



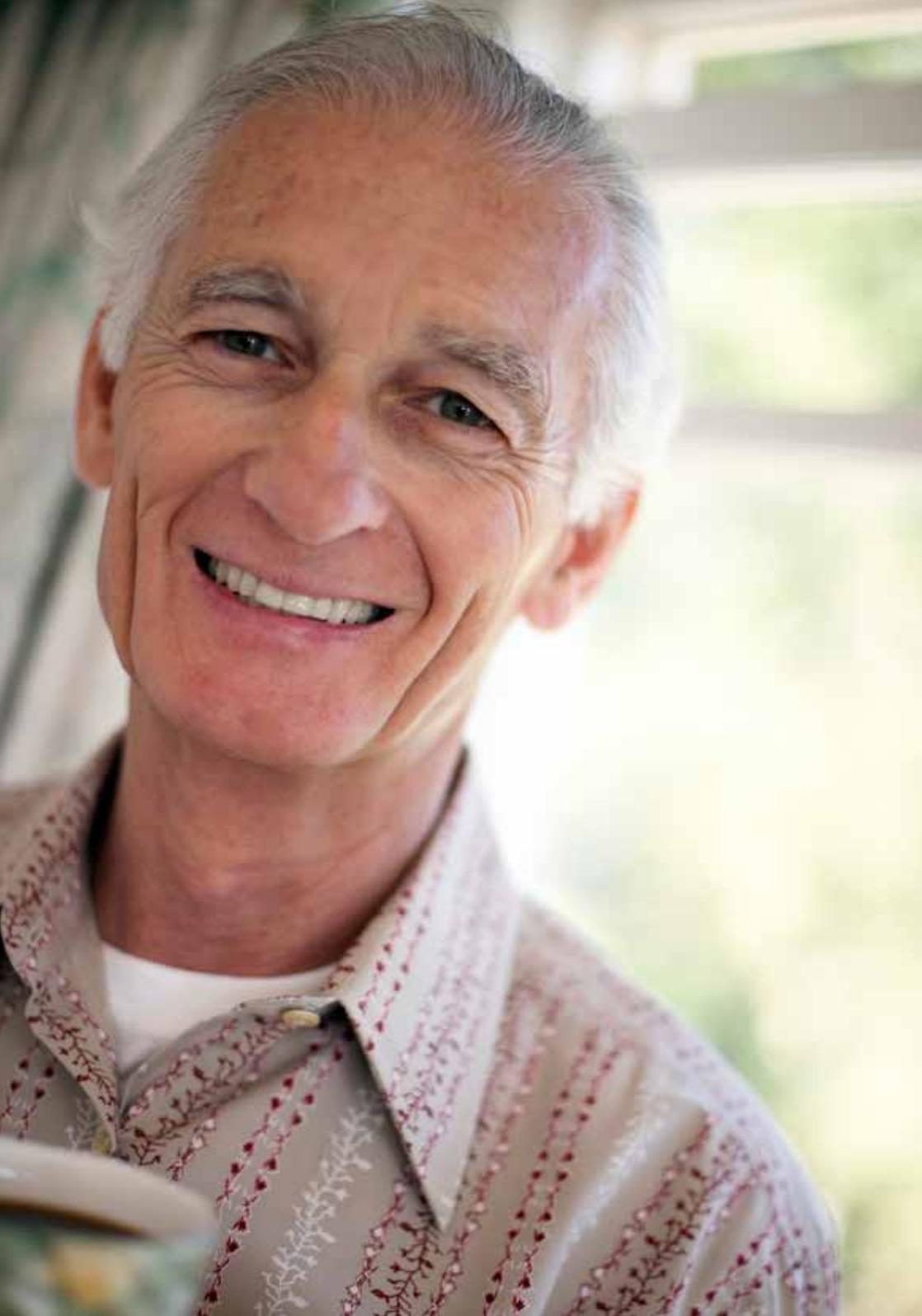
Coping with the Early Stages of Dementia

A Guide for people worried about Memory and Cognitive Problems or those recently diagnosed with Dementia.

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Introduction

The onset of dementia generates a great deal of fear and concern for all those involved. There are fears and concerns for the individual who gradually realises that a deterioration is occurring; for family members or significant others especially those who become primary caregivers and for health service providers involved in the diagnosis, support and on-going care of the individual and his/her family.

