



# Dementia Care at Home

A Guide for Family Caregivers

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## Introduction

In Ireland, approximately 64,000 people are currently living with some form of dementia. 180,000 people in Ireland are currently or have been carers for a family member or partner with dementia.

Home Instead understands the stress these conditions can cause in the lives of older people and their families. In fact, many of the older people cared for by Home Instead have dementia. So we've witnessed the fear and loss that older adults face. We've come to understand how Alzheimer's disease or other dementias affect family caregivers as well. These conditions may take their energy, peace of mind and happiness.

If you're living it now, you know all too well. If your loved one just received the diagnosis, you're likely anxious about the future – for your loved one and yourself.

You want your loved one to be safe and engaged in life. But given the cognitive and physical changes that sometimes accompany dementia, how can you ensure this happens? And how do you also take good care of yourself while providing excellent care to your family member?

Wherever you are on the journey, Home Instead can help in a dramatic and positive way. **CARE: Changing Ageing Through Research and Education ("CARE")** is a unique training approach for Home Instead CAREGivers. In addition to explaining some of the basic facts about the different forms of dementia, this booklet provides practical assistance from our CARE programme to help family caregivers like you on your journey.

Featured is Home Instead's approach to Alzheimer's or other dementias care. The approach focuses on personalising the care experience and looks at practical ways of dealing with some of the most common issues associated with dementia such as keeping your loved one engaged in life. There is also a section about you, the caregiver, which provides realistic ideas about how you can take good care of yourself. Finally, additional information and resources will offer other avenues of support.



## What is Dementia?

**Dementia is the umbrella term for the variety of conditions that can cause the brain to fail. The World Health Organisation (WHO) describes dementia as:**

Dementia is a term for several diseases that affect memory, thinking, and the ability to perform daily activities.

The illness gets worse over time. It mainly affects older people but not all people will get it as they age.

Functions such as memory, orientation, comprehension, emotions and judgement may be affected in a person with dementia.

The following are 10 warning signs you should look out for:



## Warning Signs

- 1. Memory loss that disrupts daily life:** The person's short term memory is usually affected so one of the most common signs is memory loss, especially forgetting recently learned information such as names or recent events.
- 2. Challenges in planning or solving problems:** Some people may experience changes in their ability to develop and follow a plan or work with numbers.
- 3. Difficulty in completing familiar tasks at home, at work or at leisure:** People sometimes may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favourite game.
- 4. Confusion with time or place:** Losing track of dates, seasons and the passage of time. A person with dementia may become lost even in a familiar environment.
- 5. Trouble understanding visual images and spatial relationships:** For some people, having vision problems is a sign. They may not realise they are the person in the mirror, for instance.
- 6. Comprehension – New problems with words in speaking or writing:** There is trouble following or joining a conversation as the person may have difficulty understanding what it is you are trying to explain to them or what you are asking of them.
- 7. Misplacing things and losing the ability to retrace steps:** Placing things in random unusual places. Sometimes the person may accuse others of stealing the items.
- 8. Decreased or poor judgement:** Experiencing changes in judgement or decision making. For example, a person with dementia may leave doors to an empty house unlocked.
- 9. Withdrawal from work or social interaction:** Some people with a dementia may remove themselves from hobbies, social activities, work projects or leisure pursuits.
- 10. Changes in mood and personality:** Very low tolerance to stress can occur in someone with dementia and they may therefore overreact to seemingly ordinary situations and misinterpret situations. Some can become confused, suspicious, depressed, fearful, anxious, they may be easily upset at home, at work or with friends or in places where they are out of their comfort zone.

**If your loved one is experiencing difficulty in any of the above areas and you are concerned please contact a healthcare professional immediately.**

## Types Of Dementia

There are many types of dementia — the most common types include:

### (1) 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 signs, 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 passes everyday tasks become an issue and processing information becomes difficult.

