



Australian Government
Department of Health and Ageing

Dementia – The Caring Experience



A guide for families and carers
of people with dementia

DEMENTIA

*prevention and early intervention
care and support
information, awareness and education
research*



Dementia The Caring Experience

**A guide for
families and carers
of people
with dementia**

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Introduction

Dementia – The Caring Experience has been put together to help people who are caring for a family member or friend who has dementia. It is based on the well-regarded book *The Carer Experience*, first published in 1996.

This handbook contains information that you may need and ideas you could use, while at the same time recognising that family and carers will have different experiences of caring for a person with dementia.

There are services available to assist you. They have caring, experienced, trained people who can help. These services and their telephone numbers are outlined throughout this book. Many of them have free call numbers (calls are free from local phones, however mobile phones are charged at mobile rates). Use these numbers if you have any worries or want to find the services or people who can help you.

The Caring Experience is yours to use however you want to:

- Read it from cover to cover.
- Find something that you need to know right now.
- Highlight those things that are important for you and the person with dementia.
- Use it to start a diary.
- Use it to find a group of carers or a service.
- Give it to your family to read.
- Send a copy to a relative or friend to help them understand dementia.
- Lend it to your neighbours.
- Point out bits of it to your doctor.

Additional copies of this book are available from any of the services listed on the back cover.

A companion book, *Living with Dementia*, has been written especially for people with dementia. Copies can also be obtained by contacting any of the services listed on the back cover.

Topic 1

Understanding dementia

In this topic

- What is dementia?
- The most common forms of dementia
- Can dementia be inherited?
- What are the early signs of dementia?
- The brain and behaviour
- Why is correct diagnosis important?
- Who gets dementia?
- Younger onset dementia
- Treatment for dementia
- Some effects of dementia



What is dementia?

Dementia is the term used to describe the symptoms of a large group of illnesses that cause a progressive decline in a person's cognition and ability to function. It is a broad term to describe a loss of memory, intellect, rationality, social skills and what would be considered normal emotional reactions.

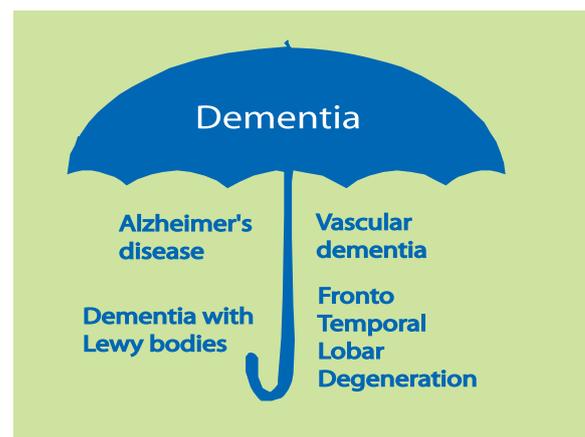
These changes affect the physical, social and emotional life of the person with dementia, and their families, carers and friends.

It is not a normal part of ageing.

There are many different forms of dementia and each has its own causes.

Alzheimer's disease is the most common form of dementia. It accounts for between 50% and 70% of all cases. Vascular dementia is the second most common form.

The diagram below shows the relationship between dementia and its many forms.



The most common forms of dementia

Alzheimer's disease

Alzheimer's disease is a progressive, degenerative illness that attacks the brain. As brain cells shrink or disappear abnormal material builds up as "tangles" in the centre of the brain cells and "plaques" outside the brain cells. These disrupt messages within the brain, damaging connections between brain cells. The brain cells eventually die and this means that information cannot be recalled or assimilated. As Alzheimer's disease affects each area of the brain, certain functions or abilities are lost.

Vascular dementia

Vascular dementia is the broad term for dementia associated with problems of circulation of blood to the brain and is the second most common cause of dementia. There are a number of different types of Vascular dementia. Two of the most common are Multi-infarct dementia and Binswanger's disease. Multi-infarct dementia is caused by a number of small strokes, called mini-strokes or Transient Ischaemic Attacks (TIA) and is probably the most common form of Vascular dementia. Binswanger's disease (also known as Subcortical vascular dementia) is associated with stroke-related changes to the brain. It is caused by high blood

pressure, thickening of the arteries and inadequate blood flow.

Vascular dementia may appear similar to Alzheimer's disease, and a mixture of Alzheimer's disease and Vascular dementia can occur in some people.

Dementia with Lewy bodies

Dementia with Lewy bodies is caused by the degeneration and death of nerve cells in the brain. The name comes from the presence of abnormal structures, called Lewy bodies, which develop inside nerve cells. It is thought that these may contribute to the death of the brain cells. People who have dementia with Lewy bodies tend to see things (visual hallucinations), experience stiffness or shakiness (parkinsonism), and their condition tends to fluctuate quite rapidly, often from hour to hour or day to day. Dementia with Lewy bodies can occur by itself, or together with Alzheimer's or Parkinson's disease.

Fronto Temporal Lobar Degeneration (FTLD)

This is the name given to a group of dementias when there is degeneration in one or both of the frontal or temporal lobes of the brain. It includes Fronto Temporal Dementia, Progressive non-Fluent Aphasia, Semantic Dementia and Pick's disease. About 50% of people with FTLD have a family history of the disease.

Huntington's disease

Huntington's disease is an inherited, degenerative brain disease that affects the mind and body. It usually appears between the ages of 30 and 50 and is characterised by intellectual decline and irregular, involuntary movement of the limbs or facial muscles. There is no treatment available to stop the progression of the disease, but medication can control movement disorders and psychiatric symptoms. Dementia occurs in the majority of cases.

Parkinson's disease

Parkinson's disease is a progressive disorder of the central nervous system, characterised by tremors, stiffness in limbs and joints, speech impediments and difficulty in initiating physical movements. Late in the course of the disease some people may develop dementia.

Alcohol-related dementia (Korsakoff's syndrome)

Too much alcohol, particularly if associated with a diet deficient in thiamine (Vitamin B1), can lead to irreversible brain damage. If drinking stops there may be some improvement.

Creutzfeldt-Jacob disease

Creutzfeldt-Jacob disease is an extremely rare, fatal brain disorder caused by a protein particle called a prion. It occurs in one in every million

people per year. Early symptoms include failing memory, changes of behaviour and lack of coordination. As the disease progresses, usually rapidly, mental deterioration becomes pronounced, involuntary movements appear, and the person may become blind, develop weakness in the arms or legs and finally, lapse into a coma.

Other conditions that may produce or be associated with dementia are:

- HIV/AIDS
- multiple sclerosis
- certain types of head injuries
- brain tumours and brain haemorrhages
- infections of the brain
- exposure to certain toxins
- substance abuse.

Can dementia be inherited?

Having a close relative with dementia is not evidence of a genetic link, depending on the cause of the dementia. Dementia can happen to anybody but is more common after the age of 65. About one-third of the people with dementia have a close relative who has, or has had, dementia. Alzheimer's disease occurs relatively frequently in the elderly. For people over 80 years, about 1 in 4 have the condition regardless of family history.

If you are concerned about the risk of inheriting dementia, Alzheimer's



Understanding dementia

Australia provides professional staff for counselling and support. Ring the **National Dementia Helpline** on **1800 100 500** to arrange an appointment with a counsellor.

What are the early signs of dementia?

The symptoms of dementia can vary widely with different diseases and different people, even in those with the same condition such as Alzheimer's disease. The early signs can be very subtle and vague, and may not be immediately obvious. Usually though, people seem to notice a problem remembering recent events.

Common symptoms may include:

Changes in memory

- Repeating the same questions and stories
- Being absent-minded or forgetful
- Losing valuables, keys, wallet
- Getting lost in once-familiar environments

Changes in orientation

- Difficulty remembering the year, date, month, day
- Difficulty remembering the names of friends, family, home address

Changes in behaviour

- Impaired judgement
- Poor planning and organising ability
- Deterioration in appearance and hygiene
- Behaving in ways that are not normally the way the person would behave, such as swearing more, or becoming more withdrawn

Changes in emotions

- Easily aroused, readily changing moods
- Unable to handle stress or noise, perhaps becoming agitated
- Withdrawing socially
- Losing drive and interest in things that used to provide interest and motivation, such as fishing, bowls or clubs

Changes in thinking

- Less flexible, more rigid
- Difficulty mastering new tasks
- Difficulty finding the right word, reduced language fluency
- Difficulty starting new topics, thinking beyond the present

Understanding Dementia

“My father, Zvonko migrated from the island of Korcula, Croatia in the early 1950s. Twelve months later my mother Maria and the rest of my family joined him. Like many others, they came to Australia in search of a better life. Dad loved Australia, and he worked hard and provided well for his family.

“In 1988 Dad made a return visit to Croatia and realised his decision to migrate had been the right one for himself and his family. However, shortly after his trip, Dad’s life began to change. Just as he was looking forward to retirement and an easier life, Alzheimer’s disease began to sneak up on him.

“At first it was unclear to anyone in the family exactly what was happening. Dad had always been a quiet man and relished his moments of relaxation. When he retired the family simply thought Dad had just ‘switched off’ and was overdosing on relaxation. However, as his disease progressed and when Mum retired and was spending all day with Dad, it became apparent that something was wrong.

“When Dad was given his diagnosis of Alzheimer’s disease, my first thought was ‘No. Not my Dad. He has never had a day sick in his life. How can this be?’ And so for my family, and me the role of caring and support began.

“With the benefit of hindsight, we could look back and piece together

the bits of the puzzle. Mum recalled when they were in Croatia on holiday and an old friend had asked Dad what he did in Australia. Dad turned to Mum and asked ‘What do I do in Australia?’ At the time she thought nothing of it, but looking back she realised this must have been the beginning of Dad’s disease.”

The brain and behaviour

When a person has dementia:

- One or more areas of the brain are damaged.
- These areas of damage can differ between people.
- The person cannot help his or her behaviour resulting from this brain damage.
- Dementia develops at different rates; there is no normal progression and the rate of the progression can depend on the cause of the dementia.
- In most cases of dementia progressive deterioration occurs over time; however temporary conditions such as stress, illness, medication and time of day can make symptoms appear worse.
- People with dementia are all different individuals both in the way they are affected (their behaviour) and the nature and extent of the underlying brain damage.

Imagine the brain as a factory

It can help to understand how the brain works if you think of the brain as a factory. The factory runs at peak efficiency when all parts are working properly.

