



Aged Care

Caring for someone living with dementia



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Introduction

You are probably reading this booklet because a relative or friend has or may have dementia. This may be something you suspect or perhaps they have been diagnosed by a health professional. Either way, this is likely to be a worrying time for both of you.

We know that much of your concern or fear may come from not knowing what is likely to happen in the future. This guide will provide you with some useful information and how you can help look after your relative or friend. We also remind you to look after yourself because we understand that caring for someone living with dementia can be challenging.

There is also a Useful Contacts section at the back of the book which gives details of further sources of information and support.

Bupa Aged Care is a leading provider of dementia care in Australia. This guide draws on our wide experience of caring for people living with dementia and our understanding of the sadness and stress it can cause for relatives and friends. We recognise that every person living with dementia is different and every carer's situation is different, but we hope you will find some useful advice, information and support in this book.



What is dementia?

Dementia is a term used to describe the loss of memory, reduced language skills, impaired reasoning and loss of daily living skills that arises because of irreversible and progressive deterioration of brain function. Changes to behaviour and emotions are also common. There are more than 100 different types of dementia.

The most common types are Alzheimer's disease, vascular dementia and dementia with Lewy bodies.

An individual may have a combination of different causes of dementia, in particular Alzheimer's disease and vascular dementia. Initially, each of these diseases tends to affect particular areas of the brain and will cause different changes in a person's behaviour.

In Australia, dementia affects approximately one person in 10 aged over 65 years, and almost half of people over 80. In 2010, over 257,000 people were affected by dementia, and by 2030 this number is predicted to rise to approximately 591,500 people. You are not alone in caring for someone living with dementia.

How can I tell if someone has dementia?

Although there are common symptoms of dementia, each individual can be affected in different ways.

Depending on the type of dementia and its progression, symptoms can include:

- Memory loss – especially for more recent events. In the early stages of dementia, the person may misplace objects or forget what they were planning to do
- Difficulty finding their way around, especially in new or unfamiliar surroundings
- Problems finding the correct words or understanding what others are saying to them
- Poor concentration
- Problems learning new ideas or skills

- Difficulties with thinking, such as having trouble using logic during a discussion
- Problems in perception and judging distance, for example, missing the edge of a chair when attempting to sit down
- Changes to physical abilities, such as difficulties coordinating movement during domestic chores.
- Psychological changes, for example, becoming irritable, saying or doing inappropriate things or becoming suspicious or aggressive.

However, these symptoms can be caused by other health issues, such as stress, depression, diabetes, vitamin deficiency, infection and many other illnesses. It is therefore always important for a person to be examined by a doctor and an

accurate diagnosis made by a specialist.

The later stages of dementia are associated with severe cognitive, psychological, communication and physical problems, including loss of speech, immobility, incontinence and frailty.

Throughout the journey of dementia psychological changes, for example, becoming irritable, saying or doing inappropriate things, or becoming suspicious or aggressive can occur. These are not so much symptoms but indications that the person is struggling to cope and understand what is happening around them.

It can be difficult to determine exactly when dementia starts, as it usually begins with mild forgetfulness or changes in behaviour. Although the speed of progression varies widely between different people, it typically takes 8-12 years from diagnosis to severe dementia and death. This time frame varies for people diagnosed depending on the type of dementia and age.

There is no cure for dementia, however medications can be prescribed for people living with mild to moderate dementia that may slow down the rate of decline for a number of months. Research into finding a cure is continuing daily with many studies being completed around the world.

It is often the case in dementia that short term memory is the first to deteriorate.

People may not remember a recent family event or the details of an upcoming appointment. With dementia, 'what you learn first is often what you lose last'. The information and skills that are learnt at a young age stay with a person the longest.

These skills and information are described as being stored in 'long term memory'. A person living with dementia may not be able to remember what happened a few moments ago, yet they can recall detailed information about their life as a child. As the disease progresses their long term memory may also fade.

We give some practical tips for coping with the symptoms of dementia later in this book. But it is important to remember that even as someone's memory and

skills deteriorate, the person you care for is still the same individual with their own views, reactions and feelings.



Different types of dementia

Alzheimer's disease

Alzheimer's disease is the most common type of dementia. In Australia, about 50-70 percent of those living with dementia have Alzheimer's disease.

Alzheimer's disease causes the number of nerve cells in the brain to gradually reduce and the brain shrinks. The nerve signals that are essential for activities such as language and physical movement become increasingly impaired. These nerve cells can't be replaced, so the functioning of a person living with Alzheimer's disease declines as more cells are destroyed.

Alzheimer's disease usually starts with forgetfulness, problems with working things out and difficulty in finding the right words. Family or friends may also notice changes in mood. For example, some people may appear to be depressed.

As the disease progresses, memory loss becomes worse and people have difficulty learning new skills and information. Changes may become more obvious with the progression of the condition where people say or do things that are out of character. Everyday tasks such as getting dressed, washing, cooking, travelling and handling money may become difficult.

Disorientation is also common and this can cause people with Alzheimer's disease to lose their sense of time and place. For example, they may get dressed in the middle of the night thinking that it is morning. New surroundings and new people may be confusing and it could become difficult for people to recognise previously well known family and friends.

Some people in the early stages of Alzheimer's disease are aware of their condition while some

are not. Insight and awareness generally become more impaired with the progression of the disease.

During the late stages of the disease where impairments and changes are more severe, people with Alzheimer's disease may become totally dependent on others for their care.

Vascular dementia (Multi-infarct dementia)

Vascular dementia, sometimes called multi-infarct dementia, accounts for more than 20 percent of all dementia cases. The disease process begins when small blood vessels in the brain become blocked. These blockages prevent oxygen from reaching the nearby brain cells, leading to their death. Therefore, vascular dementia is essentially caused by tiny strokes in the brain.

Vascular dementia can usually be identified by a sudden change in a person's behaviour, speech or functioning. The exact change will depend on the specific area of the brain in which the small strokes have occurred. As more of the brain



is damaged by tiny strokes, a person's memory, language and thinking progressively declines. Vascular dementia can be treated with therapies designed to reduce the risk of further strokes in the brain, but there is no cure for the condition.

Dementia with Lewy bodies

Dementia with Lewy bodies accounts for approximately 10-15 percent of all cases of dementia in older people. Lewy bodies are tiny protein

deposits found in nerve cells. Their presence in the brain interrupts the action of chemical messengers, disrupting normal brain function. There are similarities between this condition and both Alzheimer's and Parkinson's disease. Dementia with Lewy bodies causes an impairment of memory, language and reasoning. It progresses at about the same rate as Alzheimer's disease. However, unlike Alzheimer's disease, the condition is characterised by pronounced fluctuations in attention and lucidity. Therefore, it is important to be aware that the abilities of a person living with Lewy body disease can change frequently, almost by the hour. A person may be able to carry out an activity and then suddenly be unable to do so. Without an understanding of the disease, this can be misinterpreted as laziness by other people.

Like Alzheimer's and Parkinson's disease, dementia with Lewy bodies can affect the areas of the brain that control movement, balance, vision and visual recognition

(knowing what it is that we see). As a result, people with Lewy body disease may have difficulty moving, resulting in falls, slowness, stiffness and tremors. They may experience problems judging distances and when walking on uneven or unpredictable surfaces. They may also experience hallucinations, which can (understandably) cause the person to become agitated and distressed.

Other types of dementia

There are other types of dementia, including those grouped under the heading of frontotemporal dementia. People with these conditions present with initial changes in behaviour, personality and language, more so than forgetfulness. People who consume extreme amounts of alcohol over a long period of time can also develop dementia. Some people may also develop dementia as a result of Creutzfeldt-Jakob disease or AIDS/HIV, Parkinson's disease, Huntington's disease, Multiple Sclerosis, motor neurone disease and Down Syndrome.



What should I do if I think a friend or relative has dementia?

If you are concerned about a friend, relative or even yourself, then seeking help as soon as possible is advisable. Your doctor should be the first point of call. Your doctor will want to rule out other diseases or conditions that may produce similar symptoms.

An early diagnosis can:

- Help the person become involved in making decisions about their future care – no decision about you, without you
- Help you to identify sources of support and advice
- Help you to cope with caring for the person
- Enable the person to benefit from the current treatments available

- Help you to plan for the future.

How is dementia diagnosed?

If a doctor suspects that dementia might be present, they will refer a person to a specialist (a neurologist, geriatrician or psychiatrist) or specialist service for diagnosis. It is important to remember that you are entitled to ask for a referral to a specialist or for a second opinion.

All types of dementia have similar symptoms and it can sometimes be difficult to tell which type a person has. A diagnosis is usually made based on a number of tests and procedures. This includes the assessment of a person's cognitive abilities with tests that measure memory, language and concentration.

A thorough physical and neurological examination may be undertaken to rule out other illnesses. Blood and urine tests may be completed to help exclude other causes of confusion and memory loss.