For the family, early stage dementia is often difficult to recognise, since initial signs like memory loss and confusion can be transient and may be accompanied by periods of normal and lucid behaviour. One day the person may be calm, affectionate and functioning well, the next, forgetful, agitated, vague and withdrawn. As a result of these fluctuations, the lead-in time to diagnosis can cause considerable stress for families, friends and neighbours because of the uncertainty it brings, and because early symptoms are not always evident to all. It is likely too that when dementia goes undiagnosed, both the individual and family members may struggle, unsure about what the behavioural changes mean and not knowing whether or not they should seek professional advice. In the past, the average time between when symptoms were first noticed and when diagnosis occurred was three years. Nowadays this time lag has reduced, as the public are now more aware of the signs and symptoms of dementia.

It is difficult for those who have not experienced the onset of dementia to comprehend the bewilderment and distress relatives and loved ones feel as they gradually come to the realisation that a partner, parent or sibling is beginning to act in unusual ways and to alter some of their life-long behavioural patterns. It is hoped that this booklet will be helpful in supporting people through this difficult time and that the information it contains will be of assistance to both the individual experiencing the symptoms and their family members.



Dementia and its early presentation

Dementia is an umbrella term used to describe a variety of illnesses, which have different causes but produce similar symptoms. These symptoms vary depending on the cause of the dementia, i.e. the dementia sub-type. Alzheimer's disease, Vascular Dementia, Mixed Dementia and Lewy Body Dementia are the four most common sub-types and apart from these sub-types, the area and volume of the brain affected may impact on how the person experiences the dementia.

The symptoms of Alzheimer's disease may happen in a slow gradual way- the person may have good and bad days, whereas symptoms associated with Vascular Dementia may occur much more rapidly. Broadly speaking, the early symptoms of dementia include difficulties with short-term memory, impaired language and reasoning, disorientation, and sometimes mood and personality change. In the early stages some people are also likely to present with behavioural and psychological symptoms such as apathy, anxiety, aggression, delusions and hallucinations. No two people with dementia will ever present with exactly the same symptoms and the uniqueness of the illness must therefore always be recognised.

By far the most common type of dementia is caused by Alzheimer's disease, which accounts for about two thirds of all cases. In the early stages many people with this illness will retain good insight and may be conscious of their difficulties. Consequently they may feel embarrassed and frustrated, aware they are no longer able to do things that caused no difficulty in the past.

“ *If I have been out shopping.. and I come in and I might want to go to the bathroom, I'm going around opening the doors saying that's not the place and this is out in the hall and I can't remember saying God, what did I come in here for.* ”

MRS CURREN, AGED 74



Recognising Signs and Symptoms

As mentioned, the first signs and symptoms of dementia can be subtle and can vary considerably from one person to another. In some instances, the individual who is experiencing changes may choose to visit the GP; in other cases, he/she may attempt to disguise the symptoms, fearful of the diagnosis and of what people may think, despite the fact that others may already have noticed the changes. For example, friends or family members may already have observed unusual behaviour such as the person forgetting significant events like family birthdays or anniversaries, asking the same question over and over again or recounting the same story, unaware it was told a number of times earlier. A lack of depth and logic in conversation may also be apparent. Sometimes the individual may experience difficulties with verbal and written communication. Language may become vague and sparse of meaning and the person may be unable to find the right word, have limited understanding of the correct meaning of words or may experience agnosia, which is the inability to recognise objects or people for what and who they are. The individual may be well aware of the problems.

“ I’m not as good as before. Sometimes I put things in the wrong place like I put something in the fridge and then can’t find it and it shouldn’t be in the fridge. ”

MRS. MARTIN, AGED 70

Other Early Signs



Early stage dementia is not always characterised by memory impairment or impaired reasoning, but rather sometimes depending on the dementia sub-type, a significant change in the individual's personality occurs. For example, someone who has always been shy and reserved may become very outgoing and disinhibited, or an extrovert may gradually withdraw from all social events. The person may become apathetic or display a lack of initiative in beginning or completing activities

or may be easily distracted, losing the ability to concentrate. General confusion and on-going disorientation in time and place may also be indicators of early stage dementia. Planning and sequencing events may become problematic as the person's executive functioning and frontal lobes become impaired.

Additional symptoms may include the inability to follow through on multi-stage tasks or instructions, or difficulties managing number-related activities like using money (including bill-paying, counting change) or a general loss of ability to do simple everyday tasks including household chores, like setting the table correctly or keeping the refrigerated food in date. Having one of these symptoms does not necessarily mean that a person is developing early stage dementia, nor does a person have to exhibit all of these symptoms to have dementia. This is merely a list of some early signs.

Where symptoms continue to persist to the extent that they interfere with everyday living, this would suggest that these cognitive problems are not simply age-related, and may require further examination by a doctor.

