



Helping Families Cope

*A Dementia and Alzheimer's Guide for Family
Caregivers*

You are Not Alone

Home Instead is delighted to publish this short guide to dementia. It is hoped that carers looking after a loved one with dementia will find it a sensitive and practical approach to several dementia care issues.

Until a loved one begins to show signs of dementia it is often considered a disease that happens to other people. The journey of dementia can be a long and sometimes difficult one so being prepared for the tasks ahead may help you.

You may have noticed your loved one forgetting where he or she left their keys or taking a bit longer to remember someone's name. You may put these events down to "just his/her age". There may be a series of such events that has made you wonder if it could be more than just age.

What is Dementia?

Dementia is an umbrella term for a group of illnesses including Alzheimer's disease that can cause a progressive decline in the person's personality and their ability to remember and reason.

Dementia is characterised by:

- Memory loss of recent events
- Diminished reasoning ability
- Difficulty in learning new concepts
- Stress levels are high
- Social events prove difficult
- The built environment is a problem, getting lost in the community and later in the house.

There are many types of dementia – the most common types of dementia are:

- Alzheimer's Disease
- Vascular Dementia
- Mixed Dementia (Alzheimer's Disease + Vascular Dementia)
- Lewy Body Dementia
- Pick's Disease (Fronto – temporal Dementia)

Alzheimer's Disease:

This is the most common form of dementia, it accounts for more than 50% of cases worldwide. It is most commonly seen in those over 65 years of age. Loss of memory of recent events can be one of the first issues with memory of past events remaining intact. We all forget things from time to time, but memory loss with dementia is persistent and not just occasional. The disease progresses at a different pace for each individual and may, in the early stages, fluctuate from day to day. As time goes on everyday tasks become an issue and processing information becomes difficult.

Vascular Dementia:

This is the second most common form of dementia. It is due to problems in the circulation of the blood to the brain. It is most commonly seen following a stroke or several "mini" strokes. Vascular dementia often progresses in a stepwise fashion when the person's ability deteriorates following a stroke and then is stable until another stroke occurs. The risk factors for stroke (high blood pressure, smoking, obesity and diabetes) may contribute. It is common for

some people to have a mixed form of dementia – Vascular disease and Alzheimer’s disease

Lewy Body Dementia:

This can be very mild at the onset and can vary from day to day. There can be fluctuation in cognitive function and it is often accompanied by hallucinations and or delusions. Tremors, stiffness leading to falls, difficulties judging distance may all occur.

Pick’s Disease / Fronto – temporal Dementia:

This is due to the progressive degeneration of the frontal and temporal lobes of the brain. Damage to the temporal lobe affects language and emotion. Damage to the frontal lobe affects judgement and behaviour. It usually begins between 40 and 65 years of age. Personality changes occur and can include impulsivity, hyperactivity and being obsessive.

Leslie, who cared for her 91-year-old grandfather with Alzheimer’s disease, in her home, helps to illustrate this situation:

“Because my grandfather is home alone during the day, I come home over my lunch hour to check on him. Grandfather has been living with me for three years, but still thinks he is visiting. At first, he was quite independent and resisted any kind of help, saying he could do everything on his own. One day I discovered that he had gone into the back garden, locked the door behind him and spent the afternoon sitting in the rain. The weather was bad that day, and Grandfather had not eaten or drunk anything all day. This made me realise that for his safety and wellbeing, he shouldn’t be alone anymore.”



Communication:

When a person develops dementia, the damage to the brain may result in difficulty finding the right words or in understanding the spoken word. Attempting to communicate can be frustrating. A person's needs in communication skills should be addressed early to help them to maintain social interaction, function and quality of life. Individuals with impaired memory are able to transmit meaningful communication. Carers can use their communication skills to help make up for what the person has lost.

The person may repeat a phrase or word over and over. This can often be difficult for the carer but communication can be enhanced by:

- Avoiding extra external noise and avoiding distractions. Even music during conversation can confuse communication efforts.