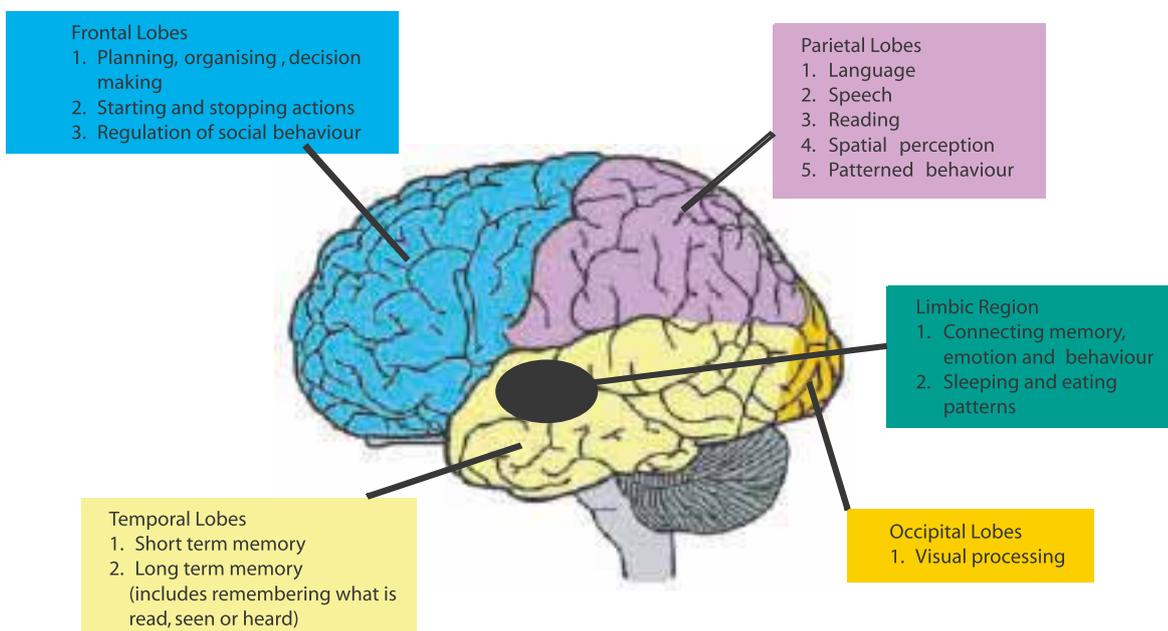
The directors

Up at the front of the factory (frontal lobes) are the directors. They make plans for the factory and decide who's going to do what and when. As things get under way, they get information as to how well things are going, and they judge it – what is good or not so good? Then they make further decisions – change that, keep this – and show appreciation and annoyance.

So up at the front you have planning, organising, decision making, judging and appreciating.

The managers

In the middle (parietal lobes) are the managers. Each manager runs a department. On the left side of the brain is a speech department (moves the throat, tongue and lip muscles); a language department (finds the words you want, knows what the words mean); a motor department (moves the right arm and leg); and a spatial knowledge department (finds your way around the building, knows where you are when driving a car). There is also a music department and



Understanding Dementia

a few incidental departments. The right side is the picture side and the left side is the talking side.

The plan

The managers know what the plan is from the directors and they make sure it is carried out.

To do this they send messages back and forth.

At the bottom (limbic region) are the workers. They don't know what the plan is from the directors but they know their job and they do the same job day in, day out. They take care of things like appetite control, need for water, staying alert and awake or going to sleep and basic emotions.

When the brain is damaged, someone can't do their job. Depending on the damage, it can be a director, manager or worker. You can also have someone go on a leave of absence. That occurs when there is a temporary swelling or loss of blood supply that is returned in a short time. The result of the injury is to reduce the efficiency of the factory. Messages are sent but aren't picked up. Directors get annoyed, the managers get tired and the emotional workers get overwrought. Confusion reigns.

Understanding who can no longer do the job and who is still on the job can help in understanding behaviour.

Source: Verna Arnell PhD, Psychologist, G F Strong Rehabilitation Centre, Vancouver

Why is correct diagnosis important?

A medical diagnosis is critical at an early stage when symptoms first appear because there are a number of potentially reversible causes and other less serious

conditions that resemble the symptoms of dementia.

These conditions include:

- some vitamin and hormone deficiencies
- medication clashes or over medication
- depression.

If the symptoms are caused by dementia, an early diagnosis will mean early access to support, information and medication, should it be available.

“I was worried about how the assessment would go but the staff provided an interpreter and treated my mother with dignity, so despite the fact that she was diagnosed with dementia the experience was not so horrible.”



Understanding dementia

Who gets dementia?

Most older people do not get dementia. It is not a normal part of ageing.

Approximately 200,000 people in Australia are currently living with dementia. The numbers are increasing due to Australia's ageing population. By the year 2050, it is estimated that there will be more than 730,000 people with dementia.

How the prevalence of dementia increases with age

- Under 64 years, less than 1% may have dementia.
- From 65 to 74 years, 1.5% may have dementia.
- From 75 to 84 years, 6.3% may have dementia.
- Over 85 years, over 30% may have dementia.

Source: Access Economics P/L, Dementia Estimates and Projections: Australian States and Territories, February, 2005

Younger onset dementia

Dementia has been diagnosed in people in their 50s, 40s and even in their 30s, although this is much less common than dementia occurring after the age of 65. Younger onset dementia can be difficult to diagnose and its incidence in the community is still not clear.

Consulting a doctor to obtain a diagnosis is critical at an early stage. A complete medical and psychological assessment may identify a treatable condition, or it may confirm the presence of dementia.

A person with younger onset dementia will need extra consideration because the condition appears at an earlier stage of their life when they are likely to be more physically and socially active. They may be in full-time employment, raising young children, managing financial responsibilities and be physically strong and healthy

Changed behaviours associated with dementia may be more difficult to accept and manage in a younger person. Families may have to face many very personal and difficult emotional issues.

“Getting the diagnosis is so important and that doctors understand ... When David was diagnosed by the specialists, our GP said ‘I can’t understand it, he’s too young’.

“You expect this sort of thing only happens to older people. I can’t take it in – you can’t visualise what’s going to happen. That’s why I think counselling is vitally important. You’re trying to cope with loss of income, possible loss of your partner and, as well, loss of freedom.

“I used to associate dementia with old age. I had never known anyone young with dementia before David.”

Treatment for dementia

A number of drugs are currently available in Australia for use by people with dementia. These include drugs that may have a temporary effect of improving mental functioning in some people.

Dementia can cause a number of behavioural and psychological symptoms that can be very distressing. Sometimes they may require medication for relief. All medications should be discussed with your GP or specialist.

Some effects of dementia

Behaviour and personality changes

As we can't see what is happening to the brain, we can only observe the changes in the person. Have you observed any changes in behaviour, personality, emotions and attitudes?

Some examples of possible changes are:

- strange or uncharacteristic behaviours: easily upset or unusually aggressive
- unduly suspicious: blaming others for lost items, accusing others of stealing
- memory loss: increasing forgetfulness, poor or confused recall of events, distorted recall of past events
- changes in the ability to do everyday tasks: dressing, eating, driving.

If any of these changes worry you, discuss them with the doctor.

Communication changes

How the person with dementia lets you know what they need, or how they generally get a message across, will change.

Verbal communication refers to the words used by the person when speaking. While these words might be expressed clearly in the early stages of dementia, they may become jumbled and confused later.

The ability to communicate through spoken or written language may deteriorate or may be lost. The person then has to use other forms of communication to express a need.

Non-verbal communication refers to all other forms of communication and includes:

- facial expressions (such as smiling or frowning)
- gestures (such as pointing, touching or arm waving)
- eye contact (such as looking at or away from others)
- behaviour (such as walking away or crying)
- volume (such as speaking loudly or softly)
- tone of voice (such as high or low pitch).

Being aware of non-verbal communication can help you and the person with dementia when verbal communication becomes difficult.

“Tone of voice is important when the person can’t understand what you are saying. My father got to the stage where he couldn’t understand English but would respond to the tone of my voice.”

“People with dementia may enjoy being touched by some people but not others. Use touch carefully and don’t continue if it is not appreciated.”



Topic 2

You and your doctor

In this topic

- Diagnosing dementia
- Breaking the news
- Confidentiality
- About family and carers
- Communicating with your doctor
- Speaking up for yourself
- What doctors can and can't do

“On our frequent consultations with the family doctor and my request for answers to my wife Ruth’s problems with driving, counting money, mislaying things and other memory lapses, he would pat her head and say, ‘Oh, this happens to all of us’.

“He resisted my request for referral to a specialist until I demanded such action and he reluctantly conceded. Dementia was never in my vocabulary until the day when, after interviewing Ruth and me, the specialist physician said to me, ‘Almost certainly your wife has Alzheimer’s disease’. Up until he followed on with us what our expectations could be, he may as well have said she needs a trip to the moon, for I did not have a clue what he was talking about. The physician’s comments of what I could expect proved to be not only, seven years hence, completely accurate, but also prepared me for and conditioned me to cope with Ruth’s disintegrating limited life span.”

Diagnosing dementia

To be able to make a correct diagnosis of dementia a thorough psychological and medical examination is involved.

This may reveal a reason other than dementia for the person’s behaviour. Examples include psychological and medical causes such as hormonal disturbance, vitamin deficiency, a brain tumour, excessive alcohol consumption, depression or a reaction to drugs. These conditions can sometimes be reversed or helped with treatment.

Checklist for diagnosis

- A detailed history
- A checklist of behaviour and memory changes by asking about the person’s thinking, conversation or general behaviour
- Blood and urine tests to exclude common conditions such as vitamin deficiency, assess physical health, and exclude infection
- A physical examination
- A referral to a specialist such as a neurologist, psychiatrist or psycho-geriatrician

Only a doctor can make a diagnosis of dementia and they have to make sure that the patient really has dementia. It is best to make a diagnosis with family input. Often people attending the GP’s surgery may appear to be relatively



normal and the doctor may be unaware that they are not coping at home.

The possibility that the symptoms could be a result of depression, medication or some other treatable cause has to be eliminated. You need to tell your doctor if you think alcohol or sedative use could be contributing to the problem.

Some doctors prefer to wait for signs of deterioration, whilst others refer immediately to a specialist. A series of tests has to be done before doctors can be certain.

At any time you can request a second opinion, or a referral to a specialist if your GP has not already done so.

Finding the right doctor for you

It is important that you feel comfortable with your doctor because you may have many discussions about dementia and dementia care in the future. Feeling confident in, and comfortable with, your doctor can lead to better care for both you and the person with dementia.

If you feel you need to change your doctor, these questions may help you choose the right doctor for you:

Has dementia been diagnosed? Yes/No

Was it explained in a way that you could understand? Yes/No

Did you have an opportunity to ask questions? Yes/No

Were you able to discuss the effects on you? Yes/No

Did you get the answers you needed? Yes/No

Do you feel you were given enough time? Yes/No

Do you feel that you can go back with your questions at any time? Yes/No

If you can answer yes to each question you have probably found a doctor who is right for you. A caring doctor, who has knowledge of you and your situation, could be of great support and benefit to both you and the person with dementia.

You and your doctor

Breaking the news

Some doctors have been criticised by families and carers for not providing the information they need when they need it. Many are becoming better informed about dementia and dementia care. They are also becoming better at explaining the condition, appreciating what is needed and providing advice to families and carers.

The time of diagnosis can be very difficult for the person with dementia and their family and friends. Often they find it hard to understand or remember what has been said when they are told of the diagnosis. Feel free to ask your doctor to explain anything you don't understand and to write down anything you need to remember.

It may help to contact the **National Dementia Helpline** on **1800 100 500** to obtain support around the time of diagnosis, or the **Commonwealth Carer Resource Centre** for carer-specific advice on **1800 242 636**.

Confidentiality

Doctors cannot talk about their patients without their consent. If you wish to be included in discussion about the person's medical problems, try to come into the consulting room together; do not ring the doctor later.

While this rule has to be broken at times, especially in the context of dementia, it

is not unusual for patients to specifically request the doctor not to discuss their condition with their family, and doctors must abide by this request.

It is usual to ask the family to choose one spokesperson who can then explain what is said to the rest of the family.

Doctors won't take phone calls from family members they don't know because there is no way of knowing exactly who they are talking to.

About families and carers

Many doctors regard the family and carers as patients too.

They understand how time-consuming and stressful caring can be. They also understand that if members of the family or the carer are ill the person with dementia will suffer too.

It is important that families, carers and the person with dementia visit their doctor regularly. This is to make sure that any health difficulties are addressed before they cause major problems. Doctors may provide counselling or suggest other counselling options if appropriate for the person with dementia or for family members.