Seeking Help

In the past it was widely believed that memory loss was a normal part of ageing and that there was no point in seeking medical help when significant memory and cognitive problems arose. Nowadays we know a lot more about dementia. We know for instance that significant memory loss is not a normal part of ageing but rather indicative of a pathology, which means that an illness is causing the problem. Therefore seeking out a clinical diagnosis of dementia and ideally finding out the dementia sub-type is strongly recommended.



If the presenting symptoms suggest dementia, getting a clinical diagnosis by a doctor can be the gateway to treatments, which may slow down the progression of the illness. A diagnosis may also be helpful in mobilising support and care services. Obtaining a diagnosis also gives those involved a chance to come to terms with the diagnosis, and can empower the individual to become more involved in his/her future care including obtaining medical and psychosocial interventions. Despite this, many people avoid or delay making an appointment to see a doctor because they are frightened and may not be ready to hear about their condition.

“ “ *After the assessment I could tell myself that I understood more the reason for why things were going on... because until you know the reason , you just think its bad behaviour. ” ”*

MRS BURNS, FAMILY CAREGIVER

Sometimes family members, friends or neighbours do not know how best to approach the person who they are concerned about as they may be afraid this might upset that person. Often the family may have great difficulty getting the person experiencing the symptoms to agree to see the doctor. For those people who may be particularly frightened about their memory problems and reluctant to attend their doctor or a Memory Clinic, a Memory Assessment service like that currently available at Dublin City University may be a less frightening alternative. This type of service is not diagnostic and offers individuals an opportunity to discuss with a trained nurse practitioner, their fears and concerns. Based on the Nurse's assessment and if necessary, the person may then be referred on to the appropriate service. A similar type of service has recently been established in Ballina, Co Mayo. In the future it is hoped that more of these services will be available throughout Ireland.

It also needs to be kept in mind that not all memory problems mean that a person has dementia. Assessment by a doctor can rule out the existence of such conditions and may result in treatments and strategies which will help address these non-dementia related memory problems.

Seeking a Diagnosis of Dementia

Making an appointment with a GP to discuss your concerns about memory or cognitive problems is the first step towards obtaining a diagnosis. The GP will most likely start by trying to exclude any other reason for the problems experienced, by taking blood tests, asking for collateral history, conducting memory and cognitive tests and talking with the individual and with his or her next of kin. In some cases, after an initial assessment, the GP may make a referral to a Memory Clinic (generally an out-patient service) for further specialist evaluation, including more in-depth memory testing. Other specialists such as Geriatricians, (doctors with expertise in assessing and treating health problems in older people), Neurologists (doctors with particular expertise in the brain) and Old Age Psychiatrists (doctors with particular expertise in mental health problems and ageing) are also specially trained to diagnose dementia and advise people about their prognosis and about how they can live well with dementia.

“ *It just gives a person the peace of mind that yeah, we definitely know what it is and life goes on.* ”

MRS BARRY, FAMILY CAREGIVER

Reactions to a Diagnosis of Early Stage Dementia

When a diagnosis of dementia is made and disclosed, the person and family member receiving the diagnosis may experience a range of different emotions including shock, anger, fear, frustration, anxiety, loss, guilt or sadness. The person may feel stigmatised or labelled and may think that others will perceive all his/her behaviour as inadequate or clumsy. Different coping mechanisms may be adopted such as covering up or disguising the difficulties, distancing oneself from the illness, normalising or denying the symptoms, or merely focusing on one's physical health. In some cases, the person affected may feel relieved since the diagnosis explains why these changes are occurring.

After news of the diagnosis is conveyed, several dilemmas may confront those most immediately affected. One such dilemma concerns whether to tell other family members, friends and neighbours about the diagnosis. Differences of opinion may arise as to whom to tell. Some people may carefully select out those whom they believe it is appropriate to tell, - perhaps close friends



and family members but may avoid telling others. Remember, the decision about who to tell is the prerogative of the individual and his/her close family members.

If a friend or relative comments about the person's memory loss or changed behaviour, or asks questions about how the person got on at the doctor's appointment, rather than brushing over the topic, it may be helpful to simply explain to that person what the doctor said, the difficulties that are being experienced and how much that person's friendship is appreciated during this difficult period. It may also be helpful at this stage to talk to someone who can be trusted such as a doctor, social worker, other trained health service professional or a staff member from the Alzheimer Society of Ireland.

