



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive



Caring for the Person with Dementia in their Home



Information Booklet for Health Care Staff

November 2011

Acknowledgements

We would like to acknowledge the following for making this work possible:

- The National Council for the Professional Development of Nursing and Midwifery for providing the funding for this project.
- Patrick Glackin (Chair of the Dementia Education Steering Group) for his support and encouragement.
- The participants who engaged so willingly and wholeheartedly with the Initial Needs Analysis which helped to inform the development of this booklet.
- Clare Guihan, Home Help Co-ordinator, HSE, Dublin Mid-Leinster; Martina Gallagher, Public Health Nurse, PCC Health Centre Castlebar, Co. Mayo.
- Majella O' Donnell, Sligo/Leitrim Services Manager, Alzheimer Society of Ireland.
- Members of the Alzheimer Society of Ireland Home Care Working Group: Maureen Mannion, Galway Home Care Co-ordinator; Maura Howley, Navan Home Care Co-ordinator; Eilis Cantwell, Waterford Services Manager.
- Alzheimer Society of Ireland National Office: Avril Dooley, Grassroots Co-ordinator; Mary Connolly, Practice Development Officer and Grainne McGettrick, Research & Policy Officer.
- Members of the Dementia Education Steering Group for their support and advice.
- Sinead O'Reilly, NMPD Tullamore, for her secretarial support in compiling this booklet.

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Foreword

It is with great pleasure that I introduce the booklet *Caring for the Person with Dementia in their Home: Information Booklet for Health Care Staff*. The booklet has been developed for health care staff working in the community as part of the National Dementia Education project. It was developed in partnership with the Alzheimer's Society of Ireland.

Home care workers, in the National Dementia Education Needs Analysis (2010), identified the need to have more access to information about dementia and in particular more practical information on how best to look after someone with dementia in their home and to be able to assist their families/carers. The booklet forms part of a suite of educational programmes that have been developed to address the knowledge and skills deficit identified in the needs analysis.

The information and practical advice outlined in the booklet will enable health care staff to create a caring and dignified environment, where a person-centred approach to dementia care can be fostered.

I wish to acknowledge the support and advice received from the members of the National Dementia Training Steering Group that contributed to the successful completion of the booklet.

I also wish to express my appreciation to the National Council for Professional Development of Nursing and Midwifery, who have funded this project.

Finally, particular thanks are extended to Ms. Mary Manning, Project Officer, Nursing and Midwifery Planning and Development, Tullamore and Project Manager to the National Dementia Training Programme and Ms. Annie Dillon, Practice Development Manager, The Alzheimer Society of Ireland.



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Foreword

It gives me great pleasure to welcome *Caring for the Person with Dementia in their Home: Information Booklet for Health Care Staff*, which will provide a valuable training and information resource for home care staff.

The Alzheimer Society knows that people with dementia and their family carers strongly desire that the person with dementia can continue to live at home. Our involvement in this project has ensured that the voice of the person with dementia and their carer is heard. This booklet is filling a critical gap in staff education, especially for those working in the home care setting.

The work of this project will be an essential part of building the capacity to ensure the provision of dementia-specific supports in local communities throughout Ireland.

I am confident that this booklet will prove invaluable to home care staff and managers in their work to support people to live well with dementia at home and help make the dementia journey a better one for all.



Maurice O'Connell, CEO
The Alzheimer Society of Ireland

Introduction

*“In my several years working as a home help with Alzheimer’s patients I would have found it of benefit to be able to receive further information and support”
(Quote from one of home helps in the focus group)*

This booklet on dementia and practical advice on caring for a person with dementia has been developed for health care staff as part of the National Dementia Education Project. It was developed in partnership with Alzheimer’s Society of Ireland. From research carried out as part of the national project, home helps identified the need to have more access to information about dementia and in particular more practical information on how best to look after someone with dementia in their home, and to be able to assist their families/carers.

Information used in this booklet has been sourced with their permission from Alzheimer’s Society of Ireland; Alzheimer’s Society Australia and Alzheimer’s Society Scotland.

Further information and contact details for additional help and support for the person and their families for your local area has been provided to your Home Help Coordinator/ manager.

Please ask your manager for a copy of these.



What is Dementia?

At a glance

- Dementia is an illness which affects the brain
- The person with dementia will gradually start to need more and more help
- Dementia affects older people most often
- More rarely, people in their 40's or 50's or younger can get dementia

When someone has dementia, brain cells are damaged and die faster than they do normally. Losing brain cells means that the person begins to lose the ability to do things. Often it affects memory first. The person may become confused about where they are, what day it is and who people are. Everyday tasks become more difficult.

The main abilities affected are:

- Judgement
- Orientation
- Emotions
- Memory
- Thinking

Dementia affects almost 44,000 people in Ireland and touches the lives of 50,000 carers and hundreds of thousands of family carers.

Types of dementia

There are different forms of dementia and each has its own causes. Some of the most common forms of dementia are:

- Alzheimer's Disease
- Vascular dementia
- Dementia with Lewy Bodies
- Frontal Lobe dementia

Alzheimer's disease is the most common cause of dementia in Ireland and accounts for 66% of all cases. Individual brain cells are damaged, so the brain is unable to work as it used to. It affects memory and other mental abilities. It generally affects short-term memory first. People with Downs Syndrome can develop dementia as they get older. Alzheimer's disease is the most common type to affect them.

The second most common form of dementia is **Vascular dementia**. With Vascular dementia, there are problems with the blood supply to brain cells. The most common type of vascular dementia is caused by a narrowing of the small blood vessels in the brain, or by a series of small strokes, or a combination of the two. Small strokes are called 'transient ischaemic attacks' (TIA's). Each time the person has one of these

mini strokes, the person may get worse quite suddenly, and then not change until the next mini stroke happens. People with Vascular dementia often have difficulty concentrating and communicating.

In Lewy Bodies dementia, the person's memory and other mental abilities are affected, like in Alzheimer's disease. Symptoms progress gradually over several years. Sometimes these effects are patchy, and symptoms may vary from day to day. People often have some physical problems too, such as rigidity and stiffness, difficulty starting movements, slowness of movement or tremors/weakness of the arms or legs, clumsiness or falls. The person may also experience visual hallucinations; seeing things that are not there is also common. Sometimes people with Parkinson's disease may develop dementia which affects their memory and ability to carry out everyday activities.

Frontal Lobe dementia (also known as Fronto-temporal lobar degeneration, or Picks disease) affects the areas of the brain at the front and side of the head in particular. A person's memory may be fine but their personality, behaviour and language skills can change.

Other forms of dementia include alcohol-related dementia such as Korsakoff's syndrome **and Creutzfeldt-Jakob disease**.

For more information about the types of dementia, you can check out the Alzheimer National Helpline at www.alzheimer.ie

Dementia is progressive and the person will gradually get less and less able. However this usually happens slowly. Dementia has a life-changing physical, emotional and mental impact on the affected person and their primary carer and family. Currently there is no cure for dementia, but there is a lot that can be done to help the person with dementia and their family.

Early Symptoms and Diagnosis

Each person's experience with dementia is unique. Not everyone will experience all the signs and symptoms of their type of dementia. The condition is progressive and the early signs may be difficult to detect. How the illness progresses varies from person to person. At first, there may be slight lapses of memory and altered mood. Later, more obvious problems may develop.

Early symptoms might include

Memory:

Forgetting the names of objects and/or people.
Forgetting where things are and events that have recently occurred.

Tasks:

Finding tasks such as brushing teeth, shaving, dressing or making a cup of tea difficult.

Language:

Forgetting phrases or using incorrect words in sentences.

Disorientation:

Unsure of date, month, where they are or how to get home.

Judgment:

Putting on clothes in the incorrect order or incorrectly, and becoming accident prone.

Thinking:

Cannot understand the alphabet or having difficulty with numbers.

Misplacing:

Putting objects in the wrong places.

Mood Swings:

Becoming suspicious or lacking emotion. Losing their temper for no obvious reason.

Apathy:

Needing encouragement to do easy tasks, or lacking interest in all pastimes or hobbies.

Movements:

Pacing restlessly or unsteadily. Agitation.

It may be the person themselves who first notices they have a problem. It is quite common for the person to deny that they are forgetful, find excuses for mistakes and pretend that problems are trivial. Reluctance on the part of a person with memory problems is common and understandable. However, it is important that if there is

cause for concern, an appointment should be made with the GP as soon as possible. As a home help, you can talk with the Public Health Nurse or line manager if you are concerned about a client you are caring for.

Why is a diagnosis so important?