Doctors may also advise on some of the daily management issues regarding caring for a person with dementia and give information to carers about respite care, support groups and other services.

What would you like to know?

Answering each of these questions may help you to prepare for your visits to the doctor.

- What would you like to know from your doctor on your next visit?
- What questions will you ask to get the answer?
- What would you like the doctor to know about you or the person on your next visit?
- What will you say about yourself or the person to the doctor?

Communicating with your doctor

You should expect to be treated with courtesy and respect by your doctor.

Doctors can be expected to sensitively discuss the cause and effects of dementia and advise you on a range of issues about dementia and caring.

Unfortunately doctors do not always have the time to spend with families and carers or the person with dementia. It can help to prepare your questions in advance, and book a long appointment before you come. (Note: some doctors may charge more for a longer consultation. Discuss this with the receptionist when booking your appointment).

How to get what you need from your doctor

Families and carers made these suggestions for getting the information or advice they needed.

- Make an appointment at a suitable time of the day – avoid early morning or late afternoon.
- Be prepared. Have your questions ready – perhaps make a list of the questions.
- Know what you want from the visit and ask for it.
- Take a relative or friend with you.
- Ask for more explanation of anything you don't understand.
- Ask for a referral to a specialist if you think it could help.
- Keep a diary of the person's behaviour and use it to explain the behaviours that concern you.
- Be sensitive about discussing your concerns in front of the person with dementia. While you may usually want to include the person in the discussions, there may be times when you need a separate appointment.
- Write down or ask your doctor to write down what is said – especially about medication.

You and your doctor

Speaking up for yourself

You may find that it isn't easy to get the information, advice or support you need.

Speaking up for yourself instead of being angry or giving up helps you feel good. It also helps you get what you want.

Some people worry that by speaking up they will be come hurtful. However, doing this actually reduces the chances of hurting or offending the other person.

Here are some ideas you could try:

Believe in your rights – First you have to believe that you and the other person have a right to an opinion – even if your opinions are different. You also have to believe that you have a right to be treated with respect – and that you have a responsibility to treat the other person with respect.

Use “I” statements – One of the most useful skills is to clearly tell the person how you feel or what you want. When you do this you are using “I” statements. An “I” statement describes what you are thinking or feeling at the time without blaming or being angry.

Example “I” statements

Notice how the “I” statements below begin with “I feel...” or “I am...” This makes it easier for the other person to think about their own behaviour and its effect on you. It also makes it easier for them to reply in a helpful way without being angry or offended.

| Try saying... | Instead of saying or thinking... |
|---|--|
| I feel that you aren't interested in what is happening. | You don't give a hoot about what is happening. |
| I need you to help me. I can't cope with my mother any more. | My mother is driving me crazy. You have to do something. |
| I feel that you are too busy to take the time to explain what is happening. | You never tell me anything. |
| I'm worried about the effect of the drugs. Can something else be done? | Can't you do anything except drug Dad to the eyeballs? |
| I would like you to know how this makes me feel. | You don't know how I feel. |

What doctors can and can't do

Doctors can treat you at the surgery and may visit you in your home or other accommodation.

Doctors can suggest admission to a public hospital or a residential facility, but the hospital staff or the Aged Care Assessment Team and family have the final say.

Doctors can also refer you to other health professionals to assist you with the care you are providing for the person with dementia. Professionals such as nurses, psychologists, social workers, occupational therapists, physiotherapists and counsellors have the training and experience to provide help to families, carers and people with dementia.

For example, your doctor cannot make anybody take their medication, but they can review the prescribed medication and arrange for services to visit regularly to fill a pill box or sometimes administer the medication.

Your doctor cannot make anyone eat properly, but can organise a meal delivery service such as Meals on Wheels or assistance with meal preparation.

Your doctor can also make you aware of the respite care or any other services that may be available. You can then make the decisions yourself.

“The first indication that Anna, my wife, was having trouble was her withdrawing and being forgetful. Once there was an appointment with the family doctor for another reason. The doctor asked about her behaviour and I explained what had been happening. The doctor explained that she would refer Anna to have some tests and referred her to a specialist. After the blood tests, a psychological test and a scan, the specialist diagnosed her as having Alzheimer’s disease.

“From then on the visits to the doctor have been a regular occurrence and she encourages me to keep notes of the unusual behaviour that has occurred and discuss them with her. This has been very helpful because I can talk with the doctor about the things that I can do to look after Anna properly.”

“I rang the doctor and we discussed trying to get my husband to visit but of course that was difficult because my husband insisted there was nothing wrong with him. He has been in the care of the community health centre and our doctor since the first visit. It took twelve visits and many tests before they diagnosed the cause of the dementia as Pick’s disease.

“It has been a very stressful time but now that we know what the problem is we can understand what has been happening all those years.”

You and your doctor

“For a number of years I had noticed the decline of my father’s memory and behaviour. I collected contact numbers, brochure and pamphlets to give to my mother, to try to let her know that there was definitely something wrong with Dad. She had mentioned Dad’s symptoms to our GP who said he found it hard to believe.

“He agreed to take a closer look and ask him how he was. After a few more visits even Dad himself was mentioning that ‘the old memory box doesn’t seem the same these days’. The GP still seemed to indicate that it’s only old age and we all slow down a bit. The GP has known and treated the family for well over 25 years, but in a five to ten minute consultation what is there to see? The person can answer everyday questions coherently.

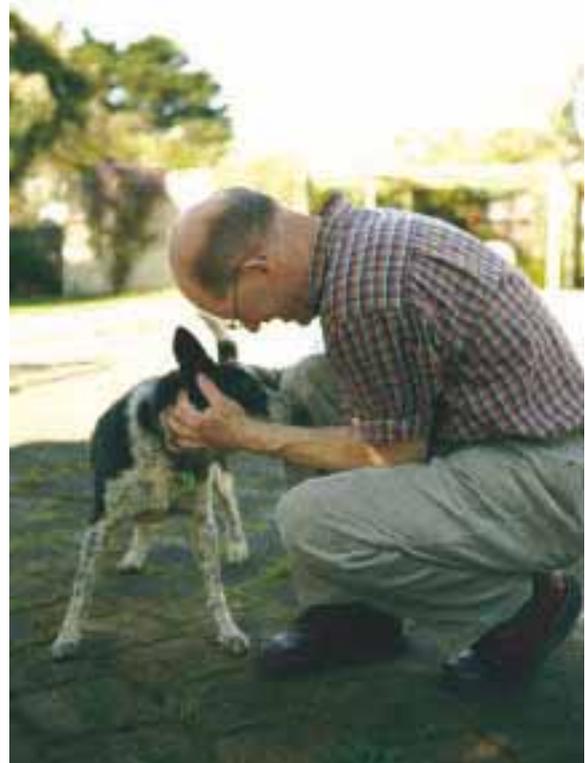
“By this stage, my husband, my mother and myself were commenting on Dad’s declining symptoms to the GP. So mother, sister-in-law and I made an extended appointment with the GP to ask him what was to be done. The situation could not go on any longer.

“With the three of us saying the same things the GP did not hesitate but referred Dad for a scan and some blood tests to eliminate physical problems. These came back negative.

“He referred us on to a physician who, after minor memory testing and

listening to past history, confirmed what we had suspected all along, Alzheimer’s disease. The GP still found it hard to believe and it came as a shock to him.

“The GP was helpful with monitoring Dad’s medication and also other health problems. The ball had finally started to roll and finally a psychiatric assessment was in agreement with the diagnosis.”



Topic 3

Information and services

In this topic

- Your legal affairs
- Benefits and entitlements
- Financial information
- Advocacy
- What services are available to help you?
- Information in languages other than English

As dementia progresses, the person's ability to make legal and financial decisions decreases.

Eventually the person becomes unable to understand these matters and is legally considered to be mentally incapable of making decisions. At this point family, carers or a legally appointed person or organisation may take on these responsibilities on the person's behalf.

By planning ahead it is possible to make sure that all legal and financial possibilities have been considered while the person can make decisions.

Getting legal and financial advice while the person can participate in the discussion is essential.

Families and carers should also get their own advice on planning their own financial and legal affairs. Caring can be

costly so early financial planning advice is important. This is especially so if you are considering leaving employment to care full time and are near or at retirement age.

Your legal affairs

These comments are a general look at how families, carers and people with dementia can organise their legal affairs. The advice will vary between states and territories and depends on state and territory law. It is always advisable to contact a solicitor or the Guardianship Board in your state or territory for specific advice.

Wills

A will gives instructions as to how the estate of a deceased person should be distributed. It is important that the person with dementia makes or updates their will while they are considered capable of doing so.

If a deceased person does not have a will, there is no guarantee that his or her wishes will be carried out. This can cause conflict, stress and even hardship.

Who can help?

The Public Trustee, community legal centre, a solicitor or law society can provide advice and assistance to make a will.

Information and services

Enduring power of attorney

An enduring power of attorney is a legal arrangement for another person to look after their financial affairs if they become unable to do so themselves.

An ordinary, or general power of attorney is also available, but it is only valid while a person is legally competent. An enduring power of attorney continues until death.

It is advisable that the opportunity to appoint an enduring power of attorney be provided as soon as possible after diagnosis if the person has not already done so.

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

Who can help?

The Public Trustee, community legal centre, a solicitor or law society can provide advice and assistance with appointing an enduring power of attorney.

“Dad was diagnosed with Alzheimer’s disease after Mum could no longer cope with his behaviour. She had put up with many difficulties for a long time. When he became incontinent it was the last straw

“The doctor asked if Mum and Dad had arranged an enduring power of attorney. They hadn’t, and he told us that it was too late to do it for Dad because he couldn’t understand what he would be signing, but we should see a solicitor about it for Mum. We weren’t sure what it all meant but we saw a solicitor. Dad had a bank account and some shares in his name. There was quite a lot of money involved and the solicitor said that it was going to be very difficult for Mum to be able to use the money. This caused a lot of trouble for her because she needed some of the money to pay some bills.

“The solicitor asked about wills too. Mum said they each had a will that had been made out many years before. She couldn’t remember exactly where. He asked to see the wills because Mum might want to make some changes. There was nothing that could be done about Dad’s will now; it couldn’t be changed because his dementia was too advanced. When Mum looked for the wills she could only find hers. It took us quite a while to find where Dad had hidden his. Mum always knew that the house was in Dad’s



Information and services

name but she didn't know that he had changed his will to leave everything to my oldest brother. Mum was living in a house that wouldn't be hers when Dad died and most of her money would belong to my brother. Of course my brother wasn't going to make Mum move out, or spend her money, but this has been very hurtful for her and she is worried about her future. After Dad died it took a long time to get it sorted out properly. This has made me realise how important it is to make sure that finances and legal affairs are sorted out early. Once the person doesn't understand what they are signing, it is too late. It made my husband and me look at our wills and other documents. We have also given our daughter an enduring power of attorney in case something happens to us."

Guardianship

In some circumstances a guardian may be appointed by a state or territory government to act on behalf of a person who has lost the ability to make their own decisions. This may occur if there are problems in dealing with the affairs of the person with dementia, or if there is conflict in the family about the person's best interest.

Each state and territory government has a board or tribunals that appoints guardians for people who can't manage their own personal affairs. The laws are slightly different in each state and territory.

In some states and territories other formal arrangements are available including medical guardianship, enduring power of medical guardianship, and an advance directive. An advance directive may allow you to define the medical treatment you wish to have, or refuse, should it become difficult for you to make these decisions later on.

A question for you

Have you considered these important legal documents?

- Wills
- Enduring power of attorney
- Enduring power of medical guardianship
- Medical guardianship
- Advance directive

Remember that different names may be used in some states and territories.

