



Confidence to Care at Home Kit

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What to Expect with Alzheimer's

A diagnosis of Alzheimer's disease can trigger anxiety for older persons and their family caregivers who wonder what's ahead as the disease progresses. So what can someone with an Alzheimer's diagnosis expect? Based on Home Instead research, those with Alzheimer's disease or other dementias who live at home without in-home care reported these common problems: challenges in planning (70% with dementia compared with 22% who did not have dementia); memory loss that disrupts daily life (86% with dementia compared with 13% who did not have dementia); confusion with time or place (76% with dementia compared with 10% who did not have dementia); and misplacing things (80% with dementia compared with 16% who did not have dementia). Other common problems identified by this Home Instead network research included:

New problems with words in speaking or writing

43% with dementia compared with 13% who did not have dementia.

Nighttime wakefulness and other sleep problems

48% with dementia compared with 39% who did not have dementia.

Rummaging around or hiding things

48% with dementia compared with 6% who did not have dementia.

Trouble understanding visual image and spatial relationships

37% with dementia compared with 7% who did not have dementia.

Belligerence, anger or aggressive behaviour

28% with dementia compared with 15% who did not have dementia.

Hallucinations, delusions or paranoia

20% with dementia compared with 6% who did not have dementia.

Wandering

22% with dementia compared with 1% who did not have dementia.

Refusing to eat

14% with dementia compared with 7% who did not have dementia.

Despite this grim expectation, there is hope on the horizon. "The currently available treatments are used when dementia has fully developed," said Dr Jane F. Potter of the Home Instead Centre of Successful Ageing.

All of the new trials are focused on early identification to target the stage before dementia – mild cognitive impairment. In the future we should be able to identify and treat people with mild cognitive impairment to keep the disease from progressing," she said. "One of the promising areas under study is exercise; it appears that avid exercisers have a lower risk of dementia. So identifying people at risk and developing an activity programme are among therapies being considered. All we would have to do is delay the onset of dementia by five years and we eliminate by half the number of years spent with dementia because we would die of other things."

Managing the Symptoms of Alzheimer's

One Example, the Repetitive Question

Mary asked the questions again and again while waiting for her lunch at a restaurant. Her eyes were fixed on the centrepiece, which included a printed list of the specials during the next three days, including Christmas. So every two minutes, she had the same request: "Please read me the menu. When is Christmas? When is Christmas?"

Repetition is one of the common behaviours of Alzheimer's disease. Others include refusal, delusions (fixed, false ideas or beliefs), aggression, false accusations, wandering and agitation.

Behavioural symptoms like constant and repetitive questions can try family caregivers to the breaking point. Alzheimer's disease is not an acute illness – the average length is eight years, but people can live with it for 20. The following are approaches from Home Instead's free Alzheimer's Disease or Other Dementias CARE: Changing Ageing Through Research and Education® Training Programme to help families manage challenging behaviours like repeated questions:

1. Redirect

The first time a question or concern comes up, take a few moments to answer the question fully and provide reassurance that all is well. If that doesn't work, try to engage the older person in a related topic. For example: "Tell me about your favourite Christmas." "What was your favourite present?" "How about your favourite Christmas meal?" Sometimes discussing the topic (in this case Christmas) a bit more will lead them away from the repetitive behaviour and calm their anxiety.

2. Utilise the person's life story for ideas

The CARE programme encourages caregivers to know older adults well. For instance, when a caregiver knows that the person loves country music or enjoyed knitting, they can ask that individual about this new and favoured topic to "change the subject," but in a meaningful and respectful way.

3. Physically move the items or older person from the environment

If the menu, in this case, or an object, in general, continues to agitate or irritate, remove the older person or the object from that situation.

4. Offer simple choices

Persons with dementia still want to feel in control of their lives. The CARE programme teaches that one way to break a repetitive question cycle is to offer a simple choice, "Speaking of Christmas, Mum, would you like to serve turkey or goose this year?"

5. Apologise and take the blame

Apologise and take the blame. Apologising or taking the blame in a situation (even when it's not your fault) diffuses many situations. In this case, the family member can apologise for not understanding her concern or question and then try to move Mum away from her anxiety about Christmas plans.

Alzheimer's experts suggest that many behaviours can be prevented by creative and well-informed caregivers. The Alzheimer's Disease or Other Dementias CARE programme teaches techniques that can turn failure into success.

Caring for the Caregiver

Caring for a family member or friend with dementia can be all-consuming. So much so that you might forget to take care of yourself. Use this worksheet to help identify the best ways to meet your physical, emotional, spiritual and social needs.



Physical

Exercise is an important part of staying healthy. But that doesn't mean you need a hot, sweaty workout every day. On the lines below, jot down an activity that would appeal to you. Consider a regular walk through a nearby park or by a lake. Spend time in your garden or grow herbs and tomatoes in pots. Consider a work-out video. Invite a friend or neighbour to join you. Who knows, your family member may want to be a part of the fun as well.



Emotional and Spiritual

Tap into your feelings. Maybe your family is not supporting you or you are at odds with your siblings. By writing down what is going on and what you are feeling, it can help you deal with your emotions. Find a support group. You may find people who are also caring for someone with dementia. Discover other ways that you could get the support you need and write those below.



Social

Are you neglecting friends or favourite activities? How long has it been since you did something fun with your spouse or best friend? Sometimes regular emails or short telephone calls to a good friend can help you stay in touch. Write down your favourite pastimes and the people with whom you would like to do those activities. Remember, it's OK to ask for help.