A proper diagnosis is needed whenever anyone develops dementia-like symptoms and does not appear to be getting any better. Diagnosis is important because:

- It can rule out the possibility that the symptoms have a different, treatable cause.
- It allows family members, friends, and, whenever possible, the person with dementia to make plans for the future if a diagnosis is made.
- Treatments are available that may help some of the symptoms; the sooner these treatments are started, the better.

What if a diagnosis is made?

A diagnosis of dementia comes as a shock, no matter how much it is expected. It is hard for the person with the diagnosis and all those close, so reassurance and support are vital. The most important thing is to **be positive** and concentrate as much as possible on what the person with dementia can do, rather than what they cannot do. Although the person will gradually need an increasing amount of help, it is important to make sure that other people don't take over and that independence is preserved as much as possible.

Understanding and Respecting the Person with Dementia

If you are caring for someone with dementia, you will want to ensure that they are always treated with respect and dignity and as an individual person, however little they may seem to understand. They are a unique and valuable human being.

Someone with dementia, whose mental abilities are declining, will feel vulnerable and in need of reassurance and support. It is important that those around them do everything they can to help them retain their sense of identity and their feelings of self worth. Carers and family should remember that:

- Each person with dementia is a unique individual with their own very different experiences of life, their own needs and feelings and their own likes and dislikes.
- Each person will be affected by their dementia in a different way.
- Everyone reacts to the experience of dementia in a different way. The experience means different things to different people.

Those caring for people with dementia will need to take account of the abilities, interests and preferences they have at present, and the fact that these may change as the dementia progresses:

- As a home help you should be prepared to respond in a flexible and sensitive way.
- If you do need to offer assistance, try to do things with the person rather than for them, so that they remain involved.
- Try to focus on what the person can do rather than on what they can't do.
- Remember the person may be forgetful and have a short attention span due to the dementia.
- Try to be patient and allow plenty of time for the completion of tasks. If you feel yourself becoming irritated, go into another room for a few minutes and take some deep breaths.
- Give plenty of praise and encouragement to the client and their families.

The more information you can get about the person's past, as well as their present situation, the easier it will be for you to see them as a whole person rather than simply as someone with dementia. You can do this over a period of time as you get to know the person and their family and they get to know you.

A person with dementia is still an adult

It is important that everyone continues to treat the person as an adult and with courtesy, dignity and respect, however advanced their dementia.

- Be kind and reassuring without talking down to the person with dementia as though they are a small child.
- Never talk over the head of a person with dementia, or across them, as though

they are not there.

- Do not talk about the person with dementia in front of them unless they are included in the conversation.
- Avoid scolding or criticising the person, as this will make them feel small.
- Look for meaning behind what they may be trying to communicate even if it seems not to make sense.

Expressing feelings

Dementia affects the thinking and reasoning part of the brain and memory. It does not mean that the person no longer has feelings.

People with dementia are likely to be sad or upset at times. They have the right to expect those caring for them to try and understand how they feel and to make time to offer support rather than ignoring them or jollyng them along.

In the earlier stages, people may want to talk about their anxieties and the problems they are experiencing. It is important that others do not brush these worries aside, however painful they may be, but listen and show you are there for them and will be there for them.

Focus on abilities

- Help the person avoid situations in which they are bound to fail, since this can be humiliating. Look for tasks they can still manage and activities they can still enjoy.
- Give them plenty of praise and encouragement and let them do things at their own pace and in their own way.
- Do things with the person, rather than for them, so they can maintain some independence.
- Break activities down into small steps so that the person has some feeling of achievement, even if they can only manage part of a task.
- Much of our self-respect is often bound up in the way we look. Encourage the person to take pride in their appearance and give them plenty of praise.

Feeling valued

The person with dementia needs to feel respected and valued for who they are now, as well as for who they were in the past. It helps if those caring:

- Are flexible and tolerant
- Can make time to listen and to chat, and enjoy being with the person
- Can show affection as appropriate

Offering choice

It is important that the person with dementia should be informed and wherever possible consulted about matters which concern them. They should also be given every opportunity to make appropriate choices.

- Even if you are unsure how much the person can understand, always explain what you are doing and why. You may then be able to judge their reaction from their expression or body language.
- Although too many choices can be confusing, you can continue to offer choice by phrasing questions that only need a 'yes' or 'no' answer, such as 'Would you like to wear your blue jumper today?'

Respecting privacy

Try to make sure that the person's right to privacy is respected.

- Knock on their bedroom door before entering, for example.
- If the person needs help with intimate activities such as washing or going to the toilet, this should be done in a sensitive way. Make sure that the bathroom door is kept closed if other people are around.

Our names are important

Our sense of who we are is closely connected to the name or names we are known by. It is important to make sure that others address the person with dementia in a way they recognise and prefer. Not everyone is happy for other people to call them by their first name or the name used by friends and family. Some may prefer younger people or those who do not know them well to use a courtesy title such as 'Mr' or 'Mrs'. Remember to ask the person what name they would prefer you to call them by.

Culture and religion

Make sure that anyone caring for the person, however briefly, has appropriate details about any relevant cultural or religious customs or beliefs so that these can be respected. These may be anything from diet, clothing and the use of jewellery, for example, to ways of undressing, doing hair, washing or going to the toilet. Some forms of touch which are taken for granted in some cultures may be thought disrespectful in others.

Person-Centred Language

As health care staff, it will be important for you to highlight and role model best practice in relation to the use of person-centred dementia language. This is not only relevant when looking after the person in their home, but also in the language you use in the general community. By doing this, you will be helping to promote dementia-friendly communities.

Language is a powerful tool. The words we use can strongly influence how others treat or view people with dementia. For example, referring to people with dementia as 'sufferers' or as 'victims' implies that they are helpless. People with dementia are still people and should be referred to as people. Failing to do so not only strips people of their dignity and self-esteem, it reinforces inaccurate stereotypes and heightens the fear and stigma surrounding dementia. We have a responsibility to use language that is empowering and inclusive of the diverse experiences of dementia. It is important to convey that life does not stop when dementia starts.

We have included guidelines which were developed by the Alzheimer's Society in Australia and in Ireland. They are intended to highlight how words and language really do make a difference.

Preferred terms	Non-preferred terms	Rationale
Dementia A form of dementia	Dementing illness	There is a need to reflect accurately that dementia is an umbrella term for a large group of illnesses that cause a progressive decline in a person's functioning.
Condition illness	Disease	Dementia is more appropriately described as a condition or an illness. There are different forms of dementia and each has its own causes. Alzheimer's disease is most common, followed by vascular dementia, fronto-temporal lobar degeneration (FTLD) and dementia with Lewy bodies.
Person/People with Dementia	Sufferer	Terms such as 'sufferer' and 'victim' contribute to the stigma surrounding dementia.
	Victim	People with dementia experience changes in their abilities over time. While their need for support may increase as the condition progresses, it is important to avoid language that implies they are helpless. Choose positive and inclusive terms that maintain the dignity of those affected and are free of value judgments.
People living with dementia (Inclusive of people with dementia, their families and carer)	Demented person	'Demented person' places the condition before the person. People with dementia are individuals first and the condition should not be regarded or referred to as the defining aspect of their life.

Communication

Remember, people with dementia will reflect the mood behaviour of others.

When caring for a person with dementia who is having difficulty communicating, remember they will pick up on negative body language such as sighs and raised eyebrows.

DO's AND DON'Ts OF COMMUNICATION

DO	DON'T
Talk to the person in a tone of voice that conveys respect and dignity.	Talk to the person in 'baby talk' or as if you are talking to a child.
Keep your explanations short. Use clear and flexible language.	Use complicated words or phrases and long sentences.
Maintain eye contact by positioning yourself at the person's eye level.	Glare at, or 'eyeball' the person you are talking to.
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.	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.
Use visual cues whenever possible.	Try and compete with a distracting environment.
Be realistic in expectations.	Provoke a catastrophic reaction through unrealistic expectations or by asking the person to do more than one task at a time.
Observe and attempt to interpret the person's non-verbal communication.	Disregard your own non-verbal communication.
Paraphrase and use a calm and reassuring tone of voice.	Disregard talk that may seem to be 'rambling'.
Speak slowly and say individual words clearly. Use strategies to reduce the effects of hearing impairment.	Shout or talk too fast.
Encourage talk about things that they are familiar with.	Interrupt unless it cannot be helped.
Use touch if appropriate.	Attempt to touch or invade their personal space if they are showing signs of fear or aggression.

Adapted from the Regional Dementia Management Strategy (Australia, 2001)

Verbal communication

Verbal communication can be very difficult for a person with Dementia. Included here are some tips on using the ABC approach that might help when talking with someone who is experiencing difficulties in their ability to use language or engage in conversation.