#### **Real Life Case Study:**

Mrs. Jones had a diagnosis of Alzheimer's disease for 2 years but her family now realise that she has had memory problems for a lot longer than this but had been able to manage. Mrs. Jones is a widow and lives alone but has a lot of support from her three daughters, two of whom live nearby. However, all of her daughters have young families and often find it difficult to give the care and attention they would like to give their mother. Mrs. Jones tends to do quite well in the morning time, and one of her daughters makes sure she visits during this time to help her mother with breakfast and her medication. As the day goes on, however, Mrs. Jones can become more forgetful and will call her daughters over and over again as she forgets that she has just called them. She can also become more forgetful in the evening and does not recognise her own home.

If you have a loved one who is demonstrating symptoms similar to Mrs. Jones please contact a medical professional immediately.

### (2) 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. The risk factors for stroke (high blood pressure, smoking, high cholesterol, obesity and diabetes) may contribute to its incidence. It is common for some people to have a mixed form of dementia, for example, someone may have both vascular dementia and Alzheimer's disease.

#### **Real Life Case Study:**

Mr. Miller was given a diagnosis of Vascular dementia following a moderate stroke. Initially in hospital he was very agitated and confused but this settled somewhat over time. When he returned home to his wife they had little support as their only son lived in the UK. Some days he wouldn't seem so confused and appeared to be in good form, other times his mood could change and he would get irritable and upset about something from the past. During these times he seemed more confused than usual.

If you have a loved one who is demonstrating dementia symptoms similar to Mr. Miller please contact a medical professional immediately.

### (3) Lewy Body Dementia

This can be very mild at the onset and can vary from day-to-day. A person with lewy body dementia may experience a fluctuation in their memory and also experience hallucinations and or delusions. Some Parkinson's like symptoms can accompany this form of dementia such as tremors, shuffling gait and stiffness leading to falls and difficulties judging distance.

#### **Real Life Case Study:**

Mr. Kavanagh was given a diagnosis of Lewy Body dementia following admission to hospital after he fell in his back garden at home. At the time of his fall he was trying to chase away what he believed were builders trying to build another house on his land. These were diagnosed as visual hallucinations and because of his unsteady gait and the rough terrain in his garden he fell over and cut his head quite badly. Following discharge from hospital he would only be intermittently confused but his visual hallucinations always remained quite prominent.

If you have a loved one who is experiencing visual hallucinations like Mr. Kavanagh please contact a medical professional immediately.

### (4) Fronto – Temporal Dementia

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

#### **Real Life Case Study:**

John's wife became increasingly concerned about him as his personality had seemed to change over the last year. He was more difficult and could become easily aggressive with others. She also found that he seemed sexually inappropriate with her in front of others. His memory didn't always seem too bad but his mood was affected.

If you are in a similar situation to John's wife please contact a medical professional immediately for help and advice.

## Capturing Life's Journey

With a dementia diagnosis comes a mountain of uncertainty. What does the future hold? What is your role? How will this condition impact your loved one? Alzheimer's disease or other dementias lead to nerve cell death and tissue loss in the brain. Over time, the brain shrinks dramatically, affecting nearly all of its functions. This means your loved one may experience changes in personality, relationships and abilities. These changes can be among the hardest for families to face.

The right approach to caring for your loved one with Alzheimer's disease or other dementias is key to maintaining your loved one's quality of life. That approach needs to ensure your loved one's needs are at the forefront.

Knowing key information, life experiences and personal preferences about your loved one helps caregivers provide dignified and respectful care. Home Instead calls this approach Capturing Life's Journey. People with dementia often use experiences from the past to make sense of the present. And accompanying that with the reality that a person with dementia can no longer store new information efficiently, gathering stories and information from your loved one's past helps to carry out this approach. By knowing and using the information, it will help you create meaningful activities, and provide personalised care.



## Techniques to Capture Life's Journey

When you are on this journey, it might be helpful to gather information chronologically, or by topic. Some examples include family, youth, parents, and the childhood house, schools, teachers, pets and family traditions. A few other examples include marriage, milestone events, favourite films, TV programmes, people, food, etc.

You probably already know many of your loved one's important experiences, and these will be a great place for you to start finding out more. Many of their most vivid memories will be of times when they were growing up with their family. Accomplishments and careers are also important facts to learn more about.

There are a few ways that you can gather your loved one's life story:

1. Asking them directly
2. Observing their surroundings
3. Asking other family and friends

When gathering information, be sure to use open-ended questions. Open-ended questions start with words like, "Tell me about"... or "Why" or "How." These types of questions prompt a more elaborate answer than a "Yes" or "No." The questions will encourage your loved one to speak more or share a memory.