- Using short simple sentences to get your point across. Working memory difficulties can interfere with verbal comprehension. Therefore presenting people with complex sentences puts increased demands on memory.
- Avoiding open ended questions which require more than a yes or no answer, use direct statements and be prepared to repeat requests.
- Ensuring that you don't interrupt the person.
- Maintaining eye contact to show the person you are trying to understand.
- Using prompts and cues.
- Remaining calm and using a soothing tone of voice. The ability to feel and sense emotions (fear, joy, excitement, pride, anxiety, sorrow, sympathy) should be assumed to remain intact in a person with dementia.
- Allowing time after a verbal prompt or question for a response. It takes a person with dementia longer to process the information.

Non verbal communication: When a person finds communication difficult there are many forms of non verbal communication that can be used. These include old photos, family videos/DVD's, singing, hobbies (gardening, cooking, etc). People with dementia can be very dependent on body language and tone of voice for communication.

Remember, to a person with dementia, if they cannot see something, then as far as they are concerned, it isn't there.



Practical Tips:

During the early months or years people may or may not have insight into their condition. Often people are depressed with low self-esteem. Some people may be passive and resigned others angry and agitated.

As the disease progresses people become more dependent and lose the ability to carry out simple tasks. The person's behaviour may surprise or shock you. You may be anxious and find coping difficult. These suggestions may help:

- Involve your loved one as much as possible – allow your loved one to do as many of the tasks they used to enjoy as possible. This will require prompting and patience. Putting a hairbrush in your loved ones hand and saying, “brush your hair” or showing the person with dementia how you brush your own hair.
- Allow more time for a task – always keep in mind that tasks take longer and give simple instruction on how to complete the task.
- Plan your day – try to schedule trips to the doctor, dentist etc at a time you know is best for the person. It also helps to carry out personal care at this time if it is a problem.
- Maintain flexibility during the daily routines – although routine is good the approach to the day should be flexible to accommodate the needs of the person with dementia.
- Relax if you can - allow the person to do as much as possible with the least amount of confusion and assistance. Try to make it seem as if you are not taking over or in charge.
- Maintain a safe environment – the risk of slips, trips and falls increases with dementia. The following may help: avoid small

rugs and trailing electric cables where the person walks, install handrails if appropriate, make the bathroom more user friendly, ensure medications are locked away, use low lights at night to light the way to the bathroom.

- Limit choices, have fewer options to aid decision-making. Reducing distractions helps the person to focus.

Making mealtimes more enjoyable:

The senses diminish with age. Healthy older adults lose their appetites, their sense of smell and taste. In addition people with dementia sometimes have difficulty recognising food and often miss meals as their hunger pangs are not recognised. Finger food can be helpful for those who will not sit to eat, those who find using cutlery difficult and those who need extra calories if losing weight.

Examples are, fruit slices, sausages, fish fingers, hardboiled eggs, filled rolls, muffins, etc.

Sometimes meals take longer as the person with dementia may need prompting to chew and swallow. Try to ensure there are few distractions and reheat the food during the meal if needed.

If you are concerned that your loved one is not eating enough then a food “diary” should be kept to determine the exact amount of food and drinks the person consumes daily.



Factors that contribute to poor eating and drinking include:

Swallowing difficulties, distractions, agitation, restlessness, poor hand to mouth coordination, reduced sense of smell and/or taste, discomfort, pain, medical illness, oral or dental problems.

The following example shows how a family caregiver involved her sister, Rebecca, in a mealtime activity:

When it came time to make dinner each night, Rebecca would want to help, but was no longer able to cook step-by-step or handle the hot foods. So I encouraged her to set the table, butter the bread, and select a drink so she could still be involved. The most challenging thing for me was to keep Rebecca busy and occupied, yet safe at the same time. It was well worth the extra effort. I could tell Rebecca was happy to be included.

Creating meaningful activities:

For an individual with dementia an activity is anything that fills time with a purpose and occupies them.

The family caregiver can also benefit in these ways:

- Better quality time spent together
- A happier loved one
- Increased free time.

Being occupied and feeling included are two of the main psychological needs of people with dementia. It is important to encourage a person with dementia to maintain a hobby or interests.

It may be necessary to create a new interest that provides opportunity for feelings of well being and relaxation.

Examples of activities:

- Helping with drying dishes/setting a table
- Sorting laundry/socks/tea towels
- Going for a walk, sweeping leaves
- Reading the newspaper, looking at pictures in magazines
- Potting plants/bulbs, watering potted plants.