Avoid Confrontation

Be Practical

Clarify the feeling, and comfort

Problem 1: Mary has a problem starting up a conversation and keeping it going.

Think why?

Mental pictures not really coming into her head.

Think A.B.C

- **Avoid confrontation:** Don't say "Can't you think of anything to say".
- **Be practical:** Take the lead and start conversation. Use old memories or shared experiences. Photographs, favourite pieces of music, singing or praying with the person may help to start the conversation, "Lets see if the clothes are dry on the line".
- **Clarify feelings:** "It's sometimes very hard to think of things to say".

Problem 2: Someone is struggling to recall the name of something.

Think why?

The person cannot find the correct words to express the idea they have in their mind.

Think A.B.C

- **Avoid confrontation:** Don't say "You know the word, just concentrate".
- **Be practical:** If you know the word it may reduce the stress if you suggest it. If you don't know, try to narrow the options. You could say "Is it something to do with going to the garden", "Is it something to do with..." or "we'll not worry about it now. It will come to you later."
- **Clarify feelings:** "Isn't it frustrating when you can't think of a word"

Problem 3: Someone is asking you the same question over and over again.

Think why?

The same idea (mental picture) keeps forming in the person's head and they make it a question.

The person forgets the answer they have been given or forgets they have already asked the question.

Think A.B.C

- **Avoid confrontation:** Don't say "I told you that five minutes ago".
- **Be practical:** Try a non-committal reply "I'm not sure". Try a short, simple answer. Try writing the answer down for the person to refer to. Avoid situations that may cause anxiety. It is best not to mention a pending appointment or upcoming event until it is absolutely necessary. Remember, for someone with dementia the fear of not remembering the date is the real issue, rather than the date itself. The person may become focused on the issue and become agitated. Try to distract with a different activity, e.g. sorting a drawer or folding clothes for ironing.
- **Clarify feelings:** "You seem worried that you can't remember the date" or "I can never remember dates either, so we will mark it on the calendar."

Non-verbal communication

When someone loses their language ability, or has difficulty in communicating verbally, there are lots of non-verbal forms of communication that we can use. The value of some of these forms is that they may engage with the person's other senses so that they may also experience a sense of well-being.

Examples

Visual representation		Photograph albums, a memory box, painting pictures
Smell/taste	-	Baking, scent of flowers, perfume different types of food
Visual direct	-	Looking at objects of autobiographical meaning, sports trophy, family video etc
Music	-	Familiar tunes, records from times past, making music singing their party piece, or a favourite song or hymn with them
Tactile	-	Manipulating materials to gain sensory experiences, e.g. planting bulbs, baking bread, feeling various textures, tweed, wool etc. Massage

Guidelines for Effective Communication

1. Make sure the environment or room you are using is communication friendly: No radio or TV on and no other noisy activities on in the same room.
2. Make sure that you have the time to give the person and that you are feeling calm.
3. Try to ensure that your facial expression and body language are relaxed.
4. Approach the person from the front, and establish eye-contact.
5. Use touch if appropriate.
6. Speak simply and slowly, but not in a patronising way.
7. Give the person time to understand before moving the conversation on.
8. Be a good listener and do not be afraid of silences.
9. Be alert for cues and prompts.
10. Remember, if the person is 'non-responsive', this may not relate to a lack of understanding. It might be: (a) The individual cannot respond (b) The individual does not wish to respond.
11. Use short sentences. Avoid double messages. Example: It is better not to ask "would you like a cup of tea or coffee"? But rather "would you like a cup of coffee?"
12. Try not to be embarrassed by a display of emotion, whether it is positive or negative.



Common Issues for People with Dementia

Memory for the past

Most people with dementia are likely to remember the distant past more clearly than what has occurred more recently. They may have difficulty in recalling what happened a few moments ago, but will often be able to recall in great detail their life when they were much younger. However, even these long-term memories will eventually decline.

- People are often anxious about their memory loss, particularly in the early stages of dementia, and opportunities to share memories of the past can help to restore their sense of confidence.
- Talking about the past can often be enjoyable and can help people retain their sense of who they are.
- Use photographs, souvenirs and other appropriate items to help jog the person's memories of the past.
- If the person seems upset by certain memories, try to give them the opportunity to express their feelings, and show you understand.

New information

People with memory problems find it very hard to take in and remember new information:

- Keep information simple and repeat it frequently.
- Break down any new activities into small stages.

Loss of sense of time

You may find that the person begins to lose their sense of time quite early on in dementia. They may find it hard to judge how much time has passed because they can't remember what they have done or what they are going to do that day. Try to keep to a regular routine. Tactful reminders of the day and time and what you are going to do next may help.

Lack of recognition

People with dementia may eventually lose the ability to recognise people, places or things because their brain is no longer able to put together or interpret information properly. They may even fail to recognise their own reflection in a mirror and think it is someone else, or they may worry that a relative or close friend is an intruder in their home.

- Tactful explanations and reminders can often help to reassure the person and enable them to continue to make some sense of their environment and the people around them.

Repetitive behaviour

Sometimes people with dementia repeat the same phrase or movement many times.

- It may be due to some kind of discomfort. Check that they are not too hot or cold, thirsty or constipated. Talk to the PHN/ line manager if you are concerned that there is any possibility that they are ill or in pain.
- They may be finding their surroundings too noisy or stressful.
- They may be bored, and trying to stimulate themselves. Try to encourage an activity such as stroking a pet, going for a gentle walk, or listening to some gentle music.
- It may be due to the damage that has occurred in the brain. Simply offer as much reassurance as you can.

Asking the same question over and over

- Try to be tactful when answering. Don't say "I have just told you that", as this will increase feelings of anxiety.
- Try to get them to find the answer for themselves if possible. For example "Is it lunch time?" "Have a look at the clock." "Do we need more milk?" "Why don't you look in the fridge?"
- Try to distract them with an activity.
- People with dementia often become anxious about future events and this can lead to repetitive questioning. If this seems to be the case, tell them that someone is coming to visit, or that you are going shopping, for example, just before the event happens. This means that they will have less time to worry.

Constantly doing the same thing, such as packing and unpacking or rearranging the furniture

- The behaviour may relate to a former activity such as traveling, organising an office or entertaining. If you can work out what this activity might be, it may help you to feel more understanding, and may also serve as the basis for conversation.
- The person may be bored, and may need more stimulating activities or more contact with people.

The person may constantly follow you or call to check where you are

- Loss of a sense of time may mean that a few moments may seem like hours and they feel safe if you are nearby.
- Try not to speak sharply. This will only increase anxiety.
- Provide the person with an activity while you are busy with something else. Sometimes a pet or even a familiar stuffed animal or doll can be reassuring.
- It may be reassuring if the person can hear you sing or hear your radio if you are in another room.

May continually call out for someone or shout the same word

There are several possible reasons for this behaviour.

- They may be in pain or ill, or they may be experiencing hallucinations. If any of these possibilities seem likely, consult the PHN/ line manager.
- They may be lonely or distressed. If they shout out at night, a night light may be reassuring.
- They may be anxious because of their failing memory. Try to reassure or distract them. If they are calling for someone from their past, then talking to them about the past may be helpful.
- They may be bored. Everyone needs to be occupied, including people with dementia. Listening to music or a gentle hand massage may help.
- There may be too much noise and bustle for them to cope with and they may need a quieter environment.
- It may be the result of brain damage due to dementia. Talk to the PHN/ line manager, as the person may need to be referred on to a specialist.

Laugh or cry uncontrollably for no apparent reason

- Inappropriate laughing or crying may be associated with hallucinations or delusions. If you think this may be the case, discuss with the PHN/ line manager.
- This may be due to the effects of brain damage and is more common among people who have vascular dementia. It does not necessarily mean that the person is very sad or very happy. They may prefer you to ignore these episodes, or they may respond to reassurance.

Lack of inhibition

The person may behave in a way that others find embarrassing due to their failing memory and general confusion. In a few cases, it may be because of specific damage to the brain. Try to react calmly.

- Undressing or appearing naked in public may simply indicate that they have forgotten when it is appropriate to remove their clothes and where. Take them somewhere private and check whether they are too hot or uncomfortable or maybe they want to use the toilet or sleep.
- Lifting a skirt or fiddling with zips may be a sign that they want to use the toilet.
- If the person does start to stroke their genitals in public, gently discourage them or take them to their own room.
- If they make inappropriate sexual advances, gently discourage them and try to distract their attention. If such advances are frequent and persistent, seek advice from the PHN/ line manager.
- If the person behaves rudely – for example, by insulting people or by swearing or spitting – do not attempt to argue or correct them. Try to distract their attention. You can explain later that their behaviour is due to dementia and not to take it personally.