Another good way to gather information is by observing the home or room for objects that will yield clues. Even though you are likely to be familiar with your loved one's surroundings, once you start to ask more questions about an object you will learn much more. You may also observe their non-verbal cues, facial expressions and gestures.

## Minimising Symptoms

Alzheimer's disease or other dementias affect the way a person thinks and feels and, subsequently, how they act. This is because one or more areas of the brain has been damaged and these areas are different for each person with dementia. Your loved one may do things that are uncharacteristic or even odd. Some common symptoms include:

- Aggression
- Agitation
- Anxiety
- Cursing
- Delusions (false beliefs)

Knowing how to respond when these symptoms occur can be difficult. Caregivers are encouraged to view dementia as a disability that can be supported through adopting positive approaches. People with dementia continue to function at an emotional level and will pick up on another person's feelings (particularly if they are stressed or upset) via body language, tone of voice and facial expression.

It is so important for caregivers to enter the world of the person with dementia. Remember that dementia disables their ability to make sense of the present so the person with dementia will often find comfort and refuge in their reality, which is more often than not their past.

But by Capturing Life's Journey, you can use the information to help reduce such problems for your loved one. This approach allows you to use the information from the past to offer comfort and minimise stress. For example, if your loved one does not want to get out of bed in the morning, you may know from the information you gathered that, as a child, they always had a big breakfast with bacon and eggs. You may offer this as a motivator to get your loved one up and ready for the day. Another example: if your loved one is trying to leave his or her surroundings, try to redirect them by saying, "Your favourite TV show is on in a few minutes." Knowing their life story helps you to engage and distract your loved one.

### Use of Language

Understand that using negative words will make your loved one feel like they are being dismissed and treated like a child. This can lead to even more resistance to any suggestions or approaches you make. Such negative words include: **don't • stop • can't • no • shouldn't**

It is the use of positive language that will make them feel important and valued and will help you cope with symptoms.

## DO'S AND DON'TS OF COMMUNICATION

### DO

- Talk to the person in a tone of voice that conveys respect and dignity.
- Keep your explanations short. Use clear and flexible language.
- Maintain eye contact by positioning yourself at the person's eye level.
- Look directly at the person and ensure that you have their attention before you speak. Always begin by identifying yourself and explain what it is you propose to do.
- Use visual cues whenever possible.
- Be realistic in expectations.
- Observe and attempt to interpret the person's non verbal communication.
- Paraphrase and use a calm and reassuring tone of voice.
- Speak slowly and say individual words clearly. Use strategies to reduce the effects of hearing impairment.
- Encourage talk about things that they are familiar with.
- Use touch if appropriate.

### DON'T

- Talk to the person in "baby talk" or as if you are talking to a child.
- Use complicated words or phrases and long sentences.
- Glare at, or "eyeball" the person you are talking to.
- Begin a task without explaining who you are or what you are about to do.
- Talk to the person without eye contact, such as while rummaging in a drawer to select clothing.
- Try and compete with a distracting environment.
- Provoke a catastrophic reaction through unrealistic expectations or by asking the person to do more than one task at a time.
- Disregard your own non verbal communication.
- Disregard talk that may seem to be "rambling".
- Shout or talk too fast.
- Interrupt unless it cannot be helped.
- Attempt to touch or invade their personal space if they are showing signs of fear or aggression.



## General Approaches and Strategies to Help Families Cope

It can sometimes be very difficult to get a person with dementia to follow instructions or redirect them away from certain situations. There is no simple solution and some time and effort is needed in these situations as the wrong approach WILL result in increased agitation or even an aggressive response from the person. If you wish to direct or redirect your loved ones consider the following steps:

### 1. Validate:

Validate the emotional state of the person. For example, you could say: "You look worried/upset/annoyed/frightened". Or you could say: "You seem to be in good form today".