The following example shows how one family caregiver created a meaningful activity for her mother:

I came up with the idea of making necklaces out of beads and string to keep Mum busy in the morning. Stringing the beads onto the string required concentration and she enjoyed doing it. I took the activity a step further and decided to give the necklaces to Mum's grandchildren. When I shared my idea with her, she was excited and wanted to make more.

Activities should be about pleasure and success, not stretching or challenging the person. Activities should in the main complement lifetime habits. To plan these activities it is essential that knowledge of the likes and dislikes are well known. Things that gave the person pleasure and made them laugh before the dementia will still do so later on.

The two essential questions?

At home did your loved one cook, clean, organise, pay bills, work in the garden, entertain, repair items, etc?

At work was the person working indoors or outside, what activities did this involve?

Activities should:

- Mirror your loved one's life experience
- Honour the need to feel useful, appreciated and give a sense of belonging
- Ensure that the minimum amount of stress is placed on the person.

Activities that mimic occupational or domestic activities can be useful. Experiment with activities that were enjoyed in the past by your loved one and concentrate on those that result in the person relaxing and being less agitated.

Sometimes creating an environment similar to the one from the person's past can be helpful. For example if the person worked in an office environment creating a similar space at home where the person can potter can be very relaxing for your loved one.

Sorting activities can be relaxing as well, i.e. items from the garage, garden shed, sewing box, photos into albums, etc.

The garden can be a source of great joy. Many happy hours can be spent weeding, watering, dead heading plants, re-planting, etc.

Working with laundry is a familiar activity and folding towels, pillow cases, matching socks can be therapeutic.

Cooking in safety can be valuable and will make the person with dementia feel they are contributing to the daily tasks in the house. Setting tables, clearing up, washing and drying are all familiar activities.



The following are some additional suggestions to use with your loved one as you do activities together:

- Plan each day one step at a time
- Be flexible, if something doesn't work, go to plan B
- Accept outside support when it is offered
- Speak slowly and refrain from asking your loved one questions
- Right now is forever, so enjoy it.

The best way to approach any activity is to simply think how you would like to be treated.

Activities where physical effort is needed can result in an improvement in sleep patterns and less agitation.

Reminiscence provides satisfaction and a sense of achievement for both carer and loved one.

Some of the issues you may encounter with a loved one and dementia:

Confusion – the person with dementia may feel very frustrated by their inability to orientate to time, place and person. To someone who is very confused, questions are an irritant. Asking someone who does not know where he or she is, where he or she is going, will only cause annoyance. Simplify tasks. Divide dressing, bathing, and grooming into smaller, discrete tasks to accommodate deficits in working memory.

Repetitive Questions, Repetitive Phrases or Movements, Anxiety and Hostility – these are often repeated requests for help. They may or may not be a response to stress, seeking attention, or lack of stimulation. Some people seem to find talking comforting. A range of interventions can be designed to lessen the effect of the repeated behaviour.

The following approaches may be helpful:

- Try to determine if the verbal behaviour or repeated movement is distressing to the person
- Investigate if it is an unmet need – could it be hunger or thirst?
- Provide reassurance if intimate care is approaching – the distress may be in anticipation of care procedures
- Allow for pain, infection, constipation or other medical issues
- Allow for more rest periods, verbal agitation can cause excessive fatigue
- Consider smell, noise, light, temperature or activity. All can contribute to these behaviours.

Aggression - can be verbal or physical and often occurs when the stress level of the person with dementia has been exceeded. Often the person with dementia feels their personal space is being invaded. Depression is often associated with verbal outbursts.

Dealing with an acute episode can include:

- Positioning yourself at the person's level, speaking slowly, maintaining eye contact and being calm
- Divert attention away from the event
- Distract and redirect the person if you can
- Investigate your loved one's fears and show them you understand their distress
- Minimise external stimuli
- Understanding the behaviour is vital and knowing the triggers are very important if you are to avoid reoccurrence.

Wandering – wandering only needs to be addressed if it presents safety issues or is causing your loved one distress. Using an identification bracelet can be helpful.

Wandering in a person with dementia can be:

- A means of coping with stress
- Trying to make sense of their environment
- Seeking something or someone recognisable
- Wanting to go “home” is often looking for the childhood home.

Sundowning – can be the change in a person with dementia which occurs late in the afternoon and is often accompanied by agitation and confusion. There are many theories why this occurs. Some feel tiredness at the end of the day is the issue, others look at hunger and hydration issues, others at light changes and some at the daily cycle of body temperature.