Pacing

People with dementia may pace up and down within a room for a number of reasons:

- They may be hungry or thirsty or constipated or simply want to use the toilet and be unable to tell you. Check on these kinds of possibilities.
- They may feel ill or they may be suffering the side-effects of certain medicines. If you suspect that it may be due to any of these causes, contact the PHN/ line manager.
- They may be bored or not using up all their energy. Try to find appropriate activities or enjoyable exercise.
- They may be upset by noisy or busy surroundings. Pacing may cease if they can find a quiet room.
- They may be angry, distressed or anxious. Try to find out how they are feeling and show that you understand.

However, in some cases pacing may be due to changes that have taken place in the brain. Try to distract the person, but if you are unable to prevent them from pacing.

- Try to find somewhere they can pace in safety without disturbing anyone.
- Make sure they have supportive shoes and comfortable clothes.
- Check feet and legs regularly for any redness, swellings or blisters which may need attention. Ask the PHN/ line manager if you are concerned.
- Try to persuade the person to rest from time to time and offer drinks and snacks.

Fidgeting

People with dementia may fidget constantly. They may be uncomfortable, bored, upset, need more exercise or it may be due to the damage to the brain.

- Check whether they are too hot, too cold, hungry or thirsty or whether they want to use the toilet, for example.
- If they seem upset, try to find the reason and reassure them.
- Try and distract their attention with an interesting activity or involve them in some form of exercise.
- Give them something to occupy their hands such as worry beads, Rosary beads, a soft toy, or a 'rummage box' with interesting objects, for example.

Hiding and losing

The person with dementia may deliberately hide objects to keep them safe and then forget where they are or that they ever had them.

- The wish to hide articles may be partly due to feelings of insecurity and a desire to hold on to the little they still have.
- Try to reassure, however impatient you feel.
- Try and find out the person's hiding places so that you can tactfully help them to find 'missing' articles.
- Some people may also hide food, perhaps intending to eat it later. If this is the case, you may need to check hiding places regularly, and discreetly dispose of any perishable items.

Hallucinations and Delusions

People with dementia sometimes experience hallucinations.

- They may see, hear, smell, taste or feel things which are not really there. Hallucinations involving sight or hearing are the most common.
- The reaction of the person with dementia to the hallucination may vary.
- They may realise that their imagination is playing tricks with them and pay no attention to the hallucination.
- They may find it difficult to decide whether or not the hallucination is real. In such instances they may find it reassuring if you go with them to look at where they saw an imaginary object, or to check the room where they thought they heard voices or other noises. You can then confirm that nothing is there.
- As the dementia becomes more severe, some people may become convinced that what they are seeing or hearing is real. This can be very frightening. It is worth trying to let them know that, although you cannot share their experience, you do understand that it is distressing for them. Try to distract them. There is no point in arguing about whether or not what they are seeing is real.
- Hallucinations are less likely to occur when the person is occupied or interested in what is going on around them.

If the person with dementia is distressed by their hallucinations or if the hallucinations persist, speak to the PHN/ line manager; medication can sometimes help.

Delusions

People with dementia may become suspicious, and worry that other people are taking advantage of them, or out to harm them in some way. For example, they may accuse someone of stealing from them when they mislay an object, or imagine that a friendly neighbour is plotting against them. Such ideas may be partly due to failing memory or an inability to recognise people they know, and partly due to a need to make sense of what is happening around them.

- Although such attitudes can be very trying, avoid arguing with the person. State calmly what you know to be true, if appropriate, and then reassure or distract.
- Explain to others in contact with the person that any unfounded accusations are a result of the dementia and that they should not take them personally.
- Do not automatically dismiss the person's suspicions if there is any possibility that they may be based on truth.

Some of the delusions that people with dementia have include:

- Their partner is being unfaithful.
- Their partner or close relative has been replaced by an imposter who closely resembles them.
- Their home is not their own.
- Their food is being poisoned.
- Their neighbours are spying on them.

People with dementia usually have these odd ideas because of the changes that are occurring in their brain. However, sometimes these ideas may also follow on from hallucinations. There is often little point in arguing with the person, as this only causes further distress.

- Try to reassure the person that you are on their side and want to help them.
- Distract them with other activities.
- Ask for advice from a PHN/line manager.

Medication can sometimes be helpful, particularly if the person is becoming aggressive. Talk to the PHN/ line manager.

Tips for Coping with Dementia

Coping with memory loss

Many carers find that dealing with memory problems is one of the most difficult aspects of dementia. There are some ways that carers can help the person with dementia cope with their memory problems. This will allow the person with dementia retain their confidence and independence for as long as possible

Avoiding extra stress

If the person is tired, unwell, anxious or depressed it will be even more difficult for them to remember. It will also be harder for them to cope with memory problems if they try to do more than one thing at a time or if they are distracted by noise or bustle.

- If you think the person may be ill or depressed, talk to the PHN/ line manager about it. The person may need to consult with their GP.
- Try to help them to concentrate on only one thing at a time.
- Try to ensure there are no distractions.
- Provide verbal cues rather than asking questions. For example, "Here is your nephew, David, to see you" is more helpful than "Do you remember who this is?"

Maintaining independence

You will want to help the person remain independent for as long as possible. However, certain precautions will have to be taken if the person is at risk because of their forgetfulness.

Help the person continue to do things for themselves by using frequent reminders and doing things with them – not for them.

Regular routine

Although variety and stimulation are important, too many changes will be confusing.

- A regular routine will help the person feel more secure, and make it easier for them to remember what usually happens during the day.
- Leave things in the same place so that the person can find them easily.

Memory aids

Memory aids such as lists, diaries and clear written instructions can be helpful in jogging memory if the person is willing and able to use them. However, you need to be aware that as dementia progresses, it may become more difficult for them to understand what the aids are for.

Ten Top Tips for Dealing with Your Reaction to Confusion

1. **STOP!!** Think about what you are about to do and consider the best way to do it.
2. **PLAN AND EXPLAIN** – Who you are; What you want to do; Why you want to do it etc.
3. **SMILE!!** The person who takes their cue from you will mirror your relaxed and positive body language and tone of voice.
4. **GO SLOW!!** You have a lot to do and you are in a hurry but the person isn't. How would you feel if someone came into your bedroom, pulled back your blankets and started pulling you out of bed without even giving you time to wake up properly.
5. **GO AWAY!!** If the person is resistive or aggressive but is NOT causing harm to themselves or others, leave them alone. Give them time to settle down, and approach later.
6. **GIVE** the person **SPACE!!** Any activity that involves invasion of personal space **INCREASES THE RISK OF ASSAULT AND/OR AGGRESSION**. Every time you provide care for a person you are invading their space.
7. **STAND ASIDE!!** Always provide care from the side not the front of the person, this way it is less threatening and frightening for the person.
8. **DISTRACT THE PERSON!!** Talk to the person about things they enjoyed in the past and let them hold a towel etc. whilst you are providing care.
9. **KEEP IT QUIET!!** Check noise level and reduce it when and where possible. Turn off the radio and TV etc.
10. **DON'T ARGUE!!** They are **RIGHT** and you are **WRONG!** The brain tells the person they can't be wrong.
11. **KNOW THE PERSON!!** Orientate to their surroundings as necessary. If they become upset by this reality, validate their feelings instead continuing to cause upset by this truth.

(Ref.: Adapted from the *Regional Dementia Management Strategy, Australia 2001*).

Understanding Behaviour which is Challenging

Behaviour that is misunderstood and managed inappropriately may escalate. **It may be helpful to reflect on the following three points to help understand better:**

- Activating Event (what was the trigger)
- Behaviour (what behaviour resulted)
- Consequence (what was the consequence)

Tips for managing difficult situations

DO	Don't
Stay calm & relaxed	Show fear/anxiety
Respectfully call by name to gain attention	Shout or raise your voice
Maintain their dignity	Show disrespect; tease, joke, or restrain
Remove any audience	Talk in a loud /busy room
Maintain personal space	Corner them
Listen, Reassure & Touch	Move or speak in a manner that conveys authority
Acknowledge feelings	

Wandering

Wandering describes the pacing up and down or the tendency to leave home to go for a walk and then be completely unable to find the way back again, which can be a feature of the behaviour of people with dementia. Some of the reasons people wander and some ways to cope are listed below.

Feeling lost

If the person has recently moved home or is attending a new day centre, for example, they may wander because they feel uncertain in a new environment. They may, therefore, need extra help in finding their way around. This type of wandering may cease once they become used to their new surroundings.

However, as dementia progresses, the person may also lose the ability to recognise a familiar environment. They may need more reminders of where they are, or might need to be accompanied if there is a possibility of getting lost.