Brain scans may also be performed, using technology such as computerised tomography (CT) or magnetic resonance imaging (MRI) to investigate possible brain changes.

The results of investigations are considered in the context of a person's history of symptoms and other medical conditions. Therefore, input from the person and their family are integral to the diagnosis.

Getting the most from a consultation

If you are supporting the person being diagnosed, or are seeking advice because you're worried about someone else, it may be useful to write down the symptoms you have observed and the questions you want to ask before visiting the doctor or specialist. It can be difficult to

remember everything you want to say during a consultation. You may also want to write down important points that the doctor tells you. Don't be embarrassed to ask the doctor to explain any words or phrases that you don't understand.

As dementia progresses, the needs of a person will change and they may need to be regularly reassessed. A diagnosis of dementia can be very distressing for the person and their family. However, in some situations, understanding that there is a cause for the changing behaviour can be comforting or come as a relief.

The needs of a person will change and need to be regularly assessed.

Caring for someone living with dementia

Seeing the individual not the disease

This book contains a range of advice and suggestions on caring for someone living with dementia. But there is one principle that runs throughout; the person living with dementia is still the same person, however now they have a disease. Separating the person from the condition will help you to treat them as an individual and with respect. We say, "Person First, dementia second".

By remembering the disease and resulting changes are not their fault, you may find it easier to be sympathetic and patient, even when you are frustrated, tired or stressed.

The person living with dementia is not being 'difficult', 'lazy', 'demanding' or even 'just getting old'. They are attempting to cope with challenging and frustrating changes to their abilities and lifestyle.

Individual likes and dislikes

We are individuals with our own unique likes, dislikes, feelings and experiences.

Maintaining a sense of self and identity can help the person living with dementia to feel more confident and reassured. For some, this can mean completing the activities they are used to or following the same routines. Remember that even though a person may not be able to complete an activity like they used to, it is the process and resulting feelings of satisfaction that matter.

Wherever possible, appreciating and following the individual preferences of the person living with dementia may help you to find strategies that make your caring role easier. As the person living with dementia won't necessarily be aware of, or understand their condition, this can lead to arguments and upset for both of you. For example, if someone wants to eat lunch now or wear a cardigan that doesn't match with their pants, enabling them to do so might make life calmer and happier for both of you.

Explaining it to others

The actions of the person you care for may raise questions

from other people. It is common for family, friends, neighbours and other people who witness 'strange behaviours' to show concern.

Try to respect the privacy and dignity of the person you care for when explaining the situation. However, rest assured the majority of people know another person living with dementia or have experience caring for someone living with dementia, so you will be met with understanding. They may become a great source of advice or support.

It may be more difficult to explain the situation to young children. They may have a close relationship with the person living with dementia or be confused by their "strange behaviours".

Here is some advice that may help:

- Try to be as honest as you can
- Explain that the person is ill and might act strangely or be forgetful

- Some children feel it's their fault, or the person's anxiety, frustration or anger is directed at them, so reassurance may be needed
- Encourage children to ask questions so you can understand what they're concerned about
- Try to focus on the things the person living with dementia can still do, not just the things they have trouble with
- Encourage and support the child to spend time with their relative
- Try to find activities that they can still do together, like playing cards, gardening and talking about events from the past.
- You can ask if they would like to write a letter to their grandparent, aunty or uncle living with dementia, saying how they feel

In the early stages of dementia the person may be able to cope relatively well on their own. This might be improved by some adaptations around the home

and regular visits by others. This may continue to be the best option for a period of time, ranging anywhere from a few months to a few years. However, dementia is a progressive condition and the person's symptoms and abilities will worsen. By preparing and planning early for their inevitable increased dependency, you will have more time to consider the best options for all concerned.

Many people have family experience in caring for someone living with dementia and will be very understanding. Familiar surroundings and routines

Familiar surroundings and routines can be reassuring for the person living with dementia and they may be happier living in their own home for as long as possible.

People living with dementia often respond well to routines, which can help to provide a sense of meaning and security. Assisting the person to maintain a routine through modelling and demonstrating a task may help to prompt the individual to remember to shower or eat.

Friendly prompts about the times of various activities, such as visiting a friend or putting the bin out may help them to structure their day. Prompts can be provided verbally or by leaving a diary open in a visible place or writing information on a notice board. Putting associated items together can help prompt tasks, such as the tea and coffee next to the kettle, or washing powder on the washing machine. A person living with dementia may find it difficult to learn new things, so moving items that have been in the same place for years may be confusing.

Labelling cupboards, drawers and storage boxes with words and pictures or photos may also be helpful prompts.

A large clock can also be useful in orienting a person as they can easily see the time and match this to their daily activities. Try to get a clock that displays the date and day of the week so they can keep track of important information.

Speak to gas, electricity and water companies about services they offer for customers with disabilities.

Safety and security

When a person living with dementia lives alone, family members often have concerns about their safety and ability to cope. People living with dementia can unknowingly place themselves in danger due to their reduced concentration and impaired judgement.

They may forget to close doors and windows before they go out or go to bed. They may lock themselves in the house if they feel frightened or, because they have trouble recognising people, they may welcome strangers into their home. Despite these obstacles, there are many things that can be done to enable a person living with dementia to stay at home for as long as possible. It might be a good idea for a trusted neighbour to have a spare set of keys and keep an eye out for any unknown visitors. If you know and trust local work people, such as postmen, gardeners or visiting nurses, explain the situation to them so they can keep an eye out.



Here are some points on safety that may be useful:

- You might need to place a list of important numbers in large print close to the telephone so it can be used by the person living with dementia or a neighbour in an emergency
- Your local police may offer security advice. It can be useful to make them aware of the person's situation, particularly if the individual gets lost walking outside
- Speak to gas, electricity and water companies about services they offer for customers with disabilities. They may be able to install safety devices or adapted controls, and ensure those who do call understand the situation
- Gas appliances can potentially be dangerous when used by people with memory problems. You may want to consider replacing gas cookers or fires with electric ones. If so, try to do this in the early stages of dementia as the individual is more likely to learn how to use them
- Make sure boilers and water heaters are regularly serviced by a professional
- Install smoke and carbon monoxide detectors
- Check older fireplaces, heaters and equipment like irons and toasters to ensure they are safe. For example, check for an automatic cut-off which prevents overheating. Replace or repair any devices that are unsafe, and fit guards to heaters and fires to help prevent accidents.
- To prevent flooding, taps can be adapted to only let out a set volume of water. It is also possible to have temperature control devices installed to reduce the risk of burns
- Removing or changing locks from bathroom doors and bolts from external doors may make access easier in emergency situations.

Technology that can help a person living with dementia to stay at home can be accessed through your local Independent Living Centre. For further ideas about assisting someone living with dementia to stay at home, you can access the website dementiatechnology.org.au.

Your local Commonwealth Respite and Carelink Centres are another good resource for home adaptation and modifications. See the Useful Contacts list at the back of this book for further details.

Personal alarms

Some people might find they have an increased peace of mind by having a home personal alarm. This immediately links you with a support person who can action additional support in the form of ambulance or police. Information about these types of services is available through your local Alzheimer's Australia branch, Independent Living Centre or personal alarm service provider. See the Useful Contacts list at the back of this book for further details.

Driving

A diagnosis of dementia does not mean that a person must stop driving immediately.

However, it is likely that as dementia progresses, a person will lose their ability to drive safely. In all states and territories, apart from Western Australia, drivers have an obligation to their licensing authority to report any medical condition that might affect their ability to drive. You should discuss driving with your doctor, who may refer you for further specialist assessment. Car Insurance policies will not provide cover for an unfit driver. Insurance companies require that any condition likely to affect a driver's ability be disclosed to them. If conditions are not disclosed, the company has the right to turn down a claim. More information is available through your local licensing authority or Alzheimer's Australia branch.

Help with managing finances

Arranging for regular bills to be paid by direct debit may be easier than paying them at the post office or you could arrange for bills to be sent to a relative or carer.

However, if the person living with dementia is not comfortable with this then it is a good idea to contact the utilities suppliers to explain the situation so that services are not suddenly cut off. When supporting a person living with dementia, in nearly all instances an enduring power of attorney will need to be appointed. However, for many people this decision is left until it is too late and then cannot happen because the person living with dementia is no longer fit to make that decision.

The impaired judgement caused by dementia can pose a risk to financial security, especially if the person has the use of

cheque books and credit cards. A solution may be found in a joint account that requires two signatures for bank withdrawals and cheques. If possible, encourage the person to organise their affairs before the dementia progresses to a stage where they cannot be involved in decisions.

Even gathering their important papers together in one place will help. This could include bank and building society statements, bills, wills, pension details and insurance policies. If they consider this to be private or if they are suspicious of your motives, you can reassure them it is 'just in case', and you don't need to see the details.