### 2. Align:

Try to align your behaviour with the person's behaviour as much and as safe as possible. For example, you could say: "You're looking for someone/something? I lost something too, let's look together". If your loved one still feels very focused on a task such as looking for someone or something, encourage them to reminisce about where it is they want to go or who they are looking for. For example, you could say: "You're trying to get home? What's your home like? Tell me about your home". Or you could say: "You're looking for your mother? Tell me about her". This helps you to develop a rapport with your loved one and aides them to reminisce. However, it is important not to remind him or her that a loved one has passed away or that they no longer live in their childhood home. Here is an example of what NOT to say: "You want to go home, but this is your home now, you must miss your other home". Or: "Are you looking for your mother? You must miss her now that she is no longer here?"

### 3. Establish a Common Goal or Interest:

Once a common goal or interest is established, such as looking for something together, it will be much easier to distract your loved one from their task. For example, you could say: "I'm getting tired now, how about you? Will we have a cuppa?"

### 4. Redirection:

Now that your loved one has been distracted from their original task without becoming distressed it is easier to redirect them to another task. To do this you could say something like: "Come to the kitchen and give me a hand making the tea". Or: "Sit down on the couch and I'll turn on the TV so we can watch a programme together".

### REMEMBER: VALIDATE TO EMPOWER AND REMINISCE TO DISTRACT

This technique can take a little while to master, and you may have to go over the align step a number of times to help make your loved one feel listened to and more in control of the situation.

## Understanding Aggression and Agitation

It is important for family caregivers to try and understand why a person with dementia may act in an aggressive or an agitated manner as most of the time the person is reacting to something that happened to them. For example, invading an individual's personal space will result in a defensive or resistive manner. Exposing a confused person to the upsetting reality that they are unwell can also distress them, or explaining that a loved one has passed away will just upset the person and make them relive the painful memory. An abrupt or sudden approach to a person with dementia or unexpected physical contact may result in the person being physically alarmed.

Attempting to restrict or control the wishes and choices of the person may provoke an aggressive response. In some cases aggression may be linked to delusions, for instance, your loved one may be convinced that the neighbours are trying to kill them or poison them. It is therefore important to understand what might be the meaning behind the aggression or agitation the person is exhibiting. This will help you avoid doing anything that may trigger aggression or agitation in the person.

## Wandering

People with dementia may wander for a number of reasons:

### Exit seeking behaviour

This is where the person repeatedly attempts to leave their home even though they have lived there for many years. In such a scenario the person with dementia may state that they need to get home and often they mean their childhood home.

### Self stimulation

This type of over active behaviour where they always seem to be 'on the go' can also intensify in the evening times and is usually the result of a lifetime pattern of active behaviour traits or boredom. If your loved one wanders about the house and is NOT distressed or is NOT in any danger it is advised to let them continue to wander – trying to make them stop often results in an aggressive situation.

It is also important to keep doors securely locked at night time and ensure alarms are set every night so a person who wanders will be deterred from wandering from the house. People with dementia also suffer a higher risk of slipping or falling so it is important the home is clutter free.

## Keeping Your Loved One Engaged

When you know more about what your loved one may have enjoyed, engaging them in meaningful activities helps them feel safe, secure and valued. A meaningful activity is anything that fills time with a purpose and keeps your loved one occupied. Being occupied and feeling included are two of the main psychological needs of people with dementia. Such an approach can also help them stay connected to daily life.



Research conducted for Home Instead tells us activities are very important for those with Alzheimer's disease or other dementias because they create positive, emotional experiences helping to diminish the distress. Socialising is also important, for the same reason. We may think of activities as something "special" that we do, but this does not have to be the case. Even simple tasks like folding the laundry or making a meal can be considered activities.

The goal is to engage your loved one in activities that are meaningful to their life and enjoyable for you both. There are several benefits to engaging your loved one in activities:

- **Bring fun and happiness** – Laughter is great for all of us and doing a fun activity can create happiness.
- **Reduce boredom** – Boredom can prompt older people to become frustrated, agitated or depressed, causing them to wander off or insist on going somewhere. Activities can help maintain familiar routines which may help reduce confusion.
- **Help make activities of daily living (ADLs) easier** – When you turn a bath into an opportunity to smell different soaps, or when getting dressed becomes a chance to discuss fashion or special colours, personal care tasks often are easier because your loved one is happier and less stressed.