Loss of memory

Wandering may take place due to loss of short-term memory. The person may sometimes set off to go shopping or visit a friend, and then forget where they are going. Or they may forget you have told them you are going out, and set off in search of you. It is possible they may become distressed and need reassurance.

Continuing a habit

People who have been used to walking long distances for pleasure or because of their job may simply be continuing a habit. Wherever possible, try to give them the opportunity to continue.

Boredom

Sometimes people wander because they are bored. They may need encouragement to take part in activities that they can still enjoy at home or at a local day centre.

Pain or discomfort

One fairly common reason for wandering is that the person is in some sort of discomfort or pain, and they are walking either to ease the problem or in search of a solution. If you think that this may be so, talk to the PHN/ line manager to arrange for an examination.

Confusion between night and day

People with dementia may wake in the early hours and think it is day. You may need professional advice if someone wanders at night, as it is far more hazardous, particularly if they are still in their night clothes. The person may need to go to bed later or need more activities during the day to use up their energy. If this is an issue you need to discuss with the PHN/ line manager.

Tips That May Be Helpful to You

1. Ensure that the person carries some form of identification in case they get lost, such as their name and the phone number of someone who can be contacted if needed.
2. If the person is determined to leave the place, it is usually better not to confront them as they may become very upset. Try accompanying them a little way and then diverting their attention so that you can both return.
3. If the person does disappear, don't panic. But if you are unable to find them in your neighbourhood, contact the local Garda station so they can help you in your search.
4. Do not scold the person or show your anxiety when you find them, as they may be confused and frightened themselves.
5. Reassure them and get them back into a familiar routine as soon as possible.
6. Alarm mats can also be helpful to alert you if the person with dementia has got out of bed during the night, even if it is just to allow you to help them find the bathroom.

Helping the person to maintain their independence and skills

As a carer, you will want to ensure that the person with dementia makes the best use of their skills and abilities at each stage of the illness in order to preserve their dignity and confidence. Of course, each person experiences dementia in their own way, but you can often help through encouragement and commonsense measures as well as with a reassuring routine.

You will want to encourage the person with dementia to do whatever they can for themselves, and only offer as much help as is necessary. Avoid the temptation to take over completely if they are struggling with a task, even though it may be easier and quicker for everyone. If you do, they are likely to lose whatever remains of their confidence and to cope less well as a result.

People with dementia may find it hard to cope with certain tasks because of the dementia or because of other disabilities. An occupational therapist (OT) can advise on aids and adaptations and other ways to help the person with dementia retain their independence for as long as possible. Any changes involving equipment or different approaches are more likely to be successful if they are introduced at an early stage, when the person with dementia is more capable of absorbing new information.

Feeling safe

The less anxious and stressed the person with dementia feels, the more likely they are to be able to use their skills to the best advantage. A relaxed, uncritical atmosphere is therefore important.

- Familiar surroundings and a regular routine are reassuring for people with dementia.
- Too many conflicting sounds or too many people can be confusing. Turn off the radio or TV or take the person to a quiet place if they need to concentrate on a task.
- The person may be upset or embarrassed by their declining abilities or clumsiness, and will need plenty of reassurance.
- Although you need to be tactful and encouraging, sometimes you just have to laugh together when things go wrong.

Feeling useful

We all need to feel useful and needed. Helping with simple tasks around the home or in the garden is a good way for people with dementia to practice everyday skills and feel useful at the same time.

Suggestions for chores in the home include dusting, polishing, folding clothes, laying and clearing tables, drying dishes, and sorting cutlery. Work in the garden might include digging, watering, raking or sweeping leaves. Try not to worry if such tasks are not done well. What matters is that the person with dementia is active and involved, and still using their abilities.

- It is more important that the person feels they are helping rather than that everything is done perfectly.
- Be very tactful if you do have to redo a chore. Make sure that the person is not aware of this fact.
- Remember to thank them for helping.

Tips on Ways to Help the Person to Maintain their Independence

Notes and routine

A whiteboard or corkboard near the fridge is useful to record important phone numbers, messages, tasks for the day and visits to be made during the day by service providers or friends.

The person can carry a diary, notebook or communication book in handbag/pocket.

Shopping and appointments

A shopping list may become essential to avoid forgetting items or buying duplicates.

Make a sign to remind the person of today's appointments to help them get ready. Put the sign somewhere prominent like at the breakfast table.

Time and date

Use clocks and watches with large numbers. Check clocks regularly if the person with dementia lives alone. If they have difficulty using conventional clocks try digital, or vice versa.

A weekly timetable of regular visitors, day centre visits or regular appointments positioned with the clock and calendar can help orientate people to what is happening on a particular day. Cross off each task when complete or each visit after it happens.

The delivery of a daily newspaper helps many people to know the day and date. Remove old newspapers regularly so they will not be confused with the current paper.

Telephone

Suggestions for keeping track of messages, phone calls, and even ideas, include:

- Note pads beside the phone, meal table and bed.
- A regular spot like a notice board or hall table for all messages.
- A message book to record all phone calls coming in.

Display emergency and commonly-used phone numbers on a whiteboard near the phone. If the person is living alone, the phone number of the main carer or relative could be programmed into phone memory and labeled simply. This can be done using the memory dialing function on standard touch telephones.

A press-button phone with large numbers can assist with correct dialing.

Keys and commonly-used items

Put items like keys, glasses, wallet, money, and camera etc. in the same place every time, or even in a central place all together – in a bowl on the table or in a basket on the phone table. Make a note of where that place is, in case it is forgotten – and put the note somewhere accessible like the notice board.

Meaningful Activities

If you can help the person with dementia to find activities that they still enjoy, you will improve their quality of life as well as your own.

Carefully-selected activities can provide stimulation and variety within a safe environment and help people with dementia feel more confident. Try to make sure that:

- Activities chosen are those where the person will not worry about failing or being judged by their performance.
- You give encouragement and praise.

In the early stages, the person with dementia may be able to think of activities to keep themselves occupied, but as it progresses this may become more difficult, and they will need more frequent prompting and assistance.

How activities can help

- Activities can help people maintain their skills and give them a sense of achievement.
- Activities can provide interest or fun, and help the person feel better about themselves and be more alert and interested in what is going on around them.
- Some activities such as painting a picture or looking at old photographs may help people with dementia express their feelings, so be sensitive to their reactions.

Suggestions for activities

Some people may be able to continue with activities they previously enjoyed, such as playing the piano, reading, carpentry or sewing, for quite some time, and need only a little prompting to do so. Others may find their previous activities too demanding, or become upset because they can no longer carry them out to the same standard. You will need to be ready to adapt and simplify activities, or find new ones that they can enjoy.

Music

Listening to music can remain a pleasure for a long time. You might record some favourite pieces for the person to listen to while you are not there. Popular songs from the person's younger days are often appreciated. They may like to sing along with the words, or you may like to sing together.

Pets

Many people with dementia respond well to pets, particularly if they had a pet earlier in their lives. Cats and dogs they can stroke are especially suitable. If you do not have a pet, you might encourage a neighbor or friend to bring one in from time to time.

Television

Television can become increasingly confusing as dementia progresses. If they do enjoy watching television, try to select some favourite programmes they can still follow, rather than just having it on all day.

Reminiscence therapy / reminders of the past

People with dementia usually find it easier to remember events that happened when they were younger rather than the more recent past. You may find they become more lively and interested if you can find ways to trigger early memories. These might include:

- Looking through old photographs or mementos of their life, such as birth and marriage certificates, medals or awards, old invitations or postcards.
- Clothes, shoes or bags that have been kept for many years can spark off memories, as can treasured possessions or a 'rummage box' containing articles such as an old powder compact, cuff links or sea shells.
- Looking at pictures in books about subjects that are of particular interest such as old cars, former film stars or places they have visited.

Sensory stimulation

As dementia progresses, and verbal communication becomes more difficult, activities which involve the senses become even more important.

- Touching or stroking soft pieces of fabric or a cuddly toy often gives comfort. A gentle hand massage can give reassuring contact.
- Tasting flavours enjoyed in the past, such as old-fashioned sweets or distinctive foods or drinks, can bring back memories.
- Smelling flowers or perfume, or distinctive smells such as ground coffee or fresh bread, can give pleasure.
- Listening to different kinds of music can be relaxing or stimulating, depending on the choice.
- In the later stages of dementia, a pleasant view, a hanging mobile or a goldfish tank can provide a focus of interest and be calming.

Tips to remember

- The person with dementia may find it hard to concentrate for any length of time, so activities that can be enjoyed for short periods are often more satisfactory.
- Simple activities are often the best, particularly as dementia progresses. Look for those which provide stimulation, but avoid too many challenges or choices, as these can be bewildering.
- People with dementia often retain their sense of humour. Look for opportunities to share a good laugh.
- In the later stages of dementia, you may find you have to work quite hard with the person in order to get a response. Think in terms of brief activities that will help break up the day and give you contact with the person, such as hand massage or listening together to some music.