Enduring power of attorney

As dementia progresses, a person's ability to make legal and financial decisions will

decrease. People in the early stages of dementia may be able to appoint an enduring power of attorney. This is a legal arrangement for another person or persons to look after your financial affairs if you become unable to do so. Eventually the cognitive impairments associated with dementia mean that a person is unable to understand important financial matters. At this point a person is legally considered to be mentally incapable of making decisions or appointing an enduring power of attorney. If this is the case, a legal body will generally appoint a family member, carer, or organisation to assume responsibilities on a person's behalf.

Conditions of an enduring power of attorney vary from state to state, so always seek advice before granting or accepting an enduring power of attorney.

Benefits

You should check the person living with dementia, and you as a carer, are receiving all benefits to which you are

entitled. Always check whether a benefit affects any other benefits you are receiving. It could entitle you to more, but it could also reduce a benefit you are already receiving. Different support avenues are available through Centrelink. Centrelink is a government agency that provides support and financial assistance for carers of people with disabilities, such as dementia. This includes a Financial Information Service that can help with financial planning and management.

They also provide income support through the Carer Allowance and Carer Payment systems. For eligible people, assistance with day to day expenses through the Rent Assistance and Telephone Allowance programs may be available. See the Useful Contacts at the back of this book for Centrelink's contact details.

The medical and care expenses associated with dementia can place additional burden on carers and families. Many medications for dementia are listed on the Pharmaceutical

Benefits Scheme which provides reliable, timely and affordable access to a wide range of medicines. Centrelink also provides a Pharmaceutical Allowance for eligible people. Many community services, such as those related to in-home care and respite are funded by state or federal governments. If there is a fee associated with the service it is generally quite small. The Department of Veterans' Affairs provide support and services for Australia's veterans, their war widows and dependents. This includes compensation and health care services.

The Companion Card is a scheme that allows people living with dementia and their carers to participate in community activities or events without discrimination. Companion Cards can be presented at participating organisations where cardholders will not be required to pay an admission fee for their carer. You may also be eligible for a Pensioner Concession Card or Seniors Card which provides an individual with discounted access to some services such as public transport. See the Useful Contacts at the back of this book for further details.

Communication

Communication is vital for all of us. In the early stages of dementia the person may struggle to find the right words or mix up the order of words while speaking. As their dementia progresses they may lose track of what they were saying mid-sentence or forget your name and the names of others close to them. This can be distressing for carers, family and friends.

The memory loss caused by dementia can cause frustration for carers, for example, when carers must answer the same question again and again. The vital thing to remember is that the person is not trying to be annoying. They have genuinely forgotten they asked the question and you have answered it. Although it can be tiring try to remember that each time you answer the question



you are reassuring the person at that moment in time. If you do lose patience and snap at them, they will not understand the reason and may be angry or frightened by your reaction.

Here are some ideas that may help:

- Take time to answer questions slowly and clearly with eye contact. Stop doing other things while you speak to them
- Reduce noise and distractions such as the television and radio
- Dementia makes it harder to process information so give the person time and the opportunity to ask for confirmation
- Answer the question and then encourage them to start an activity that you know they enjoy, engaging them with something else
- If they are asking for something, or to do something, try to get it or do it there and then. Can other things wait?

- Sometimes the requests of the person may interfere with your planning and routine. Think about whether it really matters in which order the events of the day are done or if it makes the day less stressful for you both?

- Gently question a bit further to see if there is a reason for the question. For example, if the person is asking whether another relative is coming to visit today, it might be because they think they need to prepare a meal for them or remember to give them something.

You can reassure them there's no need for a meal, or that you could pass the item on. If they are asking whether it's time to go shopping they might be telling you they are bored. The idea is to think 'is there a message behind their spoken words?'

- If what the person living with dementia is saying starts to become incoherent, repeat the first few words and they may be able to pick up the thread again. Alternatively,

if you phrase the words as a question you might get a reply.

Treating the person with respect and patience may require you to give reasoned explanations, but they will not always be able to understand or remember the explanation later. In general, try to provide answers that are reassuring and calming.

Although it can be hard to control your frustration, confrontation and arguments will simply make your day more stressful. It may frighten and upset the person you care for. If you find yourself in an argument, try to calm down or walk away and relieve your frustration in a different manner. However we all have bad days so if you do respond in a way you are unhappy with, it is important to forgive yourself.

Body language, tone of voice and facial expressions can tell us a lot about how people are feeling.

Body language

As dementia progresses, the person may become increasingly confused. There may come a time when the person has significant difficulty communicating through words.

However, spoken language is only one form of communication and other forms such as body language, tone of voice and facial expression can tell us a lot about how people are feeling.

The following points may be useful in maintaining effective communication as the dementia progresses:

- Speak clearly using simple and short sentences. Offering too many choices or asking for complicated decisions is likely to be confusing. For example, ask 'would you like an omelette or a sandwich?' rather than 'what would you like for lunch?'
- If the individual finds speaking difficult then try to tune into their facial expressions and body language, as these can give you signals about how

the person is feeling. Angry gestures or unwillingness to do something may be their way of communicating. Likewise, smiling or being calm shows how they are feeling

- Physical contact like holding their hand can be reassuring where appropriate
- As the individual's world becomes increasingly confused, their reality may sometimes be different to yours. If they say something which is obviously untrue such as 'I have to go and collect the children from school', try not to respond with 'No you don't'. Instead, try something that doesn't directly contradict them, like 'you used to walk to pick up the children from school, didn't you?'. Attempt to enter their world and imagine what they are thinking
- Explaining the errors in what they are thinking or saying is unlikely to help and you may find it frustrating if they don't understand

- Humour can be a great release and help you to feel closer. Try to laugh about misunderstandings rather than becoming frustrated or angry. Always laugh with the person living with dementia, never at them as this can be degrading.

Your relationship

Changes in relationships are common when a partner develops dementia. You may find it difficult to cope with the way the person responds to you.

For example, they may not remember all the things you do for them or that you visited that morning. They may accuse you of not caring or of never visiting, which can be extremely hurtful.

- Try not to take it personally. Attempt to understand the situation from their point of view. Imagine living in a world of not knowing, feeling confused and frightened, and not remembering that people are supporting and caring for you. You too might feel alone and upset

- It may be helpful to have a board or book for people to write down visits and outings that have happened and when the next one is occurring
- Labelled photos of family members and regular visitors may be helpful. As the dementia progresses, photos of people at a younger age may be easier for the person to recognise

Other people

Encourage other people to include and visit the person living with dementia. Social interaction and support is important to people living with or without dementia. You might need to explain that the person requires time to comprehend a conversation and that questions should not rely on memory or logical reasoning. People may ask you what the person wants, you can set the example by referring the question to the person living with dementia and giving them time to answer. We understand how important it can be to you as a carer that other people respect the person living with dementia.

If you know there are topics that the person finds easier to talk about or remember, suggest these to visitors. Remember that many friends and family members will want to visit and chat but may not know how to do it.

Try to provide answers that are reassuring and calming at that moment.

Eating and drinking

In the early stages of dementia a person may be able to cope with eating and meal preparation, perhaps with some help with the shopping, a few prompts around the kitchen or a meal delivery service. As dementia progresses, a person may forget to eat or not remember how to cook properly. Therefore, it may be necessary for someone to be present for at least one meal a day to ensure the person has a healthy and adequate diet.

Over time, the person may not be able to remember if they have just eaten, or what they like and don't like. They may not recognise foods and request strange combinations. Once again, try to remember they are not being difficult or contrary. It can be hurtful when they refuse a meal that you have prepared for them, or they are argumentative when you are simply encouraging them to eat.

Although older people have a reduced appetite, weight loss is not inevitable, particularly in the early stages of dementia. A lack of food and drink can actually worsen the symptoms of dementia and affect the person's general health. If they are losing weight, you may need to think about altering the arrangements that are in place. While a balanced diet is to be encouraged, the key thing is to eat and drink plenty and regularly.

Here are some tips for helping someone living with dementia to consume an adequate diet:

- Leave snacks such as biscuits or fruit around the house – perhaps next to the person's favourite chair, on the kitchen table or by the bed
- Put pictures on the cupboard doors or even remove the doors completely to help the person find the food they



want. Visual clues can act as a prompt to eat

- A 'bar style' fridge with a glass door may be helpful in prompting the person about their options
- If the person has a favourite food, it's better for them to eat it frequently than under-eat
- People living with dementia may not remember to check the use-by dates of food, or even realise decayed food

is unsuitable to eat. Regular checks on their food stocks may be necessary

Eating together

You may visit the person living with dementia at mealtimes, or they may eat meals in your home. Here are some ideas to make mealtimes easier and more enjoyable:

- Provide cues prior to mealtimes to help the person recognise it's time to eat and

help stimulate their appetite. For example, talk about the approaching mealtime and involve them in setting the table and in the preparation of food

- Allow plenty of time for eating
- If the person doesn't eat a meal you've prepared, try not to get angry. Try asking what they didn't like, as there may be a simple reason
- Joining the person for a meal may enable them to copy your actions. Seeing you pick up the knife and fork may help them remember to use those utensils
- Buy a wipe-clean tablecloth so you don't have to worry if there is a mess
- Serve small portions and keep the remainder warm. You can then ask 'Would you like some more?'. This is better than serving large portions which will become cold and unappealing
- Try to use plain plates and bowls, and serve foods which

contrast with the plate. The person may not want to eat something if they can't see clearly and understand what it is

- As the person gets more confused, try using pictures to identify what they would like. Use recipe books, packaging or even take photos of favourite family meals.

