support groups and an information service which may be helpful to you.

To find out more about their services call 1800 24 07 24 or visit **www.carersireland.ie**.

Private service providers

A range of companies and individuals throughout Ireland offer services such as home care and nursing care. The HSE provide a list of preferred providers of private home care services on their website **www.hse.ie** or through their information line 1850 24 1850.

If you pay for private home care services you may qualify for tax relief. You can apply for this relief by contacting your Regional Revenue LoCall service or by logging onto **www.revenue.ie**.

When working with any service provider, remember to check:

- their experience and training in working with people with dementia
- their references
- what the service provides and how much it costs

Working with Health Care Professionals

You and your loved one may be dealing with many health care professionals over the course of the illness. Below are some suggestions to help.

- **Write down the contact details such as name, postal address, and phone number of every person who you are dealing with in one place so you can easily access them.**
- **Keep a diary of all appointments, meetings and visits to help you recall who you have been in contact with and when.**
- **Have someone you trust with you at meetings. They can provide moral support and it also gives you another person to help remember what happened.**
- **Write a list of questions in advance of any meetings; this will help you to remember what you want to ask.**
- **Keep a diary of any problems, symptoms or issues that arise in between meetings. This will help to write your list of questions and answer any questions you may be asked.**
- **Ask for information to be written down, particularly about medications or future meetings.**

3. Financial supports

There are a range of financial supports that may be available to you and your loved one.

Medical Cards and GP Visit Cards are issued by the HSE, both are means tested. Since 2009, people aged over 70 have higher income limits than people under 70, this is often called the Over-70's medical card. For information about the income guidelines and the application process, contact your local HSE Health Office or the Citizen's Information Service (full contact details are below).

Full-time caregivers can apply for a number of grants. Applicants must satisfy the criteria for each grant to receive payment. The payments are made through the Department of Social Protection. The grants are:

- The Respite Care grant - an annual, non means-tested cash payment.
- The Carer's Allowance - a means-tested weekly payment.

- The Carer's Benefit - a payment based on social insurance for those who give up full time work to provide unpaid full time care.
- Other financial supports that may be available include the Household Benefits Package, Free Travel Scheme, Drugs Payment Scheme and National Fuel Scheme
- The Citizen's Information Service provides full details on all of these payments and how to apply for them. You can contact them by calling 0761 07 4000, visiting www.citizensinformation.ie or calling into your local office.

The Alzheimer Society has a leaflet which explains the range of supports set out above in further detail; you can order a copy by calling 1800 341 341 or emailing helpline@alzheimer.ie

4. Including family and friends in your support network

It is important to think about ways your family and friends may be able to be involved and to help.

In many cases, family and friends are very willing to be supportive and to lend a hand, although sometimes it can take some time and energy to figure out how you can all pull together.

“People were always coming and going, the house was always busy. Since John’s been sick, people have stopped calling. People don’t know how to treat him, what to say or what to expect.”

Why do friends and family sometimes withdraw?

Sometimes when dementia enters a family’s life, people feel friends and some family members withdraw or even avoid them. This can be hurtful and cause a lot of upset, anger and distress.

There can be a variety of reasons;

- They don’t realise help is needed, or they may assume you are fine or that others are helping.
- They may not want to interfere and may wait until they are asked to help.
- They don’t know how to help or what is needed
- They do not know anything about dementia and are afraid they will say or do the wrong thing.
- In some cases family members and friends are unwilling or unable to help or support.

In most situations there are steps you can take that will result in family members and friends being part of your support network. In some situations there may be people who will not be part of your network. It is important, for your own well being, to accept there are some things you cannot change and to focus your time and energy on the things that you can.

How do I include Family and Friends in my Support Network?