### Examples of meaningful activities:

- Helping with drying dishes and setting a table
- Going for a walk
- Sweeping leaves
- Reading the newspaper or looking at pictures in a magazine
- Potting plants or bulbs or watering plants
- Helping with meal preparation
- Listening to music

Music as a therapy has been well documented in dementia care. Musicality and singing seem to be preserved for longer sometimes than language skills in people with dementia. Naturally music from days past helps utilise the long term memories they have and can be also be considered a type of reminiscence activity.

The following are some additional suggestions to help you and your loved one enjoy meaningful activities together:

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

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

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

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“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”.

Staying engaged and stimulated helps to lift a person’s spirits and sense of accomplishment. It fosters a positive and enjoyable relationship between people. Activities should be about pleasure and success, not stretching or challenging the person. Activities should complement lifetime habits so it is important to be familiar with the likes and dislikes of the person. The approach of Capturing Life’s Journey is essential to discovering meaningful activities for your loved one. Things that gave the person pleasure and made them laugh before the dementia will still do so later on. Refer back to the techniques of asking open-ended questions, observing surroundings and talking with other family members and friends.



## Taking Care of Yourself

The demands of caring for a person with dementia can force you to focus all your energy on their care. Neglecting your own needs could be a costly mistake. In fact, many of us feel that if we take care of ourselves we are being selfish. The truth is, it's imperative that we take care of ourselves, or we won't have the health or energy to care for anyone else. Just like the battery in our mobile phones, we need recharging, too.

Research shows that many people start neglecting their own care when they are caring for others. You want to make sure that you don't fall into that trap. It is even more important when you are a caregiver to focus on your self-care so that you have the energy and good health needed to continue caring for your loved one. Make sure you get enough sleep, exercise regularly, eat well-balanced meals, drink plenty of fluids and continue to get regular medical checkups.

Research supports the idea that to stay healthy, physically and emotionally, we need a strong social support network. Our social support network are the people in our lives to whom we can turn to for emotional and practical support. As a caregiver, you may be struggling to get everything done; however, it is important that you build in time for the relationships that nurture you – even if it is just having a phone conversation or a cup of coffee with someone who will really listen to you or if you are so inclined, maintaining spiritual or religious practices that nurture you and keep you connected to others.



There are three key areas to consider when caring for a yourself:

- Self-care
- Nourishing connections with others
- Relaxation techniques

Finally, there are many relaxation techniques that can help counter the stressful situations in our lives. When we are tense, we often take shallow breaths. This only adds to our feeling of stress. Even just breathing deeply a few times a day can reduce feelings of anxiety. Meditation or yoga are excellent ways to reduce the feelings of stress related to caregiving. Try various relaxation techniques until you find one that fits your interests and lifestyle. They don't have to take a long time – simply breathing more slowly takes no time at all.

Practicing this combination of good self-care, staying connected to others, and relaxation techniques can help you go the distance as a caregiver with less stress and more enjoyment!

## Recommendations to Help you Cope with the Demanding Role of Being a Caregiver

- **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 caregiving responsibilities for a period of respite.

- **Nurture the body**

Be sure to get enough sleep and eat properly. Take breaks from caregiving as often as possible by asking other family members to help.

- **Establish limits**

Say no to requests that are beyond your capacity and say yes to offers of help from family and friends. Friends, family and neighbours are often willing to help with caregiving but may feel uncomfortable around the person with dementia. They may not want to be seen as interfering and they don't know how they can help. People can help you best if you:

- Give them specific tasks and tell them exactly how you are feeling and what you need.
- Be specific and positive.
- Let them know you appreciate their help and that it is making your burden slightly less.
- Sometimes these tasks may be unrelated to direct caring and can be easier for some people. Examples of these are shopping, gardening and house maintenance.
- Let people know how much their efforts have helped – they will continue to assist you if they feel appreciated.



## Legal and Financial 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. Ideally, these documents are in place long before you need them. If the person is prepared during the early stages of dementia, he or she 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 solicitor 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, such as:

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

### Agency Arrangements for Social Welfare Payments

The Department of Social Protection 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.

### 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.

## Enduring Power of Attorney (EPA) / Wards of Court

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, an 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, funeral expenses and probate tax.