Who can help?

The Public Trustee, Guardianship Board community legal centre, a solicitor or law society can provide advice and assistance about guardianship.

Benefits and entitlements

Centrelink

For more information about Centrelink benefits and entitlements phone **13 27 17** or visit **www.centrelink.gov.au**

Carer Payment

You may get Carer Payment if you provide constant care in the home of the person with dementia. This is an income and asset tested payment for full-time parents or carers of children or adults with a disability or severe medical condition.

You need a doctor or health professional's report to help establish eligibility.

You can work for up to 20 hours a week while getting Carer Payment.

Carer Allowance

If you are caring for someone with dementia you may also be eligible for a Carer Allowance. Carer Allowance is an allowance for parents or carers of children and adults with a disability or severe medical condition and carers who are frail aged. Carer Allowance is free of income and asset tests and is not taxable. Carer Allowance can be paid in addition to Carer Payment or other Centrelink payments like Age Pension.

You can continue to get both Carer Payment and Carer Allowance for up to 63 days in a calendar year if you or the person you are caring for is away, for

example using respite care, as well as 63 days if the person is temporarily in hospital.

Pharmaceutical Allowance

Pharmaceutical Allowance provides extra money to help pay for the cost of prescription medicines. You get this payment if you are getting any one of a number of pensions or eligible payments, including Carer Payment.

Rent Assistance

If you are paying rent, and receiving a payment from Centrelink or the Family Assistance Office, you may be entitled to Rent Assistance. Rent can include private rent, lodgings, board and lodgings, site fees and maintenance fees in a retirement village.

Telephone Allowance

You may be entitled to get help with the rental costs of having a domestic telephone line (or mobile phone) connected in Australia.

Bereavement payment

If your partner or a person you are caring for dies you may be entitled to a bereavement payment. If you are getting Carer Payment, and you care for someone who dies, you will continue to receive Carer Payment for the bereavement period (normally seven paydays).

Pensioner Concession Card

If you get a Carer Payment or another eligible payment from Centrelink, you will get a Pensioner Concession Card. This card can save you money on a number of areas including prescription medicines through the Pharmaceutical Benefits Scheme and travel on public transport.

Your state, territory or local government may also give you reductions on rates, power bills, ambulance services and car registrations.

Non-pension concessions

All state and territory governments issue their own Seniors Card to eligible residents aged 60 years and over. Seniors Cards help reduce seniors' living costs and encourage a more active, affordable lifestyle in retirement.

The eligibility criteria and benefits vary between states and territories and are partly restricted by the weekly number of hours in paid employment.

All states and territories offer concessions on public transport.

Senior cards from any state or territory can be presented at over 20,000 businesses around Australia. These businesses display a "Seniors Card Welcome" sticker on their premises.

You can obtain a directory outlining discounts available to both residents and visiting seniors from the Senior Card office of every state and territory.

Centrelink information over the phone

For information about disability and carer payments phone **13 27 17**.

For information in languages other than English, phone **13 12 02**.

Department of Veterans' Affairs

The Department of Veterans' Affairs (DVA) provides a range of financial assistance and support services to assist families and carers who help veterans and war widows and war widowers.

DVA has state offices that can:

- answer questions and provide information about DVA pensions and allowances, and about health care eligibility
- provide up-to-date information about health and support services available through DVA and in the community
- work with local service providers to ensure that veterans, war widows and widowers have access to appropriate services
- work with community agencies to develop programs to meet the needs of veterans, war widows and widowers and their dependants.

DVA has fact sheets available on over 300 topics of relevance to veterans, war

Information and services

widows and widowers, their dependants, families and carers.

To contact your nearest DVA State office phone **13 32 54** (metropolitan) or **1800 555 254** (non-metropolitan)

Taxation

Tax is payable on income received from most pensions, allowances and benefits. However some payments received from Centrelink and the Department of Veterans' Affairs are tax exempt and should not be included on your tax return.

The Tax Pack issued by the Australian Taxation Office each year has a full list.

Medical Expenses Rebate

If you are liable to pay tax and you pay residential care fees you may be entitled to the Medical Expenses Rebate. The rebate is offered through the taxation system for residents who are assessed as requiring care. It can substantially reduce the taxation paid by residents and increase their income after paying their fees and taxes.

For more information about residential care fees contact the **Aged and Community Care Information Line** on **1800 500 853**.

Appealing a decision

If you are not happy with a decision made by Centrelink you may wish to appeal. For more information call **13 27 17**.

If you are not happy with a decision made by DVA you may wish to appeal. You can do this by lodging an appeal in writing to the Veterans' Review Board.

You may also write to the federal Minister for the Department or your federal Member of Parliament.

You can contact Alzheimer's Australia or Carers Australia for support and advocacy assistance.

Financial information

Centrelink's Financial Information Service (FIS) offers information to help improve your standard of living and enjoy a better lifestyle by using your money to the best advantage. It is independent, free and confidential. FIS officers do not recommend particular investment products or make investments for you.

For more information phone **Centrelink** on **13 23 00** or phone **13 10 21** to make an appointment with an FIS officer. **For information in languages other than English** phone **13 12 02**.

Independent financial advice can help you decide how to best manage the finances available. This is particularly important for families and carers who are unable to claim benefits, as costs can be considerable.

Contact the **National Dementia Helpline** on **1800 100 500** for advice about the likely costs as dementia progresses, for example for respite care, a residential care facility or home modifications.

A question for you

Do you know where these documents are kept?

- Wills
- House and land titles
- Mortgage documents
- Birth and marriage certificates
- Insurance policies
- Superannuation documents
- Centrelink and Department of Veterans' Affairs documents
- Share certificates
- Enduring power of attorney form

Advocacy

You may find yourself acting as an advocate, that is, ensuring the person's rights are upheld.

You may feel that you need advice and support about how to deal with what might happen if you complain about the person's rights not being upheld or the way services have been provided. If so, these organisations may be able to help. They will either help you directly or refer you to someone who can.

National Dementia Helpline
1800 100 500

Commonwealth Carer Resource Centre
1800 242 636

Call the **Aged and Community Care Information Line** on **1800 500 853** for details of the advocacy organisations in your state or territory.



Information and services

What services are available to help you?

Caring for a person with dementia can be very demanding. The Australian Government and state and territory governments allocate funds to organisations to provide services to help you.

Various government, local council, church and community organisations provide services to families and carers. This varies between states, territories and local areas.

Finding out about services

Various information services have been set up to help families and carers find out what services are available and how to contact them. These information services should be able to provide you with a list of available services in your area and should be able to give you a contact for the particular service you may require.

Commonwealth Carer Resource Centres

Commonwealth Carer Resource Centres are operated by Carers Associations in each state and territory of Australia and provide a range of free information and services including:

- practical written information about support services, home help, financial entitlements, legal matters, respite care, health and well-being, and dealing with grief

- counselling, through the National Carer Counselling Program
- referrals to community and government services
- emotional support
- educational and training opportunities.

For information and support call the **Commonwealth Carer Resource Centre** on **1800 242 636**

Commonwealth Carelink Centres

Commonwealth Carelink Centres act as a single point of contact to provide information and guidance about community care services and residential care facilities available in the local community.

Commonwealth Carelink Centres can give you free information about:

- the types of services available in your local area
- how to contact these services
- eligibility criteria
- general cost information about receiving services.

Anyone can use a **Commonwealth Carelink Centre** either by visiting personally or by telephoning **1800 052 222**.

Aged Care and Community Care Information Line

The Aged and Community Care Information Line is a single hotline number that provides you with information about Australian Government funded residential aged care and community care.

The information line can also refer you to services in your region and one of 54 Commonwealth Carelink Centres around Australia. Contact the **Aged Care and Community Care Information Line** on **1800 500 853**.

Commonwealth Carer Respite Centres

Commonwealth Carer Respite Centres can assist you to quickly find out what respite is available when you need to take a break from caring. The centres keep an up-to-date record of the organisations providing respite care and its availability.

Respite care may be for part of a day or longer and can be on a regular basis, for a special occasion or when there is an emergency. It can be provided in your own home, community centre or in a wide range of residential facilities.

Centre staff will assist you, where they can, to access respite care services. If you would like them to do so centres may act directly to get you the service you need. Contact the **Commonwealth Carer Respite Centre** on **1800 059 059**.

Alzheimer's Australia

Alzheimer's Australia provides information, counselling and support for people with all forms of dementia and their families and carers. Call the **National Dementia Helpline** on **1800 100 500**, or visit Alzheimer's Australia at **www.alzheimers.org.au**

“In search of answers and assistance, I contacted Alzheimer's Australia. I called the Dementia Helpline in a desperate bid to organise respite care to give Mum a break. I believe that telephone call changed my life. I received understanding and information that helped me and my family deal with our problems.”

The Age Page

The Age Page is near the front of most telephone directories. It provides contact details for services in your area. It may list:

- Aged Care Assessment Teams
- aged care organisations
- Community Options programs
- day care and respite care services
- Meals on Wheels
- carer and other community support organisations
- relevant government departments and agencies.

Information and services

Education

You may want to learn more about dementia and caring for a person with dementia.

Alzheimer's Australia Education Services in each state and territory offer information sessions and a variety of more detailed courses for families and friends of people with dementia. These include general information about the nature of dementia and the impact of the disease on the individual and those who care for or have a close relationship with a person with dementia.

Longer courses may include useful strategies for maintaining effective communication, interacting to minimise some of the changed behaviours that may occur with dementia and activities that promote independence, self-esteem and enjoyment.

Courses vary from state to state and can also include information about other issues of concern, such as driving and dementia, navigating the service systems and powers of attorney.

To find out more contact the **National Dementia Helpline** on **1800 100 500**, or visit **www.alzheimers.org.au**

Your local community health service should also be able to give you information about dementia and caring.

There are also books and videos that can be borrowed from these organisations.

Support groups

You may want to meet other people who are caring for someone with dementia so you can share experiences, provide mutual support, develop networks and obtain information and advice.

Alzheimer's Australia and Carers Resource Centres can link you to support groups in many areas.

Other groups may be organised by your local day respite centre, community health centre or other community groups.

Alzheimer's Australia's *Living With Memory Loss Program* is available in each state and territory. It provides opportunities for both people with early stage dementia and family members to get information and talk through issues in a group program.

Counselling

Alzheimer's Australia provides sensitive, flexible and confidential counselling services in each state and territory. Professional counsellors are available for individual support and practical advice to people with dementia and their families and carers. **Contact the National Dementia Helpline** on **1800 100 500**.

The National Carer Counselling Program provides counselling and related emotional and psychological support services for carers. Counselling is available for such issues as:

- stress management or crisis counselling
- coping skills and strategies
- bereavement and loss for former carers
- transition issues relating to the person being supported moving to a residential aged care home
- practical problem-solving techniques.

The counselling service is delivered by the Commonwealth Carer Resource Centres in each state and territory. Contact the **National Carer Counselling Program** on **1800 242 636**.

Some local service organisations offer services to families and carers who may wish to talk through the problems of caring for someone with dementia with a counsellor. Contact the **National Dementia Helpline** on **1800 100 500** or your local **Commonwealth Carer Resource Centre** on **1800 242 636** for more information.

Government departments such as Centrelink and the Department of Veterans' Affairs also provide social work assistance.

For further information call **Centrelink** on **13 27 17**. For information in languages other than English call Centrelink on **13 12 02**.

General services

Organisations usually offer various kinds of practical help to families, carers and people with dementia. Each of them will have an assessment procedure, which may include a referral from a medical practitioner.