Changing tastes

Taste may change as dementia progresses. The person may suddenly start to have sugar in their tea or go off their favourite food. A rational discussion about the fact they have always liked a particular dish is not likely to be successful. Try to be in the present by asking what they really fancy for dinner or as a treat. They could surprise you, or it may be a dish from their past. It may seem like extra work but can be worth it for a stress-free mealtime.

Visitors

Social contact is important for all people living with or without dementia. We all have routines when entertaining visitors and

would feel uncomfortable if we couldn't do them. If the person is living in their own home, it may be important for them to offer you a cup of coffee when you visit, or to invite you to stay for lunch. Don't feel as if you need to do everything they ask, just keep an eye out that they are safe or offer to help. If you have time, cooking together can be a relaxing and familiar way of spending time together.

Eating out

You may worry about taking the person out to a café or restaurant, but people in the early stages of dementia are often able to cope with eating out and will enjoy it as a treat. Some people may find it confusing and disruptive so it is important to think about this before embarking on an outing.

Drinking enough

Some people will limit the amount they drink if they are worried about getting to the toilet in time (there are practical tips on this in the section 'Using the toilet and continence problems').

Drinking enough is vital to health and dehydration can worsen the symptoms of dementia, so encourage the person to drink plenty of fluids. You could make a covered jug of water or fruit juice easily available by placing it next to their favourite chair or out on the kitchen counter. You could suggest having a cup of coffee or tea more often than you otherwise would. It is a good idea to remind people to drink plenty while you are present so you can help them go to the toilet. If incontinence at night is an issue, try to reduce their intake of liquids in the evening.

Physical problems with eating

Physical changes as a result of dementia can include a reduced sense of taste and smell, loss of coordination and difficulties in feeding.

Other physical problems may include:

- Mouth problems – the person may have bad or few teeth, poorly fitting false teeth, mouth sores or ulcers. If you suspect this might be a

problem try to get the person to see a dentist as soon as possible

- Problems with swallowing – some people living with dementia have a delayed or diminished swallowing reflex. It may be necessary to consult a speech therapist for specialist advice
- Not recognising food – the person may not recognise food or may try to eat non-food items. Consuming the food first to demonstrate that it is safe might encourage the person to eat appropriately.

Helping with eating

For the person living with dementia, losing the ability to feed themselves may lead to strong feelings of loss and frustration. Therefore, try to make sure the help they are given at mealtimes is sensitive and appropriate.

Finger foods that don't need cutlery may enable the person to continue to feed themselves, reduce frustration, maintain their independence and importantly reduce work for you. If you are

eating as a family it may be tactful to ensure everyone is eating some finger food.

Specialist crockery and utensils, such as adapted cutlery which is easier to hold or plates with raised edges may also be helpful. These types of technology are available from your local Independent Living Centre.

In the later stages of dementia, you may need to feed the person you care for.

- Maintain eye contact and be at eye level when helping the person to eat as it helps keep them engaged
- Make sure you have plenty of time so the meal doesn't have to be rushed
- Attract the person's attention before placing the food in their mouth
- Serve small portions so the food doesn't get cold
- If you feel comfortable, arrange for someone to feed you so you can see how it feels and how to do it well.

Don't feel you need to do everything for them – just keep an eye out that they are safe, or offer to help.



Activities

Activities can really help to improve the quality of life for the person living with dementia. They also provide stimulation and allow people to express themselves.

In the early stages of dementia, encourage the person to continue any outside activities that they already enjoy and are still able to do. They may just need a bit of encouragement or prompting, such as reminders of when they are due to play bowls, go to church or go fishing. Leaving equipment for an activity in an obvious place, or giving them a ring before they are due to go, may help to prompt their memory. If someone is having trouble when starting an activity, try demonstrating what is involved.

By helping a person to keep up the activities they enjoy, you can help maintain a sense of self-identity and purpose.

While respecting the person's privacy and dignity it might be sensible to tell a friend or the organiser of their condition, so they can provide any extra support or help that is needed.

Find some activities that enable you to spend calm, peaceful time together.

Calm time

You might want to find some activities that the person finds calming, or that will allow you to spend a relaxing time together. For example, you could sit together knitting, watching TV, painting, watching cricket or listening to music. These 'calm times' can help take the pressure off you for an hour or two.

Activities that are fun and enjoyable help to improve the mood of everyone involved.

Think about dancing or singing, a game of darts or a trip to the beauty salon. Whatever you do, remember that it's about enjoying the activity, not the quality of the end result. If you end up laughing together, you have enjoyed the activity.

Don't forget that for many people household chores can be satisfying activities which provide the comfort of routine and a feeling of contribution. While activities like dusting, hanging out the washing or washing the car may require a bit of prompting and a watchful eye, they provide engaging activity.

If the person finds it easier to talk about the past or there are items they enjoy reminiscing about, you could keep them together in a box for the person to look through or to get out when the conversation is flagging. Younger relatives or old friends really enjoy doing this with the person. Items in the box might include old photos or objects from the person's past, such as trophies or antiques.

However, it is important to recognise that the exact symptoms and capabilities of the person will depend on the type of dementia they have been diagnosed with and the length of time they have had the condition. Their functioning may also change from day to day or as the day progresses. In particular, the capabilities of a person living with Lewy body disease can change hour to hour. People living with dementia often have a short concentration span and can easily become frustrated by an inappropriate or ambitious task.

When dementia becomes severe and remembering and concentration are fleeting,

activities can be meaningful moments, like talking about a view, reminiscing about a photograph or laughing while dunking a biscuit in a cup of tea.

Key points to remember:

- Give plenty of encouragement to increase their confidence
- Be patient – don't step in and take over
- Give instructions and guidance as short, clear sentences. Pointing and demonstration can be more useful if spoken words are not easily understood. But remember, the aim is to guide, not to do it for them
- Avoid giving too many choices or challenges as people living with dementia can find it hard to process multiple options
- Break tasks down into steps or provide staged tasks such as sweeping or folding towels
- Keep tasks short to allow for the person's reduced concentration span

- Use your sense of humour to enjoy spending quality time together.



Television and radio

Many people enjoy watching television or listening to their favourite radio station. However, as they become more confused and their short term memory deteriorates, they may find it confusing and distracting. Too much music or too many voices may sound like blaring, confusing noise to a person living with dementia.

- Try turning the television and radio off, particularly when the person is doing other things. See whether this makes them calmer or increases their ability to focus on other tasks
- Try different stations. For example, find old movies or history programs on television or tune into a 'golden oldies' radio station. Ask them whether they like it and observe whether they seem to be enjoying it
- Try a DVD, video or CDs of programs or music from their younger days.



Dressing and personal care

What we wear helps to express who we are and how we feel. Maintaining a person's choice and involvement in their clothes for as long as possible can help to promote a sense of identity and dignity.

Here are some tips on helping the person living with dementia to dress themselves:

Making it fun

- Try to leave enough time for dressing so neither of you feel rushed or stressed
- If the person is largely able to dress unaided, use the slow process as time for you to relax with guiding or helping as required
- Offer simple choices such as 'Would you like the red jumper or the blue jumper?', rather than offering too many options like 'What would you like to wear today?'
- If they get it wrong, keep it in perspective – does it matter if their buttons are not fastened correctly or the top doesn't go with the shirt?
- Lay the clothes out in the order they should be put on, i.e. start with underwear and finish with a cardigan or jumper. Alternatively, hand each item to the person in the correct order
- They may need instructions about how to dress. Keep these simple and short, such as 'Now put your socks on your feet'. Demonstrating what to do may also be useful. You could do this by getting dressed together if appropriate.
- The individual may have particular things they always like to wear, like matching jewellery or a handkerchief in their pocket. Try to maintain these little touches.

- If you need to directly help a person to dress, reassure them by explaining what step you are taking in dressing them, such as 'I am now going to put your jumper over your head'.

Make it easier

- Altering fastenings from buttons and zips to Velcro or elastic will make self dressing easier. You may need to demonstrate how these new fastenings work
- It may be useful to label the drawers or cupboards where different clothing is kept. Pictures can be better understood than words. Storing whole outfits together could also help.

Hair dressing and grooming

Appearance is important to most of us and it affects the way we are perceived by other people. Being well groomed may be important to the person living with dementia, and rightly or wrongly it may help other people to treat them with the respect they deserve.

It may seem superficial but if the person you care for is well dressed and well groomed you may also find the situation less frustrating and it may help you feel you are coping.