Some practical tips

- Write a list of things or areas you or your loved one need help and support with. If your loved one with dementia cannot contribute to this task, consider things they enjoy and who they may want or not want to spend time with or receive help from. Remember your needs too, such as being able to spend time with friends and time to relax.
- Consider if you will ask a person to help with one specific thing or tell them about a number of things which they could choose from.
- Think about the person you want to ask and consider when is the best time to approach them. Timing can be an important factor in having a positive conversation.
- When talking to family and friends, consider their likes, dislikes, and interests. If someone likes cooking, then the likelihood of them helping with meals is better. Also consider what the person may be comfortable with and knows something about. Some people are not comfortable with some care-giving tasks but may be only too happy to help with non-care giving tasks, such as cutting the grass or helping with practical household jobs. Respect and accept that people are different and have different strengths.
- Be careful with your tone of voice. Try to be matter of fact and practical and not to involve emotions such as guilt.
- Be as specific as you can in your language. 'I need help' is vague. 'I would like to keep the garden nice so we can sit out when the weather is fine - would you help with cutting the grass over the summer months?' is a specific request.

Family meetings can be a positive step, in that they bring everyone together. This can make planning help and support easier. Your list will help to provide a focus for meetings.

Some families develop a roster or calendar approach, so everyone knows who is doing what when. This also allows you to plan ahead and schedule time for yourself. The roster may need to be flexible as needs and situations can change.

“When we finally got together, we talked, dad explained the help he needed. We all picked something we could help with, suddenly it felt like there were things we could do, and that we could manage, together.”

Prepare yourself for hesitance and refusal

In most cases, people respond positively to being asked. In some cases you may be met with silence or refusal. The person may be unable to help, and an alternative could be worked out. Or a person may be unwilling to help. The person may change their mind over time, or you may be able to ask someone else.

If a person does not help, all you can do is accept their response and move on. You cannot control their actions or inactions but you can control how you respond to it and deal with it. While an unwillingness to help may be hurtful or cause anger, it does not help you to focus on these emotions. Your aim is to build a support network. Try to keep your focus on those who are part of that network and this will help you and your loved one.

planning

Legal & financial affairs

When any illness enters our lives, it can be difficult to think about practical arrangements for the future. However, it is important to consider and seek advice about legal and financial affairs as early as possible.

A diagnosis of dementia does not automatically mean that a person cannot make financial and legal decisions. While a person has the capacity to outline their wishes and to understand the effect of a legal or financial decision then they can continue to make such decisions.

A person with dementia in the early stages of the condition may still be able to make plans in this area. A person in middle to later stages of the condition may not be able to do this. If you and your loved one are not sure about whether these decisions can be made, check with your doctor or solicitor.

Areas to consider

If possible, your loved one with dementia should:

- Visit a solicitor to make a will if they have not already done so.
- Choose a person to manage legal, financial and certain personal care decisions if they are not able to do this for themselves in the future. This involves setting up an Enduring Power of Attorney (EPA), which must be done through a solicitor.

In both of these situations, professional legal advice is required. The solicitor must be satisfied that the person understands what they are doing and the effect it will have, and is not under undue pressure from anyone else.

When a person has a diagnosis of dementia, the solicitor may - and best practice suggests they should - ask for a medical opinion to confirm the person has the capacity to understand what they are signing, at the time of signing it.

In July 2013, the Assisted Decision Making (Capacity) Bill 2013 was published. The bill proposes changes to the Enduring Power of Attorney process and to the Ward of Court system. At time of writing it is unclear exactly what changes will become law or when these new laws will take effect. Speak to your solicitor about how these proposed changes may affect you and how you plan for the future.

Further areas to consider include:

- Organising banking arrangements to make them easier. This can include organising for income payments to be paid directly into a bank account and for regular bills to be put on direct debit or standing order.
- Encouraging the person with dementia to ensure another person knows where important documents are: the deeds to a property, saving and investment details, insurance policy details, pension arrangements, details of income and outstanding loans such as mortgage payments, rent agreements etc.

- Agreeing safeguards, such as making sure large amounts of money are not left in the house.
- Joint Accounts are often used and can be useful if one person is ill or has mobility problems. It is important to know that if one of the account holders does not understand the transactions involved in operating the account due to mental incapacity, the account may be frozen. This would mean that neither account holder may operate the account. It is important to speak with a solicitor and or financial advisor / bank when planning how to manage bank accounts following a diagnosis of dementia.