Services are provided at no charge, by donation, minimum charge or a fee. If paying a fee is a problem it may be negotiable.

Some services may have waiting lists.

The HACC program

The Home and Community Care (HACC) program provides a comprehensive range of basic maintenance and support services for frail aged people, including people with dementia, to support these people to be more independent in their home and community.

HACC services include: community nursing, personal care, meals, home help, home modification and maintenance, transport and community based respite care. Dementia-specific services include centre-based and in-home respite, training, support and counselling for families and carers and advocacy services.

HACC services are designed to reach people with the greatest level of need. This is determined by HACC service providers who make an assessment of



your needs, giving priority to those in greatest need.

For more information about HACC services contact your **Commonwealth Carelink Centre** on **1800 052 222**.

Home help

Some help with household chores is available through local service provider organisations funded through the Home and Community Care (HACC) program. These services assist with housework and the care of the person with dementia. Services may include house cleaning, washing and ironing, assistance with shopping, transport to personal appointments and provision and laundering of linen.

For more information contact your **Commonwealth Carelink Centre** on **1800 052 222**.

Home modifications

This varies from area to area. Sometimes local service provider organisations, local service clubs, the Department of Veterans' Affairs, and state and territory health, housing or community service departments provide this type of assistance.

These services assist families and carers to maintain their own homes, gardens and yards to ensure safety and provide an adequate level of security. Assistance may include essential repairs and maintenance, such as changing

light bulbs, carpentry and painting, referral and advice on maintenance and modification matters, modifications such as ramps and non-slip flooring and garden maintenance.

For more information contact your **Commonwealth Carelink Centre** on **1800 052 222**.

Home nursing services

If you need advice or help managing medication, showering, or other nursing-type activities, there are domiciliary nursing services in most areas of Australia. These services are provided to improve and maintain health or well-being. They are not intended to meet intensive health needs. Ask your doctor for advice regarding what services are available in your area. Alternatively contact your local **Commonwealth Carelink Centre** on **1800 052 222** or **Commonwealth Carer Resource Centre** on **1800 242 636**.

Other health services

Physiotherapy, podiatry, speech therapy and occupational therapy are available to assist people with dementia to stay as independent and mobile as possible and to give families and carers advice. Specialists in palliative care are also available to give you assistance. Continence advice is also available. Ask your doctor for advice regarding what services are available in your

area. Alternatively contact your local **Commonwealth Carelink Centre** on **1800 052 222** or **Commonwealth Carer Resource Centre** on **1800 242 636**.

Food services

Food services provide meals at home. Meals on Wheels service or other similar services may deliver meals daily to your door if you are unable to shop or cook. Ask your doctor for advice regarding what services are available in your area. Alternatively contact your local **Commonwealth Carelink Centre** on **1800 052 222** or **Commonwealth Carer Resource Centre** on **1800 242 636**.

Transport

In some areas local service provider organisations provide a small bus that may be able to help you with shopping trips.

Local taxi travel at reduced cost may also be available. Strict eligibility criteria apply and this is only given to those people who have a severe disability affecting their mobility. In some states and territories it is available to people with dementia.

If the person you are caring for has a severe mobility impairment and cannot safely use public transport, you should check with the department of transport or main roads department in your state or territory for information about applying for a disabled parking permit.

Contact your local **Commonwealth Carelink Centre** on **1800 052 222** or **Commonwealth Carer Resource Centre** on **1800 242 636** for more information.

Independent Living Centres

The Independent Living Centre in your state or territory offers several services designed to promote safe living.

There is a display showroom featuring, for example, personal alarm systems, safety furniture and a safety-modified bathroom and toilet. While items are not for sale through the centre they may be demonstrated with different brands and models.

Visits to the centres are by appointment only. You can also access their information and advisory service by telephone or by mail.

Printed handouts cover a wide range of equipment and services such as smoke detectors, hot water services and temperature regulators, and monitoring services. Advice is also available on home modifications and home design.

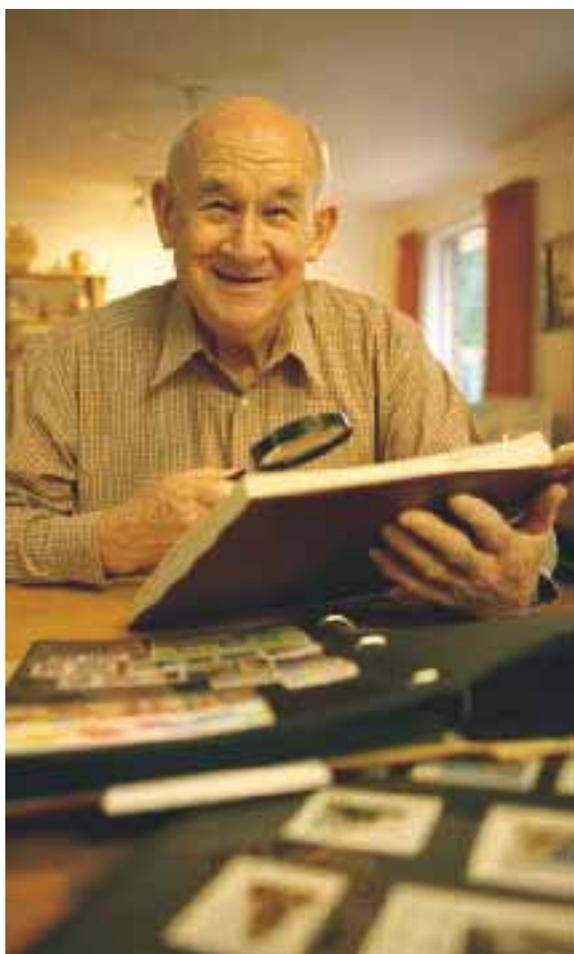
If you are in need but are unable to afford the commercial price of a product or service they may be able to refer you to a government or community organisation for assistance. Contact numbers for Independent Living Centres can be obtained from the telephone book, or by contacting your local

Information and services

Commonwealth Carelink Centre on 1800 052 222 or the **Commonwealth Carer Resource Centre on 1800 242 636**.

Community Care Packages

Sometimes people have a lot of different care needs and may need a number of services designed and coordinated especially for them. These are called packages and they are designed to help people stay in their homes by coordinating the different services they need.



Some packages that may be used by families, carers and people with dementia are:

- **Community Aged Care Packages (CACP)**
CACPs may be available to people who would otherwise require low-level care (i.e. hostel care).
- **Extended Aged Care at Home packages (EACH)**
EACH packages may be available to people with complex care needs who would otherwise require high-level care (i.e. nursing home care).
- **Linkages/community options**
Linkages packages may be available to people with complex care needs who would otherwise require high-level care (i.e. nursing home care).

You can get more information about packages or how to get an assessment to access these packages by contacting the **Aged and Community Care Information Line on 1800 500 853**.

Information in languages other than English

Translating and Interpreting Service

The Australian Government, through the Department of Immigration and Multicultural and Indigenous Affairs, provides a Translating and Interpreting Service (TIS) for people who do not speak English and for English speakers needing to communicate with them.

TIS is a national service and is available to any person or organisation in Australia requiring interpreting services.

TIS is available 24 hours a day, 7 days a week, and is accessible from anywhere in Australia for the cost of a local call. Just call **13 14 50**.

The Age Page

The Age Page is near the front of most telephone directories. It provides contact details for services in your area, including services for people from non-English speaking backgrounds.

Alzheimer's Australia Help Sheets

Alzheimer's Australia produces a range of Help Sheets containing advice, commonsense approaches and practical strategies. They cover the issues most commonly raised by people with dementia and their families and carers.

The most commonly requested Help Sheets are available in a range of community languages.

Contact the **National Dementia Helpline** on **1800 100 500** for copies. Help Sheets can also be obtained by visiting **www.alzheimers.org.au**

Commonwealth Carer Resource Centres

The Commonwealth Carer Resource Centres in each state and territory provide families and carers with practical written information to support them in their caring role. There is a wide range of information and much of it is available in community languages.

A free **Carer Support Kit** is available in English and other languages. In addition to general information, it includes information on taking care of yourself, managing health care and medications and emergency care. An **Indigenous Kit** is also available.

Contact the **Commonwealth Carer Resource Centre** on **1800 242 636**.

Centrelink

For Centrelink information over the phone in languages other than English, phone **13 12 02**.

Topic 4

Taking a break

In this topic

- How to take a break
- Who can help?
- Types of respite

How to take a break

If you are caring for someone with dementia it is important that you take regular breaks to keep up with important activities and to relax and recharge.

One way to do this is to arrange regular respite care for the person with dementia. Respite gives you a break from constant caring, which can be physically and emotionally demanding. Respite gives you time out for yourself and helps you return to your caring role refreshed. Respite can also have a positive effect for the person with dementia as it can introduce a variety of enjoyable and different activities and people.

Family and friends are sometimes available to take over from you for a while. When this is not possible there are services that can offer different types of respite care.

Some families and carers are reluctant to use respite because they may put their own well-being last or feel that it is all too much trouble. Sometimes they may want a break but the person with dementia doesn't. If you need extra

support to help you use respite services, staff at the Commonwealth Carer Respite Centre can help you.

While the change in environment can be initially disturbing to the person with dementia, they usually settle in. Many families and carers have found it helpful to start using regular respite as early as possible so that everyone can get used to sharing dementia care.

“Ensuring the person has respite care has enabled me to do things that had to be done. They could not have been done if I was providing 24-hour care, seven days a week, without a break.

“When my mother became more confused we didn't know we could get help. An uncle told us about the day respite at the community centre. Now they look after my mother on Mondays and Wednesdays. She likes going there because they all talk to her in her language.

“My mother's dementia is now advanced and as I am her only child I care for her at home. I have employed the next door neighbour, who is also Italian and has known my mother for many years, to help with her care and provide some respite for me. My mother also attends an Italian dementia-specific day program two days a week. This has worked really well for my family and for my mother.”

Who can help?

Commonwealth Carer Respite Centres

Commonwealth Carer Respite Centres can assist you to quickly find out what respite is available when you need to take a break from caring. The centres keep an up-to-date record of the organisations providing respite care and its availability.

Respite care may be for part of a day or longer and can be on a regular basis, for a special occasion or when there is an emergency. It can be provided in your own home, a community centre, or in a wide range of residential facilities.

Centre staff will assist you, where they can, to access respite care services. If you would like them to do so centres may act directly to get you the service you need. Contact the **Commonwealth Carer Respite Centre** on **1800 059 059**.

If you have concerns about using respite you can discuss this with the **National Dementia Behaviour Advisory Service** (NDBAS). This is a national telephone advisory service for families, carers and respite staff who are concerned about the behaviours of people with dementia. The service provides advice 24 hours a day, seven days a week and can be contacted on **1300 366 448**.

“I programmed the number of our Commonwealth Carer Respite Centre into my mobile phone. That way I don’t have to keep looking it up when I need to arrange a break.”

Aged Care Assessment Teams

The role of Aged Care Assessment Teams (ACATs) is to comprehensively assess the care needs of frail older people and refer them to the most appropriate care services available. They can work with other medical specialists to help in the assessment of dementia.

They assess eligibility for suitable care options to meet assessed needs and help to determine the level of care the person will need. They discuss which community services could help at home and help arrange access or referral to appropriate residential or community care, such as respite at home, in a day centre or residential care services.

The final decision is yours. You do not have to take their advice. Further information about the ACAT in your area can be obtained from **Commonwealth Carelink Centres** on **1800 052 222**.

Types of respite

Respite can take many forms: in-home, short- and long-term residential care and even breaks away together with the person with dementia but with additional support. The services try to meet your specific respite requirements.