Sharing the diagnosis may bring relief and make socialising a little easier since others may be more tolerant and understanding of the forgetfulness or changed behaviour. People with early stage dementia and their family members all cope with the challenges that dementia presents in different ways. They often become skilled at adapting their behaviour and changing daily routines in order to avoid being confronted with upsetting or frustrating incidents. Experts working in the area recommend that people with dementia and their families should try as best as possible to be honest and open and continue to lead a normal life:

“ *I still pal with my same friends that I worked with. I still go out with them. I always go out on a Saturday night.* ”

MRS. GANNON, AGED 62



After the Diagnosis: Some Practical Advice for the Individual

- Ask your doctor about anti-dementia drugs and other types of interventions that are available that might improve your quality of life or make getting through each day a little easier for you.
- Try to organise your financial affairs. Consider setting up a direct debit account, this may make bill payment a lot easier.
- Talk to a Solicitor about an Enduring Power of Attorney. By nominating someone to make legal/financial decisions on your behalf should your memory become more seriously impaired, this may help avoid significant difficulties at a later stage.
- Find out what community services exist in your area by talking to the local branch of the Alzheimer Society of Ireland, your GP, Public Health Nurse or staff at a Memory Clinic.
- Find out what type of assistive technologies are available which might make daily living a little easier
- Talk to health service professionals such as social workers or the public health nurse about where you may be able to access assistance such as Home Help (HSE/Private), Meals-on-Wheels, Carer's Association.

After the Diagnosis: Some other Suggestions for the Individual

Try to focus on activities that the person can still do and that are enjoyable and pleasurable. For example, the individual should continue with his/her favourite hobbies, gardening, golf, walking or any other activities that are fun and bestow satisfaction provided they do not pose a problem. Remember even with a diagnosis of dementia, exposure to new experiences can enrich brain connections so the person may consider taking up a new hobby like painting, gardening or singing in a choir.



The person diagnosed should try to keep physically healthy, as being healthy can help protect the brain from further deterioration. The person should try to maintain a balanced and nutritional diet, by eating plenty of fruit, green and dark coloured vegetables and fish. Brisk walking, up to five times a week, may also help to support cognitive functioning.

The person diagnosed with dementia should try to avoid stressful situations whenever possible. For example, the failure to recall information can sometimes cause frustration and stress. Accordingly the person could consider using memory aids or should consider seeking out help from a family member or close friend. The person should also try to relax as anxiety interferes with the ability to absorb and retrieve information. At all times, the person should not be afraid to ask or accept help, or to ask family or friends to repeat things over again.

“ *Sometimes I’m annoyed with myself that I’ve forgotten something and I say I have to do better than this- I laugh and say, get your act together* ”
Bernie

MR. WATTS, AGED 82

Practical Advice for Maintaining Independence after Diagnosis

In the early stages of dementia, a number of practical measures can be adopted to enable the person to remain independent and to make daily living easier:

- Keep a pen and a calendar with large writing spaces near the phone.
- Write down all-important events such as appointments, social activities, due dates for bills, and medical visits on the calendar or into one notebook and check this notebook every day.
- Write a daily to-do list and keep it in a visible spot.
- If you are taking medication, keep it organised to make it easier to remember when to take. Use a medicine dispenser or a dosette box or ask your pharmacist to blister pack the medications to facilitate correct dosage.

- Keep a large clock in a prominent place in the living room and if possible get one that also shows today's date.
- Use a mobile phone which shows the day and date and programme frequently used numbers into your phone.
- Make sure bills and other important papers that require attention are kept visible, this helps ensure that they will be dealt with.

“ *I don't feel that anything is going to change you know, sure I just get along with it. Sometimes I'm not as bad as other times.* ”

MRS. CURRAN, AGED 74

Support Services

A number of statutory and voluntary services have been developed to support people with dementia and their caregivers to continue to live at home after they have been diagnosed. But remember, service availability in Ireland varies according to where the individual lives. For this reason we cannot provide you with a complete list of services. Detailed below are some of the main services that may be of assistance to you. A good starting point however is at your Local Health Office where your Public Health Nurse should be able to advise you about services available in your area. The two key schemes through which the State supports older people living at home including those with dementia are the *Home Help Service* and *Home Care Packages*.

Home Care: The two key schemes through which the State supports older people living at home including those with dementia are the Home Help Service and Home Care Packages.

Home Help Services: These fall under the umbrella of Community Services and aim to assist older people to live successfully in their home through providing specific help, for example house cleaning, and cooking meals. By providing home help, it is hoped that the person will not only live independently at home for longer, but also be supported to avoid unnecessary hospital admissions. Applications for Home Help Services are made through the local public health nurse who will arrange to have an assessment undertaken to determine if the person is eligible for the service. The home help is provided either directly by the HSE, or by community/voluntary/private sector agencies in arrangement with the HSE.