## Joint Bank Accounts

Joint bank accounts are a particularly useful means of dealing with one's financial affairs when a person 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 authorised 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.

## Tax Relief on Home Care Fees

Home Instead clients or their family can avail of income tax relief of up to 40% on payments to Home Instead of up to €75,000 per annum. The tax credit can be adjusted so that the relief will apply on a monthly basis rather than annually, which may otherwise be the case. Home Instead also advises families to avail of home care grants, which can be applied for through your local health centre. Please contact your local Home Instead office to discuss in detail how you can go about claiming tax relief on home care fees.

## Making 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. If not already done, the person with dementia should be encouraged to make a Will as early as possible. 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.



# Family Caregiver Checklist

## 1. Do you have a care plan for you?

- ☐ Have you set goals to help you care for yourself?
- ☐ Do you know your limits?
- ☐ Will you ask for support if you need it?

## 2. Do you have a Plan B? (when you can't be there for your loved one)

- ☐ Do you know where to go to for support and what would suit your needs as a caregiver? e.g. family members; Home Instead; HSE; Alzheimer's Society; Genio and other dementia support groups.

## 3. Have you considered the following areas when planning the care for your loved one?

- ☐ Compliance with Medication    ☐ Nutrition
- ☐ Exercise                      ☐ Personal Care
- ☐ Hospital Plan                ☐ Pet Plan
- ☐ Hydration                    ☐ Socialisation

## 4. Do you understand Alzheimer's disease and other forms of dementia and how best to manage difficult symptoms associated with dementia?

- ☐ Do you understand the benefits of reminiscence and Capturing Life's Journey when caring for your loved one?
- ☐ Do you have a better understanding of how to minimise symptoms?
- ☐ Can you come up with meaningful activities that you can use to engage your loved one?
- ☐ Do you understand the need for your siblings, family and community to learn about dementia too?
- ☐ Have you contacted your local Home Instead office?

## 5. Safety at Home (where your loved one resides)

- ☐ Is there a downstairs shower (wet room) and toilet?
- ☐ Does the home require a stair lift?
- ☐ Have you addressed any hazards in the home?
- ☐ Are additional security services required? e.g. house alarm
- ☐ Have you considered a GPS tracking device to ensure your loved one's safety or any other sensible actions that can be taken in the house?

## 6. Legal Plan

- ☐ Does your loved one have a Will?
- ☐ Has an Enduring Power of Attorney been appointed?
- ☐ Would having a trust in place benefit your loved one?
- ☐ Financial budget
- ☐ Is there adequate budget set aside for future medical needs if required?
- ☐ Is there adequate budget set aside for future home care needs if required?
- ☐ Do you understand that tax relief is available on the cost of home care?
- ☐ Is there adequate budget set aside for future maintenance of your loved one's property?
- ☐ Is there adequate budget set aside for the maintenance of your loved one's vehicle or to afford alternative transport?

***If you checked no on any of these boxes please take some time to consider and record what actions could help you best care for yourself and your loved one.***

## ABOUT HOME INSTEAD

Established in Ireland in 2005, Home Instead is the country's largest private provider of home care services.

It has 26 offices around Ireland, employing nearly 4,000 CAREGivers and serving almost 7,000 clients.

Home Instead is an approved provider of HSE Home Support Services in all nine Community Health Organisations in the country, meaning that people aged over 65 can choose Home Instead for their non-medical home care services. It also serves a large and growing client base who avail of private home care services to help them continue to live an independent life at home.

These services include companionship, meal preparation, light housework, personal care, dementia care and more.



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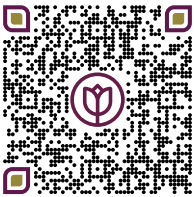
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## Home Instead Dementia Resources

[www.homeinstead.ie/specialist-care/  
dementia-care-resources](http://www.homeinstead.ie/specialist-care/dementia-care-resources)



Caring for an older loved one who is living with Alzheimer's disease or another dementia can be challenging and can result in physical and emotional stress. That's why we at Home Instead have created a series of resources covering many different aspects of dementia care at home, and we've made these available for family carers to access, free of charge.



Helping loved ones  
stay safe and secure in their own  
homes, in communities  
*all over Ireland*