In-home respite

People with dementia often do best in a familiar environment such as their own home or the home of a relative. The person is comfortable with those around them and the place they know. Relatives, friends and in-home respite services can provide in-home respite support.

“A lot of people have a block about using respite – they feel guilty letting someone else do the work, but in-home respite has given me a break and Mum has a great day out with her respite worker.”

“Having in-home respite care for my father has been a godsend. I have been able to keep my part-time job two days a week.”

Day respite centres

Day respite centres offer day respite from several hours to five days each week. Some services offer weekend or overnight care. The respite received depends on what the person with dementia needs and what the service can provide.

These services provide a program in a group setting, which may help the person to feel a sense of acceptance, satisfaction, well-being or enjoyment.

These programs aim to be helpful for both the person with dementia and their family members and carers.

“I do all the housework while my wife is at the day respite centre. This saves a lot of problems and it also enables me to give her more time when we are together.”

“Day care gives you time to get your thoughts together.”

Short-term residential respite

Some aged care homes admit people with dementia for a short-term stay while the carer has a holiday or break. Residential respite care may be used on a planned or emergency basis and can be provided in a low-level or high-level aged care home.

To be eligible you will need an assessment by an Aged Care Assessment Team.

You may have 63 days of respite care in a financial year, with the possibility of extensions of 21 days at a time if necessary.

Commonwealth Carer Respite Centres can provide information and assistance regarding accessing residential respite and can be contacted on **1800 059 059**.

If the person with dementia is an entitled veteran or war widow or war widower, or an Australian ex-prisoner of war, special benefits apply. For information about the Department of Veterans' Affairs respite care services contact your regional **Veterans' Home Care Agency** on **13 32 54**.

Emergency respite

It is important for your peace of mind to have a back-up plan in place in case of emergency. This could be your family, neighbours or a local service – but it needs to be talked about and planned in advance. You can always ask the Commonwealth Carer Respite Centre staff, who are available 24 hours a day, to assist you to find appropriate emergency respite.

An **Emergency Care Kit** is available free of charge from your **Commonwealth Carer Resource Centre** to help you plan in advance for an emergency. You can contact them on **1800 242 636** to request a kit.

Flexible residential respite

There are a number of options available through flexible residential respite so ring your local **Commonwealth Carer Respite Centre** on **1800 059 059** to find out local details. Services may include a short stay in an aged care home or a cottage that provides 24-hour care.

Some families and carers do not like to be separated from the person they care for but find they would both benefit from a break away from home. Many centres can arrange this by organising for you to stay in an accessible motel or holiday unit. Local care staff can be employed to provide a bit more help so that the break is refreshing for everyone.

“Ever since I mentioned the in-home respite to Mum, she was opposed to it. However, we managed to find a Polish-speaking worker to come and spend some time with Mum and, although it took her long time to accept her, Mum now really looks forward to going out with her.”

Topic 5

Looking after yourself

In this topic

- The importance of looking after yourself
- Your health
- Your feelings
- Stress and coping
- What is happening for you?
- How do you explain dementia to other people?
- Your friends and family
- Support from family
- Support from friends and neighbours
- Looking at your life
- Making it better for yourself
- Some suggestions for getting what you need



The importance of looking after yourself

Families and carers have to look after themselves or they can become physically and emotionally run down and find coping very difficult. Some people give up the activities they enjoy, including those involving family and friends, and they find themselves socially isolated and lonely.

Help depends on your personal circumstances, preferences and what is available in your local area. Many families and carers feel dealing with changes in their relationship with the person with dementia presents the most difficulty.

This topic is to help you recognise your needs and those times when you may need assistance from other people. This help may come from family or friends, your doctor, or somebody who is trained to talk over your worries and help you come up with solutions.

“To take care of the person you have to take care of yourself

“Carers must believe that they are entitled to a life too – if they want to care for a loved one, they must preserve time out for themselves free of guilt and worry.

“You don’t have to be alone; accept and keep realising that there are others that can help you.”

Your health

Every person's body has different strengths and weaknesses and enjoys different pleasures. Understanding how your body reacts to the demands of caring can help you to stay healthy.

What can you do to stay healthy?

- Go for regular walks.
- Watch your diet.
- Practise relaxation.
- Visit your doctor regularly.
- Keep in contact with friends.

Have regular medical and dental check ups to make sure your health is not deteriorating.

Your feelings

The constant demands of caring can affect your feelings or emotions.

These are some of the feelings that can surface from time to time. Perhaps you can add to the list.

| | | |
|--------------|----------------|--------------|
| guilt | anger | affection |
| frustration | sadness | love |
| helplessness | responsibility | loneliness |
| satisfaction | achievement | success |
| pleasure | support | appreciation |
| anxiety | happiness | resentment |

Because dementia is a progressive condition, many carers find that a feeling of loss remains with them through this progression. There can be many losses for families and carers – loss of the closeness and intimacy of the relationship, loss of the person they knew and perhaps a loss of career, friends and freedom. Many people don't accept these losses. Grief may remain long after the person dies.

This grieving may start when the person is diagnosed and continue after the person dies. When you care for, live with or care about a person who has dementia you become aware of the changes in the person as they lose their abilities, their personality and, you may believe, even their spirit. This may happen quickly, it can creep up slowly or there may be an incident that suddenly makes you aware.

You can be overcome with sadness for the person you once knew who is gradually slipping away from their body. You grieve for the person you have known so long who no longer remembers you.

You will experience many feelings during the time you care for the person with dementia. Most carers experience a mixture of feelings. For example, you may feel sorrow; you may feel miserable; you may feel numb. When you are grieving you may experience all these feelings as well as many others.

Looking after yourself

“When I realised he could not read any more, this was one of my tough times. I just seemed to be always ready to cry. I think this brought it home to me that I was so sad for him – reading the paper had been something he had always enjoyed. I was sad for myself, too, because he had always read out bits from the paper and we’d talk about them. I realised that was gone.”

It is important to talk over your feelings. There are trained people such as counsellors who will talk to you on the phone or arrange a face-to-face appointment. Discussions between you and a counsellor are confidential. You could call the **National Dementia Helpline** on **1800 100 500** or your **Commonwealth Carer Resource Centre** on **1800 242 636** for further information about making an appointment.

Stress and coping

Each person responds to the crises, demands and pressures of caring in his or her own way. Sometimes stress takes primarily a physical toll, leaving you tired and weary. For others, stress may impact emotionally making you feel down or teary. It is not always the large, significant events that cause stress, but the ongoing stress that is experienced every day.

Stress symptoms can take many forms. Some symptoms of stress may be:

- poor eating
- poor digestion
- headaches
- mood swings
- sudden anger
- being easily upset
- slowed thinking
- undue daydreaming.

Finding some strategies for dealing with stress may help you prevent more damaging stress and gives you the opportunity to control and manage your stress in the long term.

How have you coped with other difficulties in the past? Perhaps you:

- talked to friends
- had help from your family
- sought professional counselling
- used information from books and videos, or
- joined a support group.

“Support groups are our best friends. They are always ready to help each other. Just a phone call is a big help when you need to talk to someone.

“Don’t isolate yourself from your family, friends or the community.

“Continue with your existing hobbies or sports or attempt new ones.”

What is happening for you?

As the amount of care needed by the person with dementia increases, more time and energy will be needed from you.

It will help if you can balance your needs with the increased needs of the person with dementia. To do this you will need increasing support and assistance. This may come from your family, your friends, from local services and from you looking after yourself.

“This year has been OK, even though Bill needs much more care now. The nurses come every day to shower him. I have been able to go to the club every week and one of my friends always picks me up. When I feel down I go for a walk in the park. What really keeps me going is half an hour of music, when I just sit down with a cup of tea and relax while Bill has a sleep after lunch.”

“Most of our friends and people that we’ve met in Queensland have just faded away from us. All I have is one friend who has stuck with me, but I only see her occasionally. All my family and also my husband’s are in other countries so we are really on our own. I would cherish just a few moments with family at times. I have realised how important family is when you need some support. The only support I have is respite care two days a week. They are wonderful understanding people. It would ease my pain to have a little more support.”

How do you explain dementia to other people?

Many people do not understand dementia and how it affects somebody they know. This often means they stay away because of fear, embarrassment or just not knowing what to say.

Some ideas to explain dementia are:

- Tell friends and family as soon as possible.
- Take them to the doctor and let him or her explain it.
- Give them pamphlets explaining dementia from Alzheimer’s Australia.
- Lend them this book.
- Borrow books and videos from Alzheimer’s Australia.

“I tell people it’s like a jigsaw puzzle – you never know which piece is missing day by day.”

“People do look at you in a different light.”



Looking after yourself

Your friends and family

Your friends and relatives may react differently as the person with dementia changes. Some will continue to visit regularly and try to understand and help. Others will find it difficult to understand or are not able to accept what is happening. They often stop visiting.

Support from family

Some people have a lot of support, while others don't. The family may live in another state or another country. Others are very busy with their own lives and are unable to provide the support they may want to provide.

“My daughter is a great help. She will drop in for a cup of tea and a chat. Whenever she can she looks after Tom so that I can go shopping, but she has her own family too so I don't like to rely on her.”

“Hans, my son, says that I should put my husband into a home. He doesn't help and I usually feel upset after he visits. His brother mows the lawn and helps around the house. He seems to understand that I will make the decision when I am ready.”

Some family members may be a source of concern or even stress when you are caring. For example you may feel that young children and teenagers find it difficult to understand that the parent or

grandparent who they love has changed and treats them differently.

Here are some suggestions that might help with children and grandchildren:

Grandchildren and children can find the changes in memory and behaviour difficult to understand. They need to be told about dementia.

- Brain damage causes the changes.
- Their grandparent or parent will continue to lose their memory.
- Everyone in the family has noticed the changes too.
- Everyone feels sad that this is happening.
- The parent or grandparent can't remember how to do things, or they can't remember where they put things and this makes them confused and sometimes angry.
- It's no-one's fault.
- They can help by talking or listening to the grandparent or parent, especially about things in the past, by looking at the photo album, going for walks, by being a friend and not being angry or embarrassed when they do or say silly things.
- They can't catch dementia.

“My son has seen his grandfather change quickly this year. This has been hard for him. They have always been close because Dad has been the only father Greg has known, and he hasn’t coped with the changes very well. It’s got to the stage where Greg avoids visiting now. He seems embarrassed and is finding it hard to communicate with Dad.”

Support and advice on family issues is available from Alzheimer’s Australia, other carers or local service providers. You can also contact the **Commonwealth Carer Resource Centre** on **1800 242 636** for information, support and advice.

Support from friends and neighbours

Often friends drift away; but some families and carers find that the friendships become stronger as their need for support increases. Some people have very helpful neighbours; others find that their neighbours ignore them.

“I am amazed by the friendship that has been forged through this illness. We have lost a great many what we thought were close friends since my husband’s dementia was diagnosed. But certainly the ones we have made since are the true friends.”

“It was very hard for me to explain to our neighbours; they are only a young couple. But Tom has come and fixed the taps for me, and got the car started once when the battery was flat.”

Are your family, friends and neighbours providing enough support?

- Do they know what they can do to help you? Have you asked for the specific help you need?
- Do they understand about dementia and the effects on the person they know?
- Is it time to speak up for yourself so that the family knows what you want?

Information from this book may help these people to understand the changes and the behaviour of the person with dementia.. This could help them to be more understanding of the situation.

Where do you need help?