Home Care Packages: These have also been designed to assist older people to live at home for longer. There are two types, (i) short-term packages where the older person is helped to return to independence as, for example, after an operation and (ii) long-term packages, which are probably more relevant to people with dementia. The long-term packages aim to help the individual who has more complex and multiple care needs to live successfully in the home. However, not all HCP are able to provide 24-hour supervision or overnight care. The latter may be an issue if a person with dementia requires such care.



Day Care: In Ireland, three types of day care (also known as day respite) are available to older people with dementia depending on where the person lives. These are (i) generic day care, (ii) dementia-focused day care and (iii) dementia-specific day care (only people with dementia attend). The Alzheimer Society of Ireland delivers dementia day care services with help from the HSE. The country is divided into 32 Local Health Office areas (LHOs) and many of these LHOs have no dementia-specific or dementia-focused services. The generic day care centres provide care for the general population of older people, and may or may not accommodate people with dementia. Access to the Day Care centres is through the public health nurse, GP, the Alzheimer's Society of Ireland and sometimes but not always through self-referral.

In Home Respite Care: This service varies depending on where the person lives. The Alzheimer Society of Ireland offers in-home respite care where a trained caregiver spends time in the home of a person with dementia to enable the family caregiver take a break from caring. In-home respite can also be arranged through the HSE.

Residential Respite Care: This is a particular type of respite care designed to give the individual with dementia a short break or "respite" away from his/her home. The service is also available to assist family caregivers take a break from caring, perhaps go on holidays or simply get on with their own lives. The service is provided in public, private and voluntary nursing homes. The Alzheimer Society of Ireland is currently offering some limited residential respite in areas including Blackrock Day Care Centre (Dublin) and the Waterman's Lodge (Tipperary). Both services operate seven days a week offering the carer a rest and a break. Respite care can be accessed through the public health nurse or GP.



Respite Care Grant: The respite care grant is an annual payment from the Department of Social Protection made to full time caregivers. The current value of the respite care grant is €1,375 and it is normally paid the first week of June each year. The grant is paid automatically to the recipients of *Carer's Allowance*, *Carer's Benefit*, *Domiciliary Care Grant* or the *Prescribed Relatives Allowance*. Other full-time carers can also claim the grant if they meet certain criteria. Despite the fact that this is called a respite grant there is no stipulation on how exactly the respite funding is spent. If you care for more than one person you can claim the grant for each person.

Summary

The information contained in this booklet has been collated from practice experience, from the literature, from formal and informal caregivers and from other academic and health care sources. It is aimed at helping people who are coming to terms with memory loss and cognitive problems and who are unsure what to do and who to talk to. It is also aimed at those who have recently been diagnosed with dementia and are attempting to deal with their clinical diagnosis and the range of emotions that are often experienced. The booklet has also been designed to assist family members support their relatives and come to terms with the changes experienced. It also provides general information about some of the basic statutory and voluntary services available in the community to help people who have recently been diagnosed with dementia. We hope it will be helpful to you in your journey through dementia.

“ There are still many things I can do like, walking, smiling, crying, laughing, speaking my way. I am here and I hear you speak. I have not yet gone. ”

MCKINLAY, 2004

Useful contacts

Alzheimer Cafés

The Alzheimer Café is a safe and relaxed place where people with dementia and their families can meet to share experiences and talk about dementia.

www.alzheimercafe.ie

Alzheimer Society Social Clubs

Drop-in centres for carers and people with dementia.

Contact the ASI on 1800 341 341.

www.alzheimer.ie

Alzheimer Society of Ireland Home Care Service

Specialist home care/home support service that use trained dementia care workers to provide support and care in a persons home for a designated number of hours per week.

Contact the ASI on 1800 341 341

www.alzheimer.ie

Carer Support Groups

Carer Support Groups operate on a local level and details are available from the local branch of the Carer's Association or your local Alzheimer Society office.

Caring for Carers Ireland

Contact 065 6866515

www.caringforcarers.ie

Citizens Information Centres

Contact 1890 777 121

www.citizensinformation.ie

Free Legal Advice Centres

Contact 1890 350 250

www.flac.ie

Private Home Care Agencies

Several agencies now provide home care services. Lists of approved, fully insured, agencies are available from Local Health Centre's and Social Work Teams. Costs may vary.

The Carers Association

Home Care Assistance: The Home Care Assistance Service of the Carers

Contact 1800 24 07 24

www.carersireland.com



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For more detailed information on living with dementia, please see our booklet:
Cognitive Impairment and Dementia: A Practical Guide to Daily Living for Family Caregivers



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