Mealtimes and Eating

Mealtimes can be stressful, particularly as dementia progresses. Here are some suggestions that may help.

- A calm, regular routine is reassuring for someone with dementia. They are likely to cope better if meals are relaxed, unhurried occasions.
- Try to allow plenty of time for eating, and make sure there are no competing distractions.

Poor appetite

If the person has a very poor appetite and does not seem interested in eating, this may be due to a number of reasons.

- People often become depressed in the early stages of dementia and lose interest in food. If you suspect depression, consult the PHN/ line manager, as it can often be treated. Once the depression lifts, the person's appetite should return.
- The problems may be due to badly-fitting dentures or sore gums, which make eating uncomfortable. Check with the PHN/ line manager.
- The person may not feel hungry because they are not doing enough during the day. Encourage them to be more active and take more exercise.
- In the later stages of dementia, people may not understand that they are supposed to eat the food in front of them. You may need to keep reminding them or guide the food to their mouth.
- If the person is living on their own, there may come a time when they forget to eat or even hide meals which you or Meals-on-Wheels may have supplied. This is a sign that they need more help. You need to talk to the PHN/ line manager about possible alternative arrangements.

Overeating

Sometimes a person with dementia will eat far more food than they require. This may be due to changes in the brain chemistry which are not fully understood. For many people it is only a temporary phase. Sometimes the person may forget they have eaten and ask for food again, or they may continue eating whatever food is available.

People with dementia often prefer carbohydrates and sweet foods if left to choose for themselves. This is particularly the case with people who overeat. Such foods may provide comfort, and help the person to feel less depressed. However, it is important for their health to make sure that they do not overeat and that they eat a balanced diet.

You need to be alert if the person is inclined to 'scavenge' for food. As well as eating too much, they could consume unsuitable or dangerous substances.

- Anything which should not be consumed should be put of sight and out of reach.
- Try to distract the person's attention, or find them a satisfying activity as a substitute for eating.
- If they are determined to have more food, try providing non-fattening snacks such as raw carrots or celery, apples, berries or other fruits.

Encouraging the person to eat independently

It is important to encourage the person to eat independently themselves for as long as possible. Table manners may deteriorate due to forgetfulness or problems in coordination, so you will need to be flexible and tolerant.

- Try to concentrate on praising the person for their efforts in eating rather than worrying about any mess.
- Commonsense measures such as attractive plastic tablecloths, napkins to protect clothing and bowls instead of plates can make it easier for you to cope.
- An occupational therapist can advise on eating aids such as non-slips mats, plates with suction pads or cutlery with handles that are easier to grasp. You can contact an occupational therapist through your PHN/ line manager.
- Finger foods such as small sandwiches with nutritious fillings may be helpful for people who have difficulty in managing cutlery or who are restless and will not stay seated at the table.
- Cutting food up into small pieces or liquidizing may help in the later stages.
- If you do have to assist the person with their food, try putting a spoon in their hand and guiding it to their mouth to encourage their involvement. **Never try to give food to someone when they are drowsy or agitated or when they are lying down, as they are more likely to choke.**
- It is important to encourage the person to eat a balanced diet.
- Lack of certain nutrients can lead to illness or increased confusion. If the person refuses to eat certain foods that you feel they need, consult the PHN/ line manager.
- Some people develop a taste for particular foods during the later stages of dementia. While you will want to give them reasonable amounts of what they enjoy, you need to ensure that they continue to eat a healthy diet.
- Constipation is quite common, especially in the later stages. Make sure they eat plenty of fibre and drink plenty of liquid.
- If you are worried because the person is losing weight, contact the PHN/ line manager. They may be eating too few calories or there may be a medical problem. Some people with dementia need more calories because they are so restless and active.

Helpful tips

- Elaborate meals are not essential. It is probably better to devote your energy to ensuring that the person eats and enjoys their food.
- You may find that frequent small meals or nutritious snacks are more tempting for people who are restless or have poor appetites.
- You may need to offer the person salt and pepper or sauces and then remove them if they are likely to use them repeatedly.
- Make sure food and drinks are not too hot as the person may lose the ability to judge. It is possible to purchase spill-proof containers, such as convalescent feeding cups or cups made for toddlers, for fluids served at the table.
- Make sure they drink enough liquid each day. Too little liquid can lead to dehydration which can make them more confused. People vary in their thirst, but a good guide is at least eight cups of liquid a day.
- Encourage the person to help for as long as possible with activities such as preparing food, laying the table or drying the dishes. This can help them to feel useful and more involved.

Dressing

Enabling someone with dementia to choose what they wear and retain their particular style of dressing is a way of helping them to preserve their own identity for as long as possible. As dementia progresses, the person may need more assistance with dressing.

How you can help

- Dressing is a private activity for most of us, and one where we are used to making our own decisions about what to wear. If people with dementia need assistance with dressing, it should be offered in a tactful and sensitive way to enable them to maintain their dignity and make their own choices for as long as they can.
- It is important to allow plenty of time if you are helping someone to dress, so neither of you feels rushed.
- Try to use the opportunity to communicate about what you are doing and anything else of interest.
- If you can make it an enjoyable activity, the person with dementia is more likely to feel relaxed and confident.

Encourage independence in dressing

Encourage the person to remain independent and dress themselves for as long as they can.

Ways of helping may include

- Laying out clothes in the order the person will put them on.
- Removing dirty clothes to prevent confusion.
- Reminding them which garment goes on next, or handing them the appropriate clothes.
- Giving instructions in very short steps, when someone is more confused, such as, "Now put your arm through the sleeve".
- Being tactful if someone puts something on the wrong way round. On the other hand, you may both be able to have a good laugh.
- If the person with dementia lives on their own, steps such as labeling drawers with their content, or putting whole outfits together for a particular day, may be helpful.

General tips

- Make sure the room is warm.
- Try to encourage the person to use the toilet before getting dressed.
- Try to follow the routine they are used to. They may prefer to put on all their underwear first or completely dress their top and then their bottom half.
- If they resist your efforts to help, it may be better to leave them for a little while rather than cause distress. They may be more amenable if you try again a little later.

- The person may not be able to tell you whether they are hot or cold. Several layers of thin clothing may be better than one thick layer. You can then suggest removing one layer if it gets too warm.

Choice

Ask the person what they would like to put on wherever possible. People with dementia need the dignity of having some choice in what they wear. However, too many options could be confusing. It may be better to make suggestions one at a time. If the person lives on their own and has lots of clothes, select those they are most likely to wear and put them in an accessible place. It will then be easier for the person to choose.

If family/carers are buying clothes for the person with dementia, the following information may be of help.

- Check their size. They may have lost or put on weight without you realising it.
- Look for clothes that are machine washable and need little ironing, as this will save time.
- Look for clothes which are easy for the person to manage, particularly if they are living on their own. For example, larger neck openings and front fastenings, or no fastenings at all.
- If you are caring for a woman, front-fastening bras are easier for you both to manage. Never let her go without a bra as this could lead to soreness and discomfort. Avoid self-supporting stockings, as these can sometimes cause circulation problems.
- For men, boxer shorts may be easier to manager than Y-fronts.
- Shoes with laces may be hard to manage. Well-fitting slip-on shoes may help the person to remain independent a little longer.
- Slippers should not be worn for more than a few hours as they do not offer enough support.
- You may be able to adapt some clothes to make them easier to put on and take off.
- Longer zips are always helpful and Velcro fastenings are easier than buttons or hooks if the person can get used to the way Velcro works.
- You can sometimes replace shoelaces with elastic.

Changing clothes

Some people may be reluctant to undress even to go to bed, or to change clothes. You may have to use a variety of strategies to persuade them to change. For example, you may need to remove dirty clothing and substitute fresh clothing when they are washing. Or the person may agree to change because someone is visiting or because you would like to see them in something new. Try to find an opportunity without causing the person distress. Make sure they change their underwear frequently.

Bizarre clothing

As long as it does no harm, it is probably better to accept rather bizarre clothing or clothing that is out of place rather than have a confrontation. If someone is determined to wear a hat in bed or a heavy coat in summer, try where possible to respect their choice.

Other aspects of grooming

Help the person with their hair once they are dressed. Women may like make-up if they are used to it, or a dab of perfume. If someone likes wearing brooches or beads, this may be another opportunity for choice, and if they enjoy having their nails painted, you might do this at some point in the day.

Men may need reminders or help with shaving, and eventually you may need to do it for them. If they use an electric razor, they will probably be able to manage it for longer.