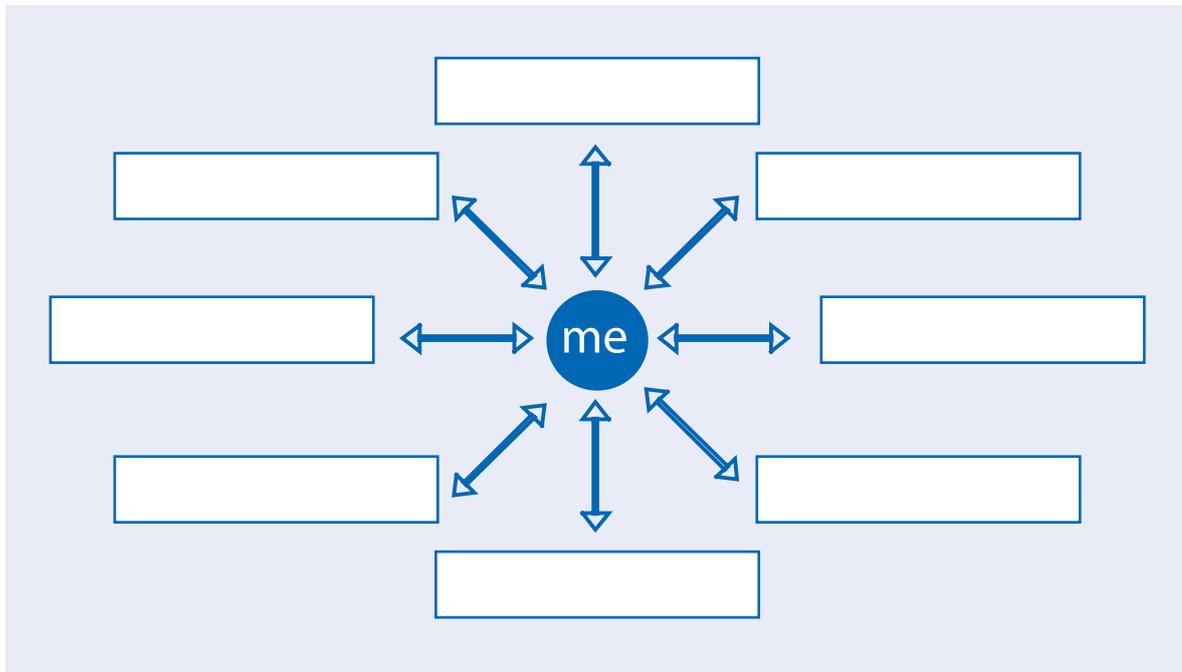
- Showering and lifting the person with dementia?
- Doing the housework?
- Feeling lonely?
- Mowing the lawn?
- Keeping the house and yard maintained?

Looking after yourself

- Running the farm?
- Feeling down?
- Managing incontinence?
- Taking time out from caring?
- Getting the shopping done?
- Cooking meals every day?
- Not being able to get the right advice?
- Not having the skills or knowledge that you need?

Those people who help in some way are part of your network. You are the person at the centre of this network. Who are the people who may give you help? This help can be friendship, help with housework, help with personal care for the person you care for, or help in other ways.

This diagram helps you to identify those people you can depend on in some way to help. You can fill in the boxes with names and the help they might give.



Looking at your life

You may find it difficult to continue to do the things you are doing because you will increasingly have more to do. For example, some people reduce the hours they work or stop work altogether to help the person remain safely at home.

Try listing your activities as **have to do** and **like to do**. You must keep some time for yourself. This may mean finding ways to balance those things you have to do with those things you like to do.

It's important that you continue with some of your **like to do** activities.

Sometimes the **have to** tasks can be done differently. For example:

- It might be possible to get home help with some household tasks.
- Organising regular attendance at the day respite centre for the person with dementia might give some time for yourself.

| | Have to do | Like to do |
|-------------------------|--|--|
| At home | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> |
| Outside my home | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> |
| With family | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> |
| Other activities | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> |

Looking after yourself

“I used to do all the washing and cleaning myself but now I get the help I need from the Home Help service.

“My mother shifted into the granny flat, but she really began to be more and more of a worry to me when I was at work.

“I am a primary school teacher in a very demanding job so I seemed to have two demanding jobs as well as my own family.

“I felt guilty because I never had time to listen to her and always seemed to be snapping at her. I just seemed to be rushing from work to home to look after my mother and the family.

“I became quite exhausted and got a very severe virus. So I decided to take six months leave and spend the time getting my mother organised with some services to help her during the day when I was at work.

“I’m glad I made the decision; I have been able to organise services for my mother. It has always been good to be able to spend this time with her.

“When February comes I will be able to return to work without feeling guilty and knowing Mum is looked after.”

Making it better for yourself

We all approach each day differently. We all have our own way of doing the work we have to do. Ask any group of people how they hang out washing. You will probably be surprised at the different rules people have for hanging up a shirt or shorts.

We also have our own rules for approaching the difficulties that we have and the sadness that comes into our lives in some way or another.

As you can change the way you do things, you can change the way you think and feel about things.

Having to live with and care for a person with dementia brings many feelings and lots to think about.

Family, friends and people from services can help you but it is only you who really knows your thoughts and feelings, your dreams and fears.

How you say things is affected by how you feel and think about them. It is hard to change the way we think and feel but we can change what we say.

If we think about the past or worry about the future we can miss out on what is happening for the moment, which is really all we can do something about.

The past has gone – we can’t change that. We really don’t know what is

around the corner – what the future will be really like – so we can't change that.

But we can change what we do right now what we think and feel right now. This may improve our future circumstances.

“One day I was feeling down – sitting there looking at my lovely wife who didn't even seem to know who I was, thinking about the holidays we had planned but wouldn't have, when Julie woke up. I asked her if she would like a cup of tea. She looked so happy and smiled and said, ‘yes, please’. I feel so good that I was able to make her happy and I thought I'm not going to make myself sad thinking about what we can't do; I'm just going to enjoy these moments that we have and enjoy. Doing this helped to keep me going while I cared for Julie for two and half years before she passed away.”

Sometimes we just think about what we haven't got or what we can't do and forget about what we have and what we can do.

“I've got a list on the fridge. Every time I think of something I want to achieve I write it down. It feels great to be able to cross them off when I've finished.

“I tried to find something funny in the most frustrating situations. Sometimes it was HARD!!”

“When I started looking after Norma I stopped seeing my mates. Now a couple come over on Saturday afternoon; we listen to the races and talk football. Norma wanders in and out but they seem to accept that okay. I don't feel so cut off now and it helps me to get through the week.”



Looking after yourself

Some suggestions for getting what you need

- Don't hesitate to ask for assistance.
- Talk to family and friends as openly as possibly.
- Join a support group – here you meet others who know what you are going through.
- Plan your visit to the doctor so that you can explain what you need.
- Use the support services of Alzheimer's Australia and Carers Australia.

Checklist of services that may be available for you

- Information
- Education
- Support groups
- Counselling
- Home help
- Home modifications
- Home nursing services
- Physiotherapy, podiatry, speech therapy, occupational therapy
- Food services such as Meals on Wheels
- Transport (bus or taxi)
- Medical aids such as incontinence pads
- In-home respite
- Day care
- Short-term residential care
- Emergency respite

Who could I contact?

**National Dementia Helpline
1800 100 500**

Commonwealth Carer Resource Centres 1800 242 636

Commonwealth Carer Respite Centres 1800 059 059

**Commonwealth Carelink Services
1800 052 222**

When am I going to do it?

Now!

When do you want someone to talk to you about getting some services?

As soon as possible.

How do I get the service I want?

Communicate your needs clearly

For example:

- “I need help on my bowls day, which is Thursday.”
- “Going out upsets my mother; someone must come to the house.”

Give important information to the service

For example:

- “My father doesn't like to talk much.”
- “Mum doesn't like a shower early in the morning.”

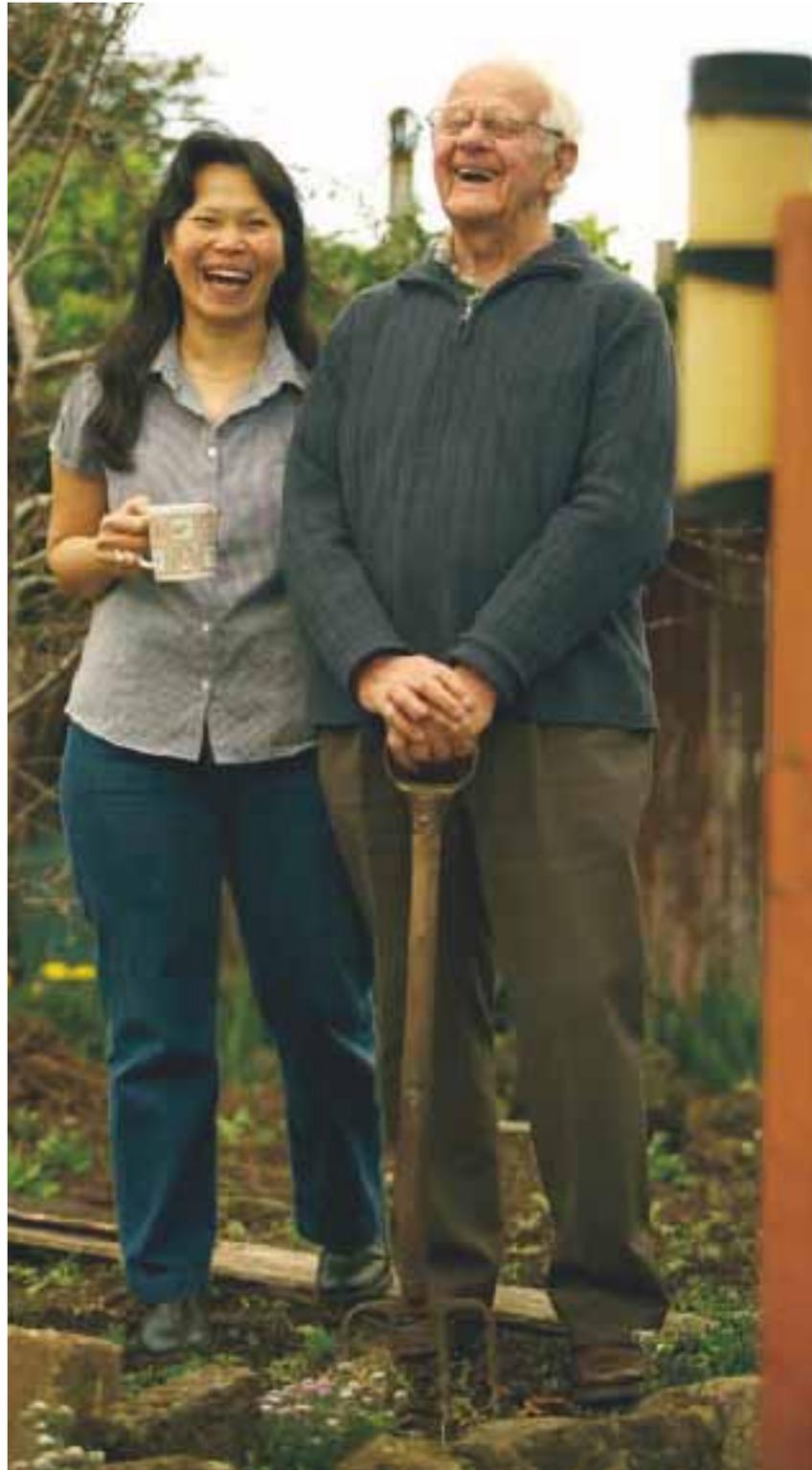
Explain to them what is most important to you about the service

For example:

- “Workers must be experienced.”
- “All workers must be female.”