A trip to the hairdressers or barbers can be a familiar and enjoyable experience. Such trips may be something that the person used to do routinely, and they will recognise the place and the people. Particularly for women, a trip to the beauty salon may be a real treat.

For other people, especially those whose dementia is more progressed, it may be better to get the hairdresser or manicurist to come to the house.

Here are some tips that will make the process easier and you can share with the visiting person:

- Explain to the person living with dementia what you are going to do at each stage while getting their attention and making eye contact. You could imagine that having your head doused in water or someone coming towards you

with a pair of scissors can be concerning for someone living with dementia.

- Involve the person living with dementia in decisions by offering them simple options, such as a choice of two nail colours
- If the person is enjoying the activity, make the experience as pleasurable as possible, perhaps with a scalp or hand massage

- Don't neglect toe nails. Long or painful toe nails can make walking difficult and reduce mobility.
- Take the opportunity to relax while the person is being looked after by someone else.

If they get it wrong, try to deal with it using humour and keep it in perspective.



Washing and bathing

Personal hygiene routines are a common source of anxiety for people living with dementia and their carers, so this needs to be handled sensitively. The person will have been carrying out their own personal hygiene activities for a long time. Requiring help or becoming dependent on others can be embarrassing and awkward for both the person and for you as the carer. This is a key area in which it is important to prolong the independence of a person living with dementia for as long as possible and offer unobtrusive help.

It is important to talk to the person to find out their preferences and feelings. Try to establish exactly what the person can still do for themselves, for example, miming the action of brushing your teeth may be enough of a prompt to maintain independent brushing.

Most people now shower or bathe at least daily, however

this was not the case 40-50 years ago. The norm was to have a bath about twice a week and showers were much less common. So be aware that routines you are used to may not suit the person living with dementia. Personal hygiene can be maintained without a shower or bath every day.

Here are some practical tips which you may find useful:

- We all have long established personal care routines, especially in the mornings and before bed. Encourage the person to continue with their own routines for as long as possible
- The person may require some prompting, such as handing them the hairbrush to brush their own hair
- Encourage involvement and choice by asking questions such as, 'Which bubble bath would you like in your bath?'

or 'is the temperature of the water ok?'. Simply asking 'do you want a bath?' could prompt a response of 'no and it may be difficult to encourage the person to have one

- Thorough drying is important in order to prevent sores or chafing. This can be made easier by allowing the person to sit for a while in a clean towel or absorbent bathrobe
- If the person spends long periods sitting or in bed, try to check for red areas or sores on their skin whilst the person is undressed. These can be the first signs of pressure sores (bed sores). If you have concerns talk to your GP
- If the cold temperature of the bathroom is a barrier to washing, consider installing a heater. This will also assist with drying after a shower or bath.

If a person is resistant to a bath or shower, try encouraging them to wash one part of their body every day. For example, on Monday they could wash their legs and feet, and on Tuesday wash their hair. For people with continence issues, it might help

to encourage them to wash their genitals on multiple days during the week.

Privacy

Most of us consider the bathroom to be a private place. The person may be unwilling to undress in front of you, be undressed by you, or bathe in front of you. You may also find these things uncomfortable. Allowing the person some privacy may make bathing easier for you both.

- You could leave the room while they undress and get into a dressing gown, then walk with them to the bathroom
- Run the bath for them and let them step into it wrapped in a towel
- Have a thermostatic valve fitted to the hot water system so they cannot scald themselves if they run the bath themselves
- You won't necessarily need to help them wash, at least not every time. So long as they are bathing regularly they will be clean.

Using the toilet and continence problems

Continence issues can be very distressing for both the person living with dementia and the carer. An individual might feel they are losing control of their dignity and their life.

Many people find it very hard to accept they need help with such an intimate area.

They may try to hide their continence problems. By treating the issue in a matter of fact way, or using humour, you can help to prevent the issue from becoming a bigger problem than necessary.

Problems with using the toilet and continence issues

Incontinence, or bladder control, is a specific physical problem and only one of the reasons why a person may have problems with their toileting. Continence problems may also develop due

to forgetfulness (not being able to locate the toilet), mobility problems, depression, difficulty arranging clothing or mistaking other items, such as bins for toilets.

Helping to make toileting easier

Here are some practical tips that can make using the toilet easier and help with the management of continence issues:

- Remind the person where the toilet is. A picture of a toilet on the door may help or arrows and signs to direct them to it
- People may be more confused at night and not able to find the toilet. It can help to leave the door ajar and lights on in the hallway and bathroom to direct the person to the toilet

- Having a contrasting toilet seat can assist the person in locating the toilet
- Installing handrails will make it easier for a person to go to the toilet and may reduce their fear of falling
- Make sure their clothes are easy to undo, try using Velcro fastening instead of fiddly buttons or zips
- Make sure the bathroom is well lit and warm as a person living with dementia may not tolerate discomfort well
- If the toilet is difficult to get to, such as being upstairs, then a commode may be useful

Getting into the habit

- Regularly remind the person to go to the toilet if they are not doing so.

Establishing a routine of set time will help to train the bladder and bowel
- Drinks that are high in caffeine, such as tea and

coffee, are diuretics and will increase trips to the toilet. If this is an issue, try to reduce the number of cups of tea and coffee a person consumes. Alternatively, you could introduce caffeine free tea and coffee

- Giving a warm drink at breakfast and visiting the toilet about 20 minutes later may help to promote toileting and routine
- Watch for signs of 'needing to go', such as fidgeting or pulling at their clothes
- Try to establish a routine of going to the toilet before getting dressed or going to bed.

Getting help and advice

Continence issues are often easier to manage with the assistance of others, for example, your GP would be a good option to go to for help and advice. They will also be able to give you details of the local support services in your area. Your local hospital or community nursing service may

have a Continence Adviser who can make a home visit.

Advice and guidance on all aspects of continence is also available from the Continence Foundation of Australia through the National Conference Helpline, details of which are in the Useful Contacts section.

Coping with unmet needs

Understanding that the person living with dementia may no longer be able to communicate or express their feelings and their needs is important. This includes the need for identity and belonging, to be included and occupied and the need to be comforted and comfortable. It is also important to recognise such needs are shared by all people and do not change just because you have a diagnosis of dementia. When needs are not being recognised or met, the person may become distressed, anxious, agitated, frustrated or angry. They could also become apathetic or withdrawn.

Additionally, because of the progression of the disease and the brain changes the person living with dementia may be unable to interpret their environment or what people around them are saying and doing. This inability to cope and remember may lead to a reduction in self control and

cause the inhibitions and learnt rules of socially acceptable behaviour to be forgotten. Therefore, people may react or behave in ways that can be distressing for them and the people around them. This may range from repetitive questions to hurtful comments, unwanted touching or advances, verbal aggression and threats, kicking, pinching or lashing out at people or objects.

It is important to remember that each person will be different in how they react to what is happening around them and that agitation and aggression is not inevitable. There are usually triggers that prompt these episodes that could be avoided. Equally, by recognising and meeting the person's needs we can support the person effectively to express their feelings appropriately.

It is helpful to try and discover what is causing a concern,

because it is usually triggered by an event or aspect of the environment.

Think about whether any of these causes apply:

- Agitation as a result of frustration. For example, does the agitation occur as a result of a person wanting to do a particular activity and being told they can't, or finding themselves unable to do it?
 - Does the person get upset or frustrated after an argument with you?
 - Does the person get agitated or upset at certain times of day when they may be more fatigued or when they are less able to cope? Is the environment noisy, overwhelming or triggering long held routines, for example, wanting to "go home" when it is darker?
 - Annoyance at not being able to make themselves understood, or at you for having difficulty in understanding what they are saying
 - Feeling that their privacy has been invaded, for example, when going to the toilet or bathing
 - Was the person startled by a sudden approach, or an approach from behind or the side?
 - Does the person have a condition that may cause pain or discomfort? For example, urinary tract infections are common in older people and cause irritability and agitation
 - A person might be frightened, because they do not understand who you are or because you touched them when they weren't expecting it
 - A person might be confused about the aspects of a situation, for example, they may think you've taken something or not know where they are.
- Try to think about what they might be thinking or experiencing. Ask them questions to help you understand, think about the circumstances in which the

outburst occurs, or try a different approach next time. Doing this might help you to avoid the situation in the future, or at least be understanding or know how to react when it occurs.

If a person is being argumentative or aggressive, try not to argue or be aggressive and loud in return. Unless they are endangering themselves or you, give them plenty of space. Perhaps even leave the room to allow both of you to calm down. Try not to dwell on negative feelings about it. If you do react to the person in a way you would not have liked, try to forgive yourself as we are all human and have bad days. Perhaps the most important thing to remember when coping with frustration or anger is not to take it personally. The person wouldn't normally or deliberately hurt your feelings or be aggressive. Dementia often makes it difficult for people to understand what is going on around them and to control their behaviour.