Compliments

Helping someone with dementia to look nice is an important way of maintaining their confidence. Compliment the person on the way they look and encourage them to be proud of their appearance.



Personal Hygiene: Washing and Bathing

For most adults, washing is a personal and private activity. Carers need to be sensitive and tactful when offering help or when trying to persuade someone with dementia to keep clean. It is important to respect the person's dignity. A flexible approach often works best. Here are some suggestions.

As the illness progresses, the person with dementia may need reminders or help to wash. Sometimes they may be very reluctant, and you will need to find ways to encourage them which do not cause distress.

Encourage independence

Encourage the person to continue washing themselves for as long as possible.

- Try reminding them of the next step, tactfully indicating the body part to be washed, or they might like to have some assistance from you like handing them the soap or towel.
- Continue with familiar washing routines established before they developed dementia. A shower each morning or a weekly bath with a stand-up wash on days in between, undressing in the bedroom or using particular towels. It's worth taking a little time to analyse which routine works best.

Sensible precautions

- Check that the bathroom floor is not slippery.
- Make sure that the room is warm before they undress. Older people are more sensitive to heat and cold.
- Check the water temperature of the bath or shower. It should not be too hot or too cold.

General tips

If you are helping someone to wash, try to make it as pleasant and relaxed as possible.

- Make sure everything is in place before you start.
- Use the opportunity to communicate and, if necessary, to explain what you are doing.
- When they are undressed, check for any red or sore areas of skin, or skin rashes. These should be discussed with the PHN/line manager.
- Make sure the person is thoroughly dried, especially in the skin folds, otherwise skin may become chafed and sore.

Aids and equipment

Some aids and equipment may help to make washing easier and enable the person with dementia to feel safer and more in control. An occupational therapist or PHN/line manager may advise.

Depending on individual circumstances, aids and appliances might include:

- Grab rails for getting in and out of the bath.
- Hand rails by the shower, washbasin or toilet.
- Non-slip bath or shower mats.
- Raised toilet seats.
- A bath seat or shower stool.

Handling anxieties

Some people with dementia develop anxieties about various aspects of washing.

- They may be worried by the depth of water in the bath, but reassured by a shallow bath or if a bath seat is used.
- They may be frightened by the rush of water from an overhead shower and feel happier with a hand-held shower attachment that is easier to control.
- The person may feel ashamed if they are incontinent and try to disguise an 'accident' by refusing to wash. They will need plenty of gentle reassurance. A matter-of-fact approach often works well, as does humour.
- The person may be embarrassed by your presence. Sometimes strategies such as enabling them to keep one part of their body covered while you help them wash the other part may help overcome their embarrassment.
- They may become anxious about being left on their own and need reassurance that you will stay with them all the time.

Washing hair

Washing hair regularly will help the person look and feel better. Using a hand-held shower may be the easiest way. Sometimes a person with dementia will prefer to have their hair washed by a hairdresser because they recognise the routine. Some hairdressers will come to the house.

However some people really dislike having their hair washed. You will have to balance the advantages of clean hair against the disadvantages of creating tension between you.

A flexible approach

Where someone is reluctant to wash, you may find different approaches work at different times. It may depend on the person's mood and the severity of their dementia. Whatever happens, try to remain calm and find a way of coping that does not involve argument or confrontation.

- The person may respond to a gentle reminder or a matter-of-fact approach such as running a bath or putting out clean clothes.
- The person may agree to have a wash because they are going out, or someone is visiting.
- It may be a question of timing. For example they may adamantly refuse to wash when you suggest it, but be quite amenable a little while later, or they may be more prepared to wash at certain points in the day.
- Where someone is very confused, it may help if you break the process down into small stages for them. Rather than saying, 'let's have a wash' you might say 'let me help you take your dressing gown off' and so on. Handing them the soap and flannel to wash themselves and then the towel to dry themselves may make it easier.
- If bathing or showering leads to conflict or distress, a thorough wash using wash cloths may be sufficient.
- It is better to remove dirty clothes and substitute clean ones at bedtime or after a bath than to get involved in arguments about the need to change clothing.

Continence Management

Incontinence is often very upsetting and humiliating for people with dementia as well as stressful for carers. However, there are many ways in which you can help to prevent or manage incontinence which can improve the situation for everyone concerned.

There are many different reasons why people with dementia may become incontinent. It is important to seek advice as soon as possible and to ensure that the person receives appropriate help or support. Sometimes the person is not incontinent, but because of their dementia cannot find the toilet or may have difficulty realising that they need to go to the toilet.

Incontinence occurs when someone loses control of their bladder (urinary incontinence) or their bowels (faecal incontinence). It may happen all or most of the time, or just occasionally. Urinary incontinence is far more common than faecal incontinence, but both may be due to treatable conditions.

Treatable conditions

Among the conditions which may cause urinary incontinence are:

- A urinary tract infection: this usually responds to medication.
- Prostate gland trouble (in men): an operation may be advised
- The side-effects of drugs.
- Severe constipation which causes incontinence as a result of pressure on the bladder; eating foods rich in fibre and drinking plenty of liquid may deal with the constipation. Exercise may also help.

Faecal incontinence may sometimes be caused by severe constipation where diarrhoea leaks out around the hard stool blocking the bowel.

If you have any concerns, it is important to talk to the PHN/ line manager who may suggest that the person contacts their GP.

Useful strategies

- Reminding the person to go to the toilet or taking them at regular intervals. Faecal incontinence can sometimes be managed by taking the person at a set time, if their habits are regular.
- Being aware of signs such as fidgeting, getting up and down or pulling at clothes may indicate that the person needs to go to the toilet.
- Making sure the toilet is easy to use. An occupational therapist can advise on aids such as handrails.
- Making sure that the person has clothes that can be quickly removed or unfastened. Velcro fastenings rather than zips or buttons may be simpler if the person has difficulty in managing clothes.
- Avoiding drinks for several hours before the person goes to bed if the person is incontinent at night. However, you should make sure that they drink plenty during the day.

- Making sure that there are no obstacles in the person's way such as awkwardly-placed furniture or doors which are difficult to open.
- Making sure they remember where the toilet is. A sign on the door may help, or they may need reminding.
- If it is too difficult for the person to get to the toilet, a toilet aid such as a commode may be useful.

Incontinence aids

If frequent use of the toilet is not sufficient to prevent incontinence, there are a variety of measures you can take to make the person more comfortable and to protect items such as clothes and bedding. Depending on eligibility, some incontinence products may be available through the local health centre.

The PHN/ line manager can advise on other aids as appropriate.

Confused behaviour

Sometimes the person with dementia may behave in what seems a rather bizarre way perhaps because they are ashamed of their incontinence or confused about their surroundings. They may hide wet underwear, for example, urinate into a wastepaper basket, or may occasionally wrap their faeces in a parcel and hide them. It helps if you can remain calm and matter-of-fact when dealing with incontinence, and remember that it is not the person's fault.

Problems with Sleeping

Problems with sleeping and changes in the sleep/wake cycle are a common occurrence with dementia. Some people sleep during the day and are awake and restless at night. Some are no longer able to distinguish between night and day, while others are simply not as active as they used to be, and thus need less sleep. Trying to recognise the cause of the sleeping problems will help you to decide how best to deal with them.

Physiological or medical causes

- Brain damage caused by the condition has affected the 'biological clock' in the brain which directs our sleep patterns.
- Illness, e.g. angina, congestive heart failure, diabetes, ulcers.
- Pain, e.g. arthritis.
- Urinary tract infections, which cause frequent need to urinate.
- 'Restless legs' or leg cramps, which can indicate a metabolic problem.
- Depression, which can cause early morning waking and inability to get back to sleep.
- Side-effects of medication such as diuretics.
- Sleep apnoea and snoring.
- A need for less sleep as a person gets older.

Environmental causes

- Too hot or too cold.
- Poor lighting, with the effect that darkness causes the person to become disorientated.
- Changes in environment, such as moving to a new home or having to be hospitalised, which may cause disorientation and confusion.

Other possible causes

- Going to bed too early.
- Sleeping too much during the day.
- Over-tiredness causing tenseness and difficulty in falling asleep.
- Insufficient exercise, so that the person does not feel tired.
- Too much caffeine or alcohol.
- Feeling hungry.
- Agitation following an upsetting situation.
- Disturbing dreams.

It is important to encourage the person with dementia to be as active as possible during the day. It really does not matter what the activity entails, so long as they do not spend long spells sitting down. Activity provides stimulation for the senses, mobility for the joints, exercise for the lungs and assistance for the circulation of blood through the body.

It is also advisable for the person with dementia to keep to a routine of getting up at a regular time. This also applies to retiring at night-time. Routine is highly recommended for those who are confused, or who have memory defects.