At Home with Alzheimer's

Most older adults – including those with a dementia illness – prefer to age in their own homes. However, to provide care at home, it could be necessary to adapt personal care routines. The following information may help you and the one you are caring for manage the changes that could take place, allowing them to remain in the comfort of home.



Bedroom

- 1.** Go with clothing and shoes that are easy to slip on, such as those with Velcro fasteners.
- 2.** Lay out articles of clothing in sequence, arranged in order they are meant to be put on. Group Mum's clothes into outfits. When she can grab one hanger with pants and a shirt, she will feel confident in her selection.
- 3.** Offer a choice, e.g., between a white shirt and a blue shirt, always maintaining personal style.

Kitchen

- 4.** Continue food traditions for as long as possible.
- 5.** Create contrast by serving meals on a coloured plate, and keep the table setting simple.
- 6.** Include finger foods on your daily menu such as small sandwiches, and sliced fruits and vegetables.

Bathroom

- 7.** Create a spa-like atmosphere at bath time. Buy Mum's favourite lavender soaps and lotions to help create a pleasing experience.
- 8.** If you are assisting with tooth brushing, ask Dad to stand in front of a mirror while you help from behind, so he can still see what he's doing.
- 9.** If Dad is having trouble in the shower, break the task into simple, manageable steps.

Staying Engaged with Alzheimer's

Older persons with Alzheimer's disease or other dementias should strive to continue to do as much as they can for as long as possible. And home might just be the best place.

"The preferred environment for those with dementia is generally at home," said Dr Jane F. Potter of the Home Instead Centre of Successful Ageing.

Dr Potter served on the expert panel to help develop content for Home Instead's free Alzheimer's Disease or Other Dementias CARE: Changing Ageing Through Research and EducationSM Training Programme.

The following, from Dr Potter and Home Instead, are tips on how to help family caregivers continue to engage older adults with Alzheimer's in everyday activities:



1. Allow older persons to do as much as they can but don't expect them to do what they can't. Give clear instructions, which may mean giving them one step at a time.

2. Simplify the task. When dressing, put that older person in a position to do as much as possible. Make it easier to dress, for instance, by laying out clothing in sequential order, with the underwear and socks on top.

3. Start an activity and then ask the older person to help. If your Mum has forgotten how to make that favourite family recipe, begin the process and have her help with whatever she can.

4. Make activities easier or change the activity.

If that older adult can't play bridge anymore, try a more simple card game instead.

5. Remember, it's more than just about the task.

Turn a bath into an opportunity to smell different soaps or, when picking out clothing, discuss fashion or special colours.

6. Remember that exercise can help keep older persons active longer. They should get up and move more, not less.

7. No matter what the activity, bring fun and happiness to the endeavour. "Laughter is great, and use plenty of it to stay engaged with an older loved one," Dr Potter noted.

How to Preserve Family Memories

Preserving family memories for older persons who have Alzheimer's disease or other dementias is important for several reasons: Memories can help bring much happiness and joy to that older adult and preserving those memories helps establish an important legacy for future generations.

Capturing and preserving memories can happen in a number of ways. It might entail spreading photos out on the coffee table, intentionally creating a list of questions to ask, and sitting down in the living room together to record the thoughts your loved one shares. Or reminiscing might occur more spontaneously during a family gathering. If so, make sure you have a notepad or phone handy.

To accommodate your family member's cognitive ability level and make sharing memories in any situation a positive, meaningful experience, keep the following considerations in mind:

1. Do involve other family members;

don't put the person with Alzheimer's on the spot.

2. Do look at photographs together;

don't expect the person to recognise everything.

3. Do share your own thoughts as they relate to the memories your loved one shares;

don't monopolise the conversation.

4. Do ask specific, personal questions;

don't interrogate.

5. Do ask good questions and record the discussion;

don't expect a five-hour session.

6. Do focus on general memories and emotions;

don't focus on exact facts and details.



The goal is to give your family member with dementia the opportunity to share cherished memories with the people he or she loves. You don't need to record a precise journalistic account of the person's life.

Activities to capture and preserve memories with your family member living with Alzheimer's disease or other dementias should focus on what that person can and wants to remember. You can help to minimise frustration by paying attention to your loved one's limitations and adapting opportunities for reminiscing accordingly.

A Life Snapshot

Nickname _____

Date of Birth _____ Place of Birth _____

Parents _____

Grandparents Maternal _____ Grandparents Paternal _____

Siblings _____

Spouse _____

Pets _____

Children _____

Grandchildren _____

Sports or Hobbies _____

First Job _____

Education _____

Marriage _____

First House _____

Careers _____

Clubs/Organisations _____



Resources for Family Caregivers

Home Instead offers these resources for families caring for individuals with Alzheimer's disease or another dementia.

www.homeinstead.ie/specialist-care/dementia-care-resources

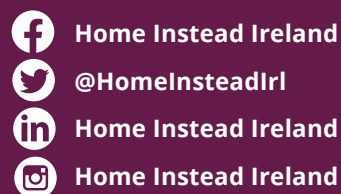
Caring for an older loved one who is living with Alzheimer's disease or another dementia can be challenging and can result in physical and emotional stress. That's why we at Home Instead have created a series of resources covering many different aspects of dementia care at home, and we've made these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

Dementia Care at Home

This booklet shares the Home Instead approach to Alzheimer's and Dementia 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, and understanding and reducing behaviour that is a sign of unhappiness in your loved one. 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.



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



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