It can be helpful to have some activity that your loved one likes at this time.

Incontinence - incontinence tends to occur late in the course of dementia.

It is important to:

- Have a medical evaluation to see if a reversible cause may be found
- Recognise signs such as fidgeting/agitation, which may alert you to the fact that your loved one needs to use the toilet
- Remind the person where the toilet is and to use it frequently
- Use incontinence pads and appropriate hygiene when necessary.

Hallucinations / Delusions

The most common hallucinations are those that involve sight or hearing, but may also include smell, taste and feeling things that are not really there. Hallucinations are most common in Lewy Body Dementia.

It is important to:

- Acknowledge the feeling
- Try to let your loved one know that although you are not sharing their experience you understand how distressing it is for them
- Offer reassurance and stay calm
- Distracting the person may help.

Delusions are fixed, false beliefs not based in reality that are out of keeping with a person's background and are held with conviction despite contrary evidence.

It is important to:

- Reassure the person that you are on their side and offer help
- Distract them with other activities.

Suspiciousness

As a result of diminished perception adding to the confusion people with dementia may be suspicious of what is going on around them. They may accuse someone of stealing from them when an item has been mislaid. There is often great paranoia around money. This may be in relation to pension, wallet, purse handbag, etc.

It is important to:

- Acknowledge the feeling calmly
- Offer reassurance
- Attempt to be straightforward and help to look for the item.

Following the Carer around

People with dementia may follow their caregiver from room to room. Initially this may be reassuring for the caregiver, ensuring the person does not wander off. After a while it becomes exasperating, but it is a real sign that somebody may feel insecure.

It is important to:

- Remain calm
- Provide enjoyable activities and distractions for the person
- Provide a safe environment by locking away dangerous items.



Caring for the Caregiver

It's estimated that half of all Alzheimer's family caregivers experience depression. Family caregivers also experience personal health issues, complications in the workplace, fatigue, and stress with other family members that result in conflicts and less leisure time.

On the positive side, some family caregivers find that providing care in the home is beneficial because it gives them a new purpose in their lives, strengthens family relationships, or fulfils commitments to their loved one.

Providing around-the-clock care requires a great deal of time and energy mixed with financial cost. These factors can take a significant physical and emotional toll.

As a family caregiver, you must learn to nurture your own needs.

The following recommendations provide you with some coping strategies for these daunting challenges:

- Look for support – Many family caregivers withdraw from family and friends because they feel no one understands. It is very helpful and in many cases, therapeutic, for you to join a support group where you can learn from others through sharing your experiences
- Let go of guilt – Let go of “the guilt trip” by realising a need to temporarily set aside care giving responsibilities for a period of respite
- Nurture the body – Be sure to get enough sleep and eat properly
- Nurture the mind and spirit – Schedule family sessions and discuss any conflicts that relate to the care of your loved one
- Take breaks from care giving as often as possible by asking other family members to help. Be sure to acknowledge your feeling of loss and grief
- Establish limits – Say no to requests that are beyond your capacity and say yes to offers of help with a loved one.

Remember you have your own needs too.

Legal Planning

Legal planning is very important for your family and your loved one with dementia. As the disease progresses, he or she will no longer be able to make sound decisions about finances or health care.

You should have legal documents in place that identify those who will make important decisions on behalf of your loved one with dementia. Ideally, these documents are in place long before you need them. If they are prepared during the early stages of Alzheimer's, the person affected by the disease may be able to participate in the process and share his or her wishes.

Legal planning can be confusing and sometimes overwhelming. Your family should seek the advice of a lawyer or financial professional as soon as possible to help you make informed decisions about estate planning and wills.

As a family caregiver and someone making important decisions, you should look at several items. These include:

- Joint Bank Accounts
- Agency Arrangements for Social Welfare Payments
- Making a Will
- Enduring Power of Attorney (EPA)
- Wards of Court
- Trusts
- Covenants
- Tax Relief.