Coffee and tea should not be given before going to bed. These are stimulants and should be avoided as they contain caffeine which can cause restlessness. A glass of hot milk may help to get the person to sleep. Lavender oil is also useful. A few drops on the pillow may aid sleep.

If possible, a night light should be left on, especially in the bathroom and landing or hallway. In the interest of safety, it may be necessary for the person to sleep alone in a ground-floor room. This arrangement may be essential in the advanced stages of the condition.

Before retiring, it is important to create an environment which will be conducive towards a restful night. This might include a certain degree of quietness and relaxation by, for example, playing gentle music. Avoid violent TV shows which can provoke nightmares.

Most important of all, try to get some sleep and rest yourself. Perhaps you have had a difficult day and, in the interest of your own health, you need your sleep. You, as carer, have the person's best interest and welfare at heart. You need your health.

Sundowning

Some people with dementia are noticeably more confused and agitated in the late afternoon or evening (this is sometimes called 'sundowning'). Problems with sleeping and sundowning are often a stage in the progression of the condition that passes.

Some suggestions for coping with sundowning include:

- Distraction (e.g. music, giving the person something to fiddle with, going for a walk, doing a simple craft activity).
- Minimising noise, confusion and having large numbers of people around.
- Being aware that it is happening – plan not to do tasks which agitate the person further.
- A rocking chair.
- Having the person spend less time in bed, e.g. get the person up earlier, or keep them up later at night.
- Maintaining a set bedtime and waking routine and continuing bedtime rituals from the past, for instance, a glass of warm milk, leaving the radio on.
- Trying to prevent day-time napping unless the person seems very tired in the early evening hours, in which case suggest a short rest after lunch

Palliative Care

Dementia and palliative care

We are used to hearing about palliative care being provided for people with cancer, but over the past few years there is a move to provide palliative care for people with other life-limiting conditions including dementia. Palliative care sees dying as a normal part of the life-cycle, and aims to help people maintain their dignity whilst dying, by keeping them comfortable, free of pain and supporting them during this time.

For people with dementia who have progressed to late stages, dying can be a process that takes place over a number of days or weeks. If the person you are caring for is dying at home, the GP and Public Health Nurse will plan their care. This sometimes involves bringing in a specialist palliative care team to assess the person and to provide advice on the care plan, especially to make sure the person is free of pain and comfortable.

As a home carer you can have a role too, for example by helping to keep the person comfortable. This will usually include some of the tasks you may have previously done for the person such as washing, mouth care, continence care and helping the person take fluids or small amounts of food. Your Public Health Nurse or manager will give you direction and support in this.

At this time, when providing care, it is important to talk to the person as you normally would, even if it seems that they are not aware of you.

This can be a difficult time for the person with dementia and their family, so having a carer that they are used to being there to help care for their loved one can help them through this.

When the person you have cared for dies, it is normal to feel upset, especially if you have been caring for them for a long time and have come to know the family. It can help to give yourself the time to feel upset. Some people find it useful to talk to someone else, such as other carers or your manager.

Conclusion

We hope that you have found the practical information and tips in this booklet useful and that it will help you when looking after a person with dementia. As home help carers, it is important for you to reflect on your approach to care when looking after a person with dementia. Adopting a person-centred approach to care is essential, to ensure the person and their families receive care which is delivered in a sensitive, respectful, caring way: care which will enable the person to feel that they matter and that they are partners in their care.

References and Resources

Alzheimer's Society Ireland Website www.alzheimers.ie

NHS Scotland (2009) *Coping with Dementia: A Practical Handbook for Carers*.

Government of Australia (2001) Regional Dementia Management Strategy.

National Council for Palliative Care (London). *Palliative Care Explained*
<http://www.ncpc.org.uk/site/professionals/explained>

www.hospicefoundation.ie Irish Hospice Foundation
Includes sections on Palliative Care & Dementia and information on Bereavement and on courses on palliative care

www.carers.ie Hospice foundation site on palliative care for carers

<http://www.hospicefriendlyhospitals.net/resources-and-courses/itemlist/category/17-resources-general> Hospice-friendly Hospitals, includes information leaflets on bereavement and resources such as cards

Alzheimer Society of Ireland Publications. These can be obtained by calling the National Helpline 1800 341 341 or download from the website: www.alzheimer.ie

- **Living with Dementia** is written for family members who are dealing with a recent diagnosis, or trying to understand what dementia is or what a diagnosis means. It is an introduction to dementia and to the services and supports that may be available to their loved one and to them. Download from the website: <http://www.alzheimer.ie/eng/Resources/Living-with-Dementia-an-introduction-for-family-carers>
- **Practical Tips for Coping with Memory Loss**. This booklet outlines many practical ways to help yourself in everyday life, if you are having difficulty with your memory. Copies are also available by calling our National Helpline at 1800 341 341.
- <http://www.alzheimer.ie/eng/Resources/Practical-Tips-for-Coping-with-Memory-Loss>

- **Understanding Alzheimer's disease and other dementias** is a booklet which provides a brief explanation of dementia and an outline of the early signs and symptoms of Alzheimer's disease and the stages of the condition. The booklet contains a memory checklist and a diary section which may help people to prepare for a visit to their doctor about their concerns. (Supported by Pfizer Healthcare Ireland)

<http://www.alzheimer.ie/eng/Alzheimer-Dementia/I%27m-Worried-About-My-Memory/Your-guide-to-Understanding-Alzheimer%27s-Disease-and-other-dementias>.

- **Alzheimer Society of Ireland: Carer's Information Pack**
A collection of information sheets which provide practical tips for everyday living and sections about particular areas such as legal and financial affairs. Copies of the pack or individual leaflets are available by calling the helpline or can be downloaded from the website: <http://www.alzheimer.ie/eng/Alzheimer-Dementia/I%27m-a-Carer/Useful-Publications>

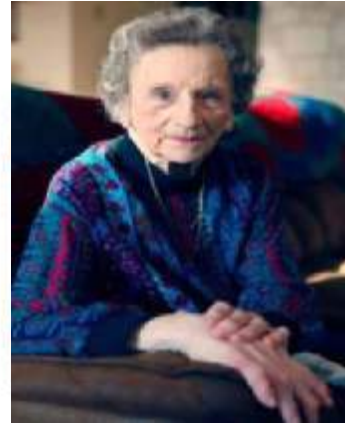
The Open Dementia e-Learning Programme is aimed at anyone who comes into contact with someone with dementia and provides a general introduction to the disease and the experience of living with dementia. This programme is designed to be accessible to a wide audience and to make learning as enjoyable as possible and so allows users to fully interact with the content and includes video, audio and graphics to make the content come alive. In particular the programme includes a considerable amount of new video footage shot by both the Alzheimer's Society (UK) and SCIE where people with dementia and their carers share their views and feelings on camera. <http://www.scie.org.uk/publications/elearning/dementia/index.asp>

Useful contacts

- The Alzheimer Society of Ireland. National Helpline: 1800 341 341, email: info@alzheimer.ie or see website: www.alzheimer.ie
- Health Service Executive: <http://www.hse.ie/eng/> Call Save 185024 1850
- Senior Helpline: LoCall 1850440 444
- Living with Dementia, Trinity College Dublin. Phone: 01 8962914, email: forsytc@tcd.ie or see website: <http://www.socialwork-socialpolicy.tcd.ie/livingwithdementia/>
- DSIDC, St James's Hospital. Phone: 01 4162035, email: dsidc@stjames.ie or see website: www.dementia.ie
- HIQA - Health Information & Quality Authority www.hiqa.ie

Further Reading

Cognitive Impairment and Dementia: A Practical Guide to Daily Living for Family Caregivers Compiled by Suzanne Cahill PhD & Vanessa Moore In association with *The Living with Dementia (LiD) Programme, School of Social Work and Social Policy, Trinity College Dublin and the Dementia Services Information and Development Centre (DSIDC), St James' Hospital, Dublin. 2*



Reflection

Do not ask me to remember.

Don't try to make me understand.

Let me rest and know you're with me.

I'm confused beyond your concept.

I am sad and sick and lost.

All I know is that I need you

To be with me at all cost.

Do not lose your patience with me.

Do not scold or curse or cry.

I can't help the way I'm acting,

Can't be different 'though I try.

Just remember that I need you,

That the best of me is gone.

Please don't fail to stand beside me,

Love me 'til my life is done.

- Author Unknown



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive



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Professional Development
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An Chomhairle Náisiúnta o Threoir
Glaisneúil na nAireanna agus
na Cuidreáraithe



THE ALZHEIMER
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Office of the
Nursing & Midwifery
Services Director