After an incident or argument, try not to take out your frustration on the person living

with dementia. People living with dementia can rarely remember what they have done and so lose the ability to learn from experience. They may be equally upset by what they think is going on, the atmosphere, or by having lost control, so try to provide lots of reassurance by talking, holding hands, or cuddling if appropriate. Try to find a healthy outlet for your own anger, such as going for a walk or talking with a friend.

If you are worried about episodes of anger or aggression and can't work out why these are happening, it may be useful to call the Dementia Behaviour Management Advisory Service. This is a free, over the phone service that provides advice and strategies for reducing the possibility of unmet needs, 24 hours a day, seven days a week. Other options include calling your local Alzheimer's Australia office or consulting your local GP. Further details are in the Useful Contacts section.

Getting help

Don't be afraid to ask for help, or feel that you are failing if you cannot cope. Much of the responsibility for care, especially in the early stages, often falls onto one relative or friend who may well be you. This can be extremely stressful and exhausting and others involved may not realise just how many demands are put on you.

Caring for a person living with dementia in the late stages of the condition can be a 24 hour a day job.

Many carers report they feel as if their health is declining with that of the person living with dementia. The stress associated with caring for a person living with dementia can lead to emotional and physical health issues. Therefore, it is important to occasionally take a break and stay well. This can be easier said than done but getting some help and moral support may enable you to cope and continue to care.

Help from family and friends

It might be helpful to maintain clear and regular communications with family and close friends. This could be achieved through regular phone calls or by holding a get together with family and friends so that issues can be discussed and shared. This can assist in sharing the burden and prevent feelings of guilt and resentment towards the people to whom you are close. It may be possible to agree to a roster of visits among family and friends living nearby. People



popping in for a cup of tea might help relieve the pressure on you and provide a social outlet for the person living with dementia.

Perhaps someone could have a game of cards with the person, or sit and watch the cricket on television with them, which would give you an hour to do other things or just have a rest.

Family members may be able to bring old photos or objects that would prompt memories and reminiscences. Those family members who live further away might be able to offer financial assistance, or blocks of care time which can enable the main carers to take a break.

It is possible that the person you are caring for may find it distressing to spend time with people they don't recognise. If this is the case, family and friends can help in other ways, for example, doing the shopping or cooking a meal. If they offer – say yes!

Outside help

As dementia progresses, the person may not have insight into

their care needs or be resistant to outside help. Therefore, help might be accepted more easily if it is introduced in the earlier stages of dementia.

There are many different types of help available from various sources. These can differ from region to region, so a good starting point is your local Alzheimer's Australia branch or Commonwealth Respite and Carelink Centre. Your GP or medical specialist can also help. The Useful Contacts section at the end of this book gives you a quick reference guide to these options.

Care needs assessment

To access many community and aged care services, a person living with dementia requires an 'aged care assessment'. This is carried out by a local Aged Care Assessment Team.

These teams assess the care needs of a person living with dementia and provide advice and access to a range of different community and residential care options. They also assess and approve

older people for Australian Government subsidised aged care, such as residential aged care and Community Aged Care Packages. An assessment can be arranged by contacting the team through your local Commonwealth Respite and Carelink Centre. Your local GP can also assist in organising an assessment. The assessment is carried out in the individual's home or in a medical setting, such as a hospital. The team will also value your input and perspective.

In home care services

In home care services can help with the personal care of the individual, for example getting the person up in the morning, washing and dressing them and putting them to bed at night. House work and shopping assistance may also be provided. The number and frequency of visits will depend on the needs of the individual. Local options for in home care might be suggested by an Aged Care Assessment Team or you can find out more by contacting the Commonwealth Respite and Carelink Centre.

Planned activity groups and day centres

Planned activity groups and day centres may be available locally. These can be a great source of enjoyment for the person, as they provide social contact through activities and/or a meal. Additionally, they provide you with the opportunity to have a break! Transport to and from the centre is often provided.

To get in contact with such centres, including those run by charities or non-government organisations, contact your local Alzheimer's Australia branch or Commonwealth Carer Resource Centre. Details for these organisations are in the Useful Contacts section of this book.

In home equipment and technology

There is a wide range of specialist equipment available, which you may find useful in assisting with daily living. The need for equipment will vary as the individual's dementia progresses but could include:

- Personal alarms

- Prompts or memory joggers, such as notice boards, large or talking clocks or thermometers
 - Mobility aids, such as wheelchairs, walking frames, stairs, lifts or handrails
 - Continence aids, such as raised toilet seats, bed pans, commodes and incontinence products
 - Washing aids, like walk-in or sit-in showers, bath seats and hoists
 - Specialist cutlery, cups or crockery which enable the person to feed themselves for as long as possible
 - Kitchen adaptations such as glass-fronted refrigerators or gas and electricity safety switches
 - Medication aids, such as boxes for tablets with sections for each day of the week and times of the day (Webster pack)
 - Safety devices, such as pressure mats that can be placed by the doors to detect movement, gas detectors, devices to control the temperature of hot water and restricted-flow taps
 - Your local Aged Care Assessment Team can make suggestions for in home equipment. These options are also available through the Independent Living Centres and Commonwealth Respite and Carelink Centres
 - Further ideas about technology for people living with dementia can be accessed through the website: dementiatechnology.org.au
 - Continence aids and advice can be accessed by calling the National Continence Helpline
- Your doctor or other health professional can make an appropriate referral, for example, to an occupational therapist. Please see the Useful Contacts section of this book for further information.

Advice and information

Many organisations, such as Alzheimer's Australia, the

Commonwealth Carer Resource Centres and the Aged Care and Community Care Information Line have telephone advice lines, websites and free resources covering a wide range of subjects.

Some will be aimed at older people in general but there is also a wealth of information available that is specifically aimed at people living with dementia and those caring for them. Many of these organisations are listed in the Useful Contacts section.

In our experience of caring for the relatives of people living with dementia, as well as those with the disease, the more they understand dementia, the easier they find it to cope with their relative's behaviour and the progress of the disease. If you are caring for someone at home, these sources of advice also provide practical information to help you cope. Alzheimer's Australia runs courses for carers and people living with dementia, which we highly recommend. These courses cover all forms of dementia.



Taking care of yourself

It is really important that you care for yourself, whether it is because you are also leading your own life, wanting to provide the best possible care to the person you look after or planning for the time when you no longer care for the person living with dementia.

You don't have to cope alone. There are many sources of support and help available, which might be useful even if you feel you are coping well at the moment.

The simple things are important. Getting enough rest, eating

well, taking breaks from caring, getting some fresh air and exercise and having support from others will all make it easier to cope with the pressures and frustrations you may face.

Money

You may have had to give up work or reduce the hours you work to become a carer. You may also be incurring additional costs of care, such as equipment or aids.

Depending on your situation you may be entitled to benefits. Check with your local Centrelink office to ensure you are getting everything you are entitled to.

Health

It is important that you have your own medical checkups. Regularly visiting the doctor will help you stay on top of your own health issues. For your own emotional health, counselling and support services are

available through your local Alzheimer's Australia branch or Commonwealth Carer Resource Centre.

Support Groups

Support groups in your area can be a great help, as they allow you to have a break from caring and talk to other people in the same situation. You can share tips and advice, as well as your frustrations and worries, and you are talking to an understanding listener.

Even if you don't normally like groups, it may be worth a try because people often find they all have something in common. You can find out about your local groups by:

- Ringing Alzheimer's Australia on the National Dementia Helpline to find out about their Living with Memory Loss Program, where carers and people living with dementia can enjoy social interaction and obtain information and support
- Checking with your local council, community centre or aged care provider.

Please see the Useful Contacts section of this book for further information.

Respite

Finally, keep in contact with your own friends and try to make time to do the things you enjoy, so you maintain your identity as an individual and not just as a carer. Often carers are reluctant to take a break because it involves leaving the person living with dementia by themselves or with people who may not understand their condition.

Respite services are a great resource for taking a break and ensuring the person living with dementia is being cared for. It also provides an opportunity for people living with dementia to enjoy themselves with new or familiar experiences. Respite is available in the home, which involves a care worker providing support for a person living with dementia while enabling carers to do things outside the house. The care worker may also accompany the person living with dementia to an activity they enjoy.

Respite can also be used to provide care in an emergency or arranged for a longer period of time in a residential care home. To access residential respite, the person living with dementia must be assessed by the Aged Care Assessment Team to determine the level of care provided. Advice about local respite options is available through the Commonwealth Respite and Carelink Centres.



Thinking about residential care

Carers often feel that moving the person into an aged care home is a 'betrayal'. You may feel that you have let the person down or you should have coped for longer. You may have previously promised the person that you would always look after them at home and now feel forced to break that promise.

When considering issues like those mentioned above, it may help to talk them through with someone who understands, and who can help you come to terms with your decision. It is often the case that promises were probably made in a completely different situation, when you had no idea of all the strains and stresses that lay ahead. Caring for the person living with dementia at home may now not be the best thing for them, as their needs have changed. It may help to talk to family, other carers at a support group or your local Alzheimer's Australia branch. Everyone's situation is different.