Joint Bank Accounts

Joint bank accounts are a particularly useful means of dealing with one's financial affairs when a person has mobility problems, or is unable to take responsibility for maintaining an account on their own. Any person can open a bank account when that person has the

necessary mental capacity (which may be the case when a person is diagnosed with early stage dementia). When an account is opened an account holder may authorise the bank to accept cheques if signed by another individual. If one account holder becomes mentally incapacitated, the legal authority to operate the account may be revoked and it may not be possible for the account to be used by the other joint account holder. Check this out with your bank when opening the account.

Agency Arrangements for Social Welfare Payments

The Department of Social, Community and Family Affairs has the power to make payments to a third party acting on behalf of the recipient. The person to whom a social welfare benefit is payable may nominate another person to receive that benefit on their behalf. The person nominated (known as an agent) has no power to deal with other financial matters.

Making a Will

If not already done, the person with dementia should be encouraged to make a Will as early as possible, disposing of their estate. It will be necessary for a doctor to certify that the person with dementia is still mentally capable of making and understanding such a document. If they are married, their spouse should also make a Will. A Will is a written document in which a person sets out legally binding wishes in relation to the distribution of an estate after death and any other personal wishes they may have.

Enduring Power of Attorney (EPA)

An Enduring Power of Attorney (EPA) is a legal arrangement whereby one person (the donor) gives authority to another or others (called the attorney) to act on their behalf in the event of a donor becoming mentally incapable of managing their own affairs. As long as the donor is well, the EPA cannot be acted upon by the attorney. A person can only grant an EPA if they are capable of understanding

what it is and what it is intended to do. It is still possible for someone to grant an EPA after dementia has been diagnosed so long as it is clear that they are fully aware of what is involved. The GP or consultant will be required to provide a statement providing that, in their opinion, the donor had the mental capacity at the time of execution to understand the effect of creating an EPA. If this is in question, it may be necessary to have the document signed by the donor in the presence of both the solicitor and the doctor.

If the dementia has progressed to the point where the person is unable to make an EPA, application may have to be made to have the person with dementia made a Ward of Court. A Ward of Court is a person who is declared to be of unsound mind and incapable of managing his/her person or property and no EPA has been executed previously.

The principle purpose of wardship is to protect the property of the ward and manage it for the ward's benefit and the ward's dependants (if there are any). Pending this, the funds are made available by the court to pay expenses, such as home care expenses as funeral expenses and probate tax.



Trusts

Trusts are another way of handling the financial affairs of another person, whether or not that person is incapable of dealing with their own affairs. A Trust exists where a person (the trustee) holds the property of another (the settlor) for the benefit of named people (the beneficiaries). The beneficiaries may be the settlor or other people. Trustees hold and manage the trust property and normally

have powers to purchase assets and services for the use or benefit of the beneficiaries rather than handing over the money. There is no supervision of the conduct of the trustees as long as they carry out the terms of the trust.

Covenants

In certain circumstances, an individual may claim relief against an assessment of income tax if that person is making payments by way of a covenant to another person. A Deed of Covenant is a legal document under which one person agrees to pay a certain sum of money each year to another person. The advantage is that the person paying the money can effectively not pay tax on it. The money is transferred to someone who does not have a taxable income or pays a lower rate of tax than the person giving the money. In order to qualify for relief, there must be a legal obligation to covenant a sum of money for a period which is in excess of six years. The circumstances in which an older person can receive sums which are deductible from the covenantor's income are:

- if the older person is permanently incapacitated (mentally or physically)
- if that individual is over 65 years of age
- through payments which are part of a maintenance agreement between separated spouses.

Tax Relief on Home Care Fees

A tax allowance may be claimed if you, your spouse or a relative are incapacitated for a tax year by reason of physical or mental infirmity and you employ home care to care for the incapacitated person. A relative includes a relation by marriage and a person in respect of whom the claimant is or was the legal guardian.

A Home Instead Senior Care Stress Resource

Home Instead Senior Care®, the leading provider of home care for seniors, is available to provide you the respite you need and the care you need for your loved one. With CAREGivers trained in Alzheimer's and dementia care, your local Home Instead Senior Care franchise office is committed to helping families like yours by providing service for just a few hours, or around-the-clock, depending on your needs.

Home Instead Senior Care also provides you a free online assessment tool that allows you to gauge your stress level. Visit caregiverstress.com for this innovative tool. Once you complete the online survey you receive tips, advice, and links to important resources.

Home Instead Senior Care contact details:

Tel: 1890 930 013 • www.homeinstead.ie

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