You should also consider your own legal and financial arrangements in light of the diagnosis and talk to a professional about your own will and financial affairs.

If you and your loved one do not have a solicitor, contact a number working in your area. Talk to them about their experience in working with people with dementia, and their charging structure for work such as setting up an Enduring Power of Attorney. Costs can vary from firm to firm. For a list of solicitors working in your area contact the Law Society at www.lawsociety.ie or call 01 672 4800. When a solicitor takes on a job for you, they are required by law to provide you with a written estimate of costs.

If your income and savings are such that you qualify for legal aid, a solicitor in the legal aid centre may be able to help in areas such as drafting a will.

For more information contact and to arrange a means test contact your local Law Centre. A list of centres is available through the Legal Aid Board – see page 41.

FLAC (Free Legal Advice Centre) is a voluntary organisation which provides information and referral on legal issues over the phone and in a number of part-time clinics usually held in Citizens Information Centres. There is no means test for the service but they do not provide legal representation or undertake work. For more information contact the Free Legal Advice Centre Information and Referral Line at 1890 350 250.

Further information about managing legal and financial affairs and areas such as setting up an Enduring Power of Attorney is available through the Alzheimer National Helpline at 1800 341 341 or helpline@alzheimer.ie.

Useful Contacts

Information about Dementia

The Alzheimer Society of Ireland

Contact the Alzheimer National Helpline

Monday to Friday, 10 am to 4 pm.

Saturday, 10 am to 4 pm

Freephone 1800 341 341.

Email: helpline@alzheimer.ie

Visit www.alzheimer.ie

The Irish National Working Group of People with Dementia is hosted by the Alzheimer Society of Ireland. The group is made up of people with different forms of dementia and meets quarterly to discuss issues that matter to them. To find out more contact the Alzheimer National Helpline at 1800 341 341 or visit www.alzheimer.ie

Alzheimer Society UK provide an online forum for carers called Talking Point at <http://forum.alzheimers.org.uk>

A dedicated online support group for people with Frontal Temporal Dementia, Lewy bodies dementia and alcohol-related dementia is available at www.pdsg.org.uk

The Scottish Dementia Working Group is run by people with dementia and provides information for people with dementia at www.sdwg.org.uk

The Dementia Advocacy & Support Network International (DASNI) provides an online support network for people with dementia at www.dasninternational.org

Service Providers

The Alzheimer Society of Ireland.

For dementia-specific specialist services such as day care, home care, social clubs, family carer support groups and training across Ireland contact:

Alzheimer National Helpline

Freephone 1800 341 341,

Email: helpline@alzheimer.ie or

visit www.alzheimer.ie

The Carer's Association.

For services such as home respite, carer training and support groups around Ireland; Call 1800 24 07 24 or visit www.carersireland.ie

The Health Service Executive (HSE)

To find out where your local HSE Health Centre is or to ask about services that may be available in your area;

Call 1850 24 1850,
visit **www.hse.ie**

The Counselling Directory

For an independent directory of accredited counsellors and psychotherapists visit
www.counsellingdirectory.ie

Irish Association for Counselling & Psychotherapy

To find a counsellor or psychotherapist in your area visit **www.irish-counselling.ie**

Information about financial grants and entitlements

The Citizen's Information Service

This is a statutory body and provides information about public services and the entitlements of the citizens of Ireland. For information about grants and income supports, how to apply for these supports or to locate the nearest office to you; Phone: 0761 07 4000 or
Visit: **www.citizensinformation.ie**.

The Department of Social Protection

The Department charged with the delivery of income supports such as the Carer's Allowance, to find out about these supports and where your local welfare office is visit **www.welfare.ie**



THE ALZHEIMER
SOCIETY *of* IRELAND

The Alzheimer Society of Ireland,
National Office, Temple Rd, Blackrock, Co Dublin
Charity No: 7868

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