A different way of caring

The move to residential care doesn't mean giving up on your caring role completely, unless this is what you want. Aged care homes simply represent another way of caring. Your involvement is still very important. Some carers feel that residential care help them have a better relationship with the person, as their time together can be more special, less stressful and more 'like it used to be', without the constant worries of practical care.

When to consider an aged care home

The effects of dementia worsen over time and most people living with dementia will need to go to special accommodation before they reach the last stages of dementia. A best practice guideline is to move people living with dementia as infrequently as possible. An aged care home is usually the

best solution when somebody has to move on from their own home. This might happen for a number of reasons. For instance:

- The person living with dementia is becoming unsafe on their own, for example, leaving the stove on or wandering onto the street
- Carers are having to provide increased physical support, like lifting the person in and out of bed
- Caring for the person is becoming too much for the primary carer because of their own health issues
- Levels of confusion or frustration are causing the person to become aggressive or upset. The person may be acting in an increasingly inappropriate and unpredictable way and this poses a barrier to providing care.

It is common to feel uncomfortable about the idea of residential care and you may feel guilty for even considering it, but most people living with dementia will reach a point after

which they will be safer and more comfortable in specialist care.

They may be resistant to the idea they are often also unaware of the impact their care needs are having on others. They may also be finding life at home increasingly difficult, confusing and frightening. Living in a residential care home not only ensures that people living with dementia receive personal care and health care within a safe setting, it also provides them with opportunities for activities and socialising. Perhaps more importantly, such a living situation can offer peace of mind to all concerned.

How to find the right care home

To access an aged care home, a person living with dementia must be assessed by an Aged Care Assessment Team, who will then suggest an appropriate level of care.

Residential care homes are generally broken down into those that provide 'low level care' and 'high level care'. Low care homes are sometimes called hostels and provide care



for people who are mobile and need some care assistance.

They may require assistance with personal care, laundry, cooking, or supervision when taking medication. High level care is also known as nursing home care and provides 24-hour nursing care for its residents. These care homes are more suitable for a person in the later stages of dementia or those with other medical conditions.

Different fees and charges are associated with residential care and it is important to consider these when reviewing care homes.

Information can be obtained directly from the homes and options for financial advice include Centrelink or a private, qualified financial advisor. The Department of Health and Ageing is another good resource.

In addition to the Aged Care Assessment Team, you can find out about aged care homes in your area by contacting:

- The Aged and Community Information Line on 1800 500 853

- The National Dementia Helpline on 1800 100 500

- The DPS Guide to Aged Care online at: agedcareguide.com.au

- Local friends, family or other carers for recommendations.

Reviewing and deciding on a care home

Try to visit a few potential care homes, so you can see the differences between them and be sure the home you ultimately decide on will be right for the person you care about.

Some care homes may have dementia specific services. It is also worth asking if the facility has 'ageing in place'. This refers to some homes that have both low and high care places, which can make the progression of care smoother on a person living with dementia through minimal environmental change.

The skills and attitude of the staff are also very important. Ask about specialist dementia care training and examine how the staff and manager interact

with residents and the person you care for (if they have accompanied you). Often the best time to do this is during meals and activities.

A dementia friendly care home will treat the person as an individual with their own preferences and abilities, rather than as someone who has to fit into the rules and routines of the home. Ask staff about how they cater for the individual needs of people living with dementia.

For example, do they talk about:

- The person's life history
- Their spiritual needs
- Their cultural and language needs
- How their food preferences will be catered for
- How they'll provide the kind of activities the person likes
- How they'll ensure the person has somewhere quiet and calm to relax
- How their room can be personalised

- Whether they are allowed to stay in their own room if they wish
- How you could be involved in their care if you want to be.

A residential care home can never be quite like your home but it should provide a safe, reassuring and familiar place for someone living with dementia and for those who visit.

Your needs

Think about your own needs as well. For example, if you want to visit frequently and the 'best' care home is difficult to get to, the 'second best' facility that is nearer might be the right choice. Can you visit at times that are convenient for you, or are there only set visiting times? Is there a relatives' or a carer support group you can join? What processes are in place for you to raise concerns about the care of your loved one with the care home? These are important things to consider.

Visiting someone in an aged care home

Visiting someone in care, particularly a specialist dementia care unit, can be distressing to begin with. However, once you have spent more time there and developed relationships with staff and other residents, you might feel more at ease.

Getting to know the person

Working with care staff can help your loved one feel more at home and gain more enjoyment out of their time in the care home. Try to talk to the staff as much as you can about the person so they understand their needs and are aware of particular likes, dislikes, habits and circumstances around unmet needs.

When the individual enters the aged care home, the staff will seek to find out all about them. It is very useful if you, or another person who knows them well, can be there at the

admission meeting to provide the information. However, be careful to let the person living with dementia express their own views and feelings, even if they are not what you were expecting. Try not to contradict the person's statements. If necessary, share your personal understanding with the staff after the meeting or via a letter.

A care plan will be written for the person, which will include all the information about their needs, preferences and abilities. The care plan should be regularly reviewed by both staff and family as the person's needs change over time.

Telling their life story

Although you may have known the person living with dementia for a long time, the care staff have just been introduced to them. Providing their life story to staff can be helpful, because you equip the staff with topics



to talk about, ideas to base activities on and ways to interact and stimulate the person. Some individuals may become very withdrawn when they enter a care home. Being able to participate in things they enjoy, like listening to their favourite piece of music, or eating their favourite meal can be very reassuring.

You could help the staff and person you care for to fill a 'memory box' or create a life board with meaningful items such as photographs, books, items from their family or favourite hobbies. Some care homes may draw a life 'map' of information, displaying when and where the person was born and grew up, where they got married, what jobs they had and favourite foods.

Understanding the person's past will help care staff understand some of the ways the person may act or react as their short term memory deteriorates and they increasingly rely on their long term memory.

Factual information can be very helpful. For example, by knowing that someone was a

baker, staff can understand why they may want to get up very early in the morning. Difficult subjects may need to be included also, like the loss of a child. You may need to help with the exercise if the person has difficult communicating.

In summary, by telling the person's life story the care staff will be able to:

- Understand and separate the person from the dementia
- Offer more person-centred and individual care option
- Give prompts for conversation topics which are more likely to engage the individual
- Identify activities and outings which may be of particular interest to the individual
- Avoid topics or activities that may upset the person or trigger negative emotions and memories
- Introduce the individual to other residents who may have similar interests or backgrounds

Joining in

Discuss with the staff whether you are welcome to join the person living with dementia for meals and activities. This may increase your enjoyment and the quality of your visits.

Don't worry if you feel a bit self conscious to start with!

All care homes should have a wide range of activities for residents. Perhaps you could time your visit to fit in with a specific activity you can join, like singing or art, particularly if the conversation is difficult. It could turn out to be a lot of fun for you both and give you some quality time together. You may be able to join them for a meal or help them eat, if that is what they need.

Some activities may not need a lot of preparation but will still be meaningful and enjoyable for the person, such as watering some plants, going for a walk or reading.

Many relatives of people in aged care homes are volunteers at the home and assist in

organising activities or are part of a committee. They often report that this enables them to remain involved in their loved one's life, while also enjoying social contact and feeling useful.

Working with the care team

Although you probably know the person living with dementia extremely well, the care staff will be experienced in caring for people living with dementia and may have ideas or suggestions that are new to you. It might be useful to discuss these with the staff and be willing to let them try new things. They may also speak to you if they see the person acting in ways that puzzle them, to see whether you can help them to understand it. For example, care staff might be concerned about a resident who always slumps to one side in their chair, with their arm over the side. Relatives can alleviate this concern by explaining that the person always sat like that while stroking their dog at the side of the chair.





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a difference**

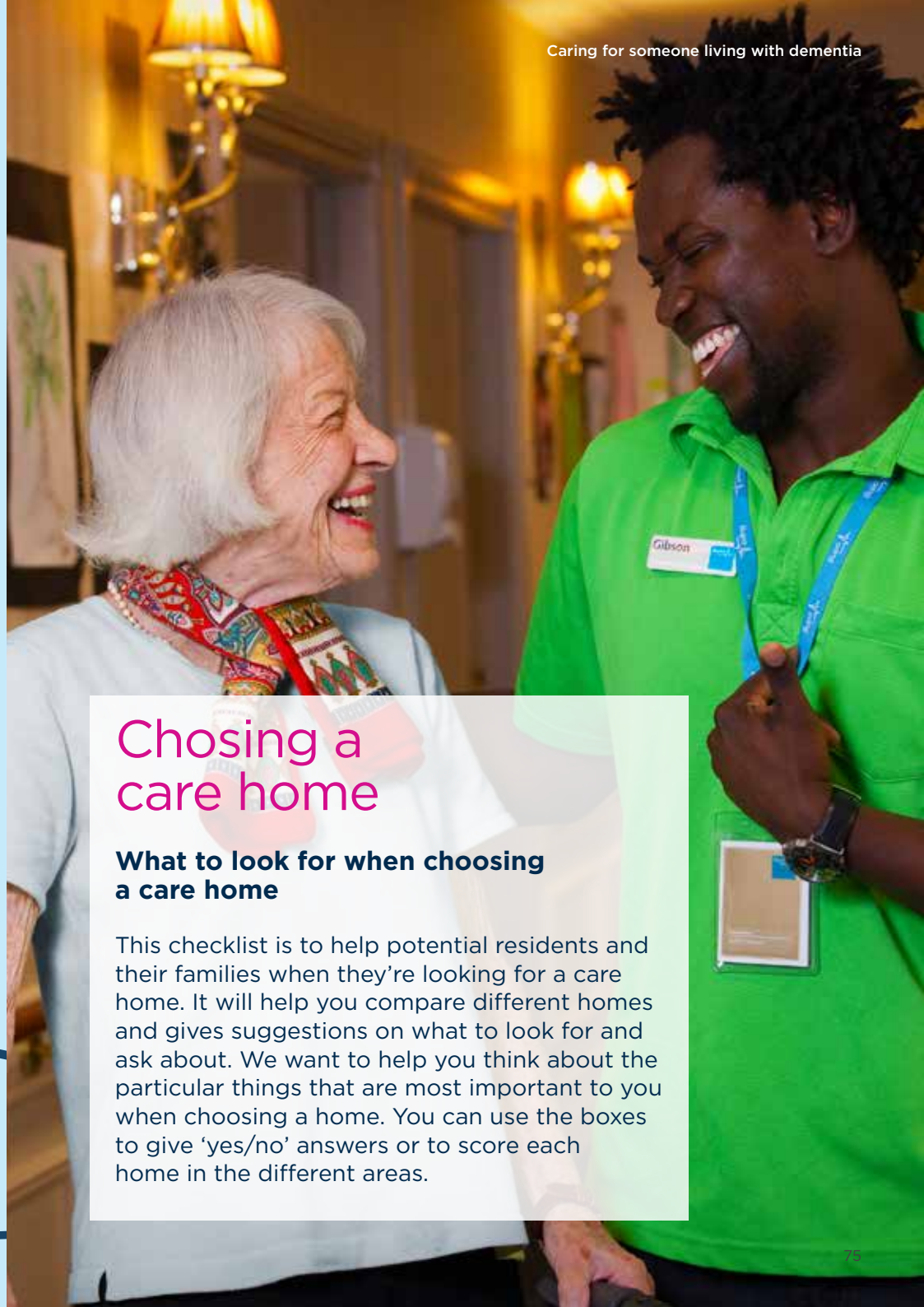
**Bupa Aged Care
Support Line
1800 780 038**

Providing information and support
to those considering aged care or
caring for a loved one

Choosing a care home

What to look for when choosing a care home

This checklist is to help potential residents and their families when they're looking for a care home. It will help you compare different homes and gives suggestions on what to look for and ask about. We want to help you think about the particular things that are most important to you when choosing a home. You can use the boxes to give 'yes/no' answers or to score each home in the different areas.



Location, first impressions and care

Location	Home 1	Home 2	Home 3	Notes
Will it be easy for friends and family to get to the home?				
Is the home convenient for shops, public transport, etc?				
Do the surroundings suit you?				
Is there somewhere you can sit outside?				
First impressions				
Did you receive a warm and friendly welcome?				
Were refreshments offered during your visit?				
Is the atmosphere homely and welcoming?				
Is the home clean and pleasantly furnished?				
Does the home smell pleasant?				
Do the residents seem happy and well cared for?				
Care				
Can the home offer care suitable for your needs?				
How often will your care needs be reviewed?				
Will the home be able to provide any future care needs?				
Will you/your relatives be involved in making decisions about the care?				
Does the home offer or arrange complementary therapies?				
Which doctor can a resident see?				
Are there visiting dentists and opticians?				
How often does the hairdresser visit the home?				
Can the home provide other services such as chiropody, physiotherapy and occupational therapy if required?				
Does the home have suitable assisted bathing facilities?				
Can residents get up and go to bed when they want to?				
Will relatives be advised as soon as a resident is taken ill?				

Communal areas

Communal areas	Home 1	Home 2	Home 3	Notes
Is there more than one room where residents can sit or see visitors?				
Is there a quiet lounge without a television?				
Are there safe gardens?				
Is there a bar?				
Are there arrangements for people who wish to smoke?				
Is there easy access for wheelchair and walking frames?				
Are there toilets within easy reach of all parts of the home?				
Are there handrails in the toilets and corridors?				

Bedrooms, meals and activities



Bedrooms	Home 1	Home 2	Home 3	Notes
Did you see the room that is available?				
Can residents bring their own possessions and furniture?				
Was it bright and well decorated?				
Are ensuite facilities available?				
Do bedrooms have a television?				
Do bedrooms have a telephone point?				
Can residents use a telephone in privacy?				
Can residents lock their room?				
Is there a lockable drawer or cabinet in the room?				
Does each room have a call system?				
Can residents keep pets in their room and can they go in other parts of the home?				
Can you change rooms if you want to?				

Meals	Home 1	Home 2	Home 3	Notes
Can residents eat when they want to?				
Can meals be taken in a resident's bedroom?				
Is there a choice of menu for each meal?				
Can special diets be catered for?				
Can residents make themselves a drink?				
Are snacks available at all times?				
Are copies of current menus available for you to look at?				
Are the menus rotated?				
Does the chef consult the residents on their preferences?				
Can residents choose who they sit with in the dining room?				
Can relatives and friends have a meal with you?				
For residents who need help with eating, are staff trained to do this sensitively?				
Activities				
Is there a weekly plan of activities?				
Did you see an example?				
Are residents consulted on what hobbies/interests they have?				
Are special events e.g. birthdays celebrated in the home?				
What form of exercise, if any, are residents encouraged to take?				
Does the home take residents on trips outside the home?				
Does the home have access to transport?				
Is it possible to take part in activities outside the home?				
Would the care home be able to help with transport to these?				
Are daily newspapers available for residents?				
Does the home have access to a library facility?				
Can residents be taken to places of worship?				
Can residents take part in the daily activities within the home if they wish, e.g. cleaning, gardening, cooking?				
Is there a residents' committee?				
Can relatives/friends help with activities?				
Did you see any photographs of activities in the home?				



Useful contacts

Aged Care and Community Care Information Line

Telephone: 1800 500 853

Alzheimer's Australia

National Dementia Helpline: 1800 100 500
www.fightdementia.org.au

ACT	02 6255 0722	SA	08 8372 2100
NSW	02 9805 0100	TAS	03 6228 4724
NT	08 8948 5228	VIC	03 9815 7800
QLD	07 3895 8200	WA	08 9388 2800

Bupa Aged Care

Telephone: 1300 302 350
bupa.com.au/aged-care

Centrelink

Telephone: 13 27 17
 Multilingual/Other language Telephone: 13 12 02
www.humanservices.gov.au/carers

Carer Resource Centre

Telephone: 1800 242 636
www.carersaustralia.com.au

Commonwealth Respite and Carelink Centre

Telephone: 1800 052 222
www.commcarelink.health.gov.au

Companion Cards

Companion Card Information Line: 1800 650 611
www.companioncard.org.au

Dementia Behaviour Management Advisory Service

Telephone: 1800 699 799 (24 hours a day)

Dementia Enabling Environments

www.enablingenvironments.com.au

Dementia technology website (Baptist Community Services)

www.dementiatechnology.org.au

Department of Health and Ageing

Telephone: 1800 020 103
www.health.gov.au

Department of Veterans Affairs

Telephone: 133 254 or for rural callers telephone: 1800 555 254
www.dva.gov.au

DPS guide to aged care

Telephone: (08) 8276 7999
www.agedcareguide.com.au

Independent Living Centres

Telephone: 1300 885 886
www.ilcaustralia.org

My Aged Care (Department of Health)

Telephone: 1800 200 422
www.myagedcare.gov.au

National Continence Foundation of Australia

National Continence Helpline: 1800 330 066
www.continence.org.au

Contact your nearest Bupa Aged Care home

-  Call us **1300 302 350**
-  Like us on Facebook
-  Follow us on Twitter
-  bupa.com.au/aged-care

Bupa Care Services would like to acknowledge the valuable contribution made by Alzheimer's Australia to the production of:

Caring for someone living with dementia.

Internationally, Bupa has a proud record of promoting research while providing aged care and dementia care services. Within Australia, Bupa is proud to support the Australian National Quality Dementia Care Network.

The Network is an initiative developed by Alzheimer's Australia and founded to promote collaboration between dementia care researchers, consumers and service providers with the objective of improving the quality of dementia care.