Some questions to ask about the service

- What does the service do?
- When is the service available?
- Can I choose the time?
- Who will come? Do I have a choice of worker?
- How is the assessment done?
- How much service is available to me?
- Is there a cost? How much?
- What will be done for me?
- Can this be increased when my needs increase?
- When is the service reviewed?
- What is the review based on?
- If I have a concern or complaint, what do I do?



Topic 6

Living with a person with dementia

In this topic

- Driving
- Communication
- Activities
- Safety
- Hygiene
- Nutrition
- Contenance
- Sleeping
- Sexuality
- If behaviours become concerning
- Wandering
- Repetitive talk and actions
- Aggressive behaviour
- Suspicions and accusations
- Hallucinations
- Over-reactions

Dementia may not be easily recognised at first. In some cases it can be years before the abilities of the person deteriorates to the point where it causes noticeable difficulties. While the changes are not always noticeable, and can happen slowly, over the years people with dementia become progressively more affected.

The daily abilities of a person with dementia can vary. For example, the person may be able to remember or do things today that they couldn't yesterday. They may be more forgetful or argumentative in the afternoon or evening. Concentration, understanding and the ability to reason may deteriorate and the person with dementia may suffer confusion and distress as they struggle with the frustrations of everyday life.

Families and carers must find practical ways to support the person with dementia with their varying and progressively deteriorating abilities.

Alzheimer's Australia produces a large number of Help Sheets on a variety of dementia-related topics including caring for a person with dementia. Help Sheets can be obtained by calling the **National Dementia Helpline** on **1800 100 500** or by visiting Alzheimer's Australia at **www.alzheimers.org.au**

“I think carers of people with Alzheimer's would do well to try to look at the caring role in an objective way, but importantly still keep their love for the person, young or elderly, they are caring for. I know this is difficult but I think it saved me a lot of stress and frustration.”

Driving

Many carers worry about the person with dementia who continues to drive. Dementia produces a progressive and irreversible loss of mental functioning and will eventually affect the person's judgement and ability to drive safely. Some people will recognise their declining ability and be prepared, or even relieved, to be rid of the responsibility.

Unfortunately, others may not recognise that they can no longer drive safely, or may simply forget that they can no longer drive. Some people find giving up driving one of the hardest things to do. The car may be an important part of their independence, and without it their life will change. This can be a very difficult situation and needs to be handled sensitively.

In most states and territories, drivers must tell their licensing authority of any condition that might affect their ability to drive. Dementia is one of the medical conditions that needs to be disclosed because it may affect a person's driving ability.

- The licensing authority will generally advise the driver to see a doctor who will assess whether it is safe to keep driving for a period of time. If the doctor determines that dementia is affecting the person's ability to drive, then the licensing authority can place conditions on their licence. Regular medical and driving tests might be required.
- The doctor may also recommend to the licensing authority that the person with dementia have neuro-psychological or occupational therapy assessment if the driving skills are in question.

Ideas

- The licensing authority in your state or territory can advise you of the steps that need to be taken when dementia has been diagnosed.
- Consider ensuring that a family member or friend drive with the person with dementia at least monthly to monitor driving and safety.
- Ask your doctor to talk to the person about their driving.
- A letter from the doctor or licensing authority may help the person accept the decision.
- Suggest good reasons for using public transport, or having someone else drive, such as being less stressful, enjoying the scenery and saving on the cost of running a car.
- Arrange outings that do not require the car to be driven.
- If safety is a major concern, hide the car keys or immobilise the car.
- Removing the car and selling it if it is no longer needed may reduce frustration.

Living with a person with dementia

Communication

Losing the ability to communicate can be one of the most frustrating problems for a person with dementia. Some changes in communication you might notice include difficulty finding the right word, not being able to understand all of what is being said or difficulty expressing emotions appropriately. Reading and writing skills may deteriorate and there may also be age-related problems with vision and hearing.

Ideas

- Don't rush; always allow plenty of time.
- Keep sentences short and simple.
- Try to avoid conversations that include a lot of questions that need to be answered.
- Consider using hand and facial gestures to help understanding.
- Try to avoid background noise such as TV or radio.
- Encourage groups and workers to use name tags to help with identifying people and their purpose.

“When the respite worker started to visit us, my husband would not let the worker in the house. He did not understand why she was visiting. He did not think she was a worker and did not recognise her as someone familiar. However, once this was realised and the worker started to wear a name tag and uniform, he politely greeted her and invited her in.”

“My husband is from Holland. We married in Indonesia. He had some strokes and now can't remember English. It is very difficult to communicate with him, as I have never learnt Dutch.

“The social worker brought a man to visit who speaks Dutch but my husband can't understand him either.”

Activities

Most people with dementia will need some assistance to carry out the activities that provide them with pleasure and enjoyment. It is important that activities promote the self-esteem of the person with dementia and maintain the skills that they still have.

What is important and enjoyable in the life of the person with dementia?

For example:

- Playing pool
- Listening to music
- Playing cards
- Travelling

Who have been the important family members and friends?

For example:

- Friends from the bowls club
- Grandchildren
- Neighbours
- Colleagues from work

Ideas

- Make use of abilities that have not been forgotten. Perhaps they can still help around the house by washing up or working in the garden.
- Make activities simple and unhurried.
- Don't let activities increase stress.
- People with dementia will have some times of the day when they perform better than others. Similarly their abilities may vary from day to day. Take this into account when organising activities.
- Many people with dementia do not enjoy crowds or noisy environments.
- If reading has deteriorated use a Walkman to listen to recorded messages or books.
- Sensory experiences, such as massage, stroking an animal or brushing hair, can be enjoyable for people whose abilities have deteriorated.



Living with a person with dementia

“I let him handle what he wants to do and then fix it afterwards, such as setting the table, doing the dishes and making the bed.

“I noticed changes in my father’s behaviour. He was always a happy, easygoing person who liked playing golf with his friends, picnics at the beach and photography. He began to have trouble keeping score at golf.

“At first this caused trouble at the club and he talked about giving it away.

“One of his friends seemed to realise what was happening and made sure they always played together. Dad was able to play golf for several more years because of this friend. He doesn’t play now but this help made a lot of difference for Dad at the time.

“The friend still calls in occasionally and while Dad doesn’t remember much about golf he enjoys hearing stories of the games they played.”

“We play Crib and although Mum’s long-term memory is about 20% her knowledge of Crib is about 80%. She has forgotten my father’s name but remembers the Crib he brought her.”

“I made a photo album of grandfather’s life from the time he came from Italy. Looking at it is his favourite pastime.”

“Mix young grandchildren, bubble blowing equipment and Granny. Allow lots of time, joy and laughter.

“She likes being busy in the kitchen. She can’t help much any more but she’ll spend hours peeling potatoes and setting and unsetting the table if you let her. It’s the same with the washing. I’ll hang it on the line and she’ll come along behind and take it straight down again.

“She really likes doing the things she has always done. She seems much more contented when she can be ‘busy’ around the house.

“Music is important. Old songs are not forgotten and bring back lovely memories.

“I’ve noticed lately that she likes things like having her hair combed, being told that she looks good and being taken on picnics to the beach

“My kids are very good with her, and as they walk along the beach she seems to enjoy it so much. It’s as if she hasn’t been to the beach before.”

Safety

Your safety, and the safety of the person you are caring for, is important. People with dementia function best in structured, quiet and uncluttered surroundings. Sometimes the layout, appliances and amenities of the home may have to be modified to make it safe for the person with dementia.

The Independent Living Centre in your state or territory offers several services designed to promote safe living. Contact numbers for Independent Living Centres can be obtained from the telephone book, or by contacting your local **Commonwealth Carelink Centre** on **1800 052 222** or the **Commonwealth Carer Resource Centre** on **1800 242 636**.



Ideas

- Remove loose mats, power cords and extension leads from the floors.
- Night-lights in the hallway and in the toilet may help in finding the way safely at night.
- Automatic cut-offs for hot water jugs and other appliances are recommended.
- Place rails in the bathroom, toilet and next to the stairs.
- Replace potentially dangerous forms of heating such as bar heaters with safer heaters like column heaters.
- Make sure smoke detectors are installed and regularly checked.
- Check safety in the front and back yards. Keep paths well swept and check gate catches.
- If you are lifting the person, make sure you get professional advice about how to do this safely, and about any aids that can help you. Back injuries often occur with unsafe lifting techniques.

Living with a person with dementia

Hygiene

It is quite common for people with dementia to forget or lose interest in bathing or changing their clothes. Hygiene is sometimes a point of great conflict between a carer and a person with dementia.

Ideas

- Make sure that a person's need for privacy is considered when undressing and bathing. Pull down blinds and close curtains and doors.
- Keep bathing and showering simple. Explain each step.
- Make sure that the bathroom is warm and comfortable.
- Provide a safe environment by using non-slip mats, hand rails or a shower chair.
- Try to develop a regular routine.
- Arrange regular visits to the dentist to check on teeth, gums or dentures. You may need to help with teeth or denture cleaning, or even do it yourself.
- Remember that it is not always necessary to shower or bathe daily, unless the person is incontinent. Frequent washing can compromise the skin integrity of elderly people. In past times many people did not bathe as often as they do today.

“Try to be relaxed and calm. This helps mother to also be calm. My facial expression, tone of voice and friendly chatter can all help – especially when Mum’s bathing, dressing and eating.”

“My father originally came from Vietnam and I have sacrificed a lot of my needs to care for him. We have some help with showering, but I do most of the things for him. Even though father has dementia he still makes all the decisions, because that is how it needs to be. My mother has limited English and she is worried what will happen in the future.”



Nutrition

For families and carers maintaining good nutrition can present extra challenges. The person with dementia may suffer from a loss of appetite, forget how to chew or swallow or fail to recognise the food or drink they are given. Some people may develop an insatiable appetite, a craving for sweets or suffer from dry mouth or mouth discomfort.

Ideas

- Meals should be shared social occasions whenever possible.
- Stock up on healthy snacks such as yoghurt, cheese or dried fruit that do not need preparation or cooking.
- Prepare a plate of nutritious food that can be picked up in the fingers.
- Don't use complicated table settings.
- Allow time for the memory to respond to food.
- Serve only one plate of food at a time.

A dietician or doctor can advise you about nutrition. If there are swallowing difficulties an assessment by a speech therapist, who may also provide appropriate strategies, is suggested.

Continence

Incontinence can be very distressing for both of you. Make sure that a medical assessment is carried out because there are many causes of incontinence that anyone can develop and which are easily treatable. Common incontinence problems can be associated with constipation, urinary tract infection or diabetes. Incontinence can often be treated.

Ideas

- Be sure that the person is drinking adequate fluids.
- Consider limiting caffeine intake. Substitute other liquids or decaffeinated drinks.
- Encourage using the toilet before and after meals, before bed and on waking.
- Use clothes that can be easily manipulated such as elastic waist on trousers and loose-fitting dresses and under garments.
- Place signs leading to the toilet and fix a picture on the toilet door as a further cue.
- Make sure that there is good night lighting so that the toilet can be found easily.
- Absorbent pads, absorbent sheets and waterproof underlays on chairs and the bed will help to reduce laundry.

Living with a person with dementia

Free professional and confidential advice is available from the **National Continence Foundation of Australia**. Contact their Helpline on **1800 330 066** or visit **www.confound.org.au**

The Helpline has a range of brochures available about incontinence and these are available in community languages, as well as English. A range of materials about incontinence designed for Aboriginal and Torres Strait Islander communities is also available.

The **National Public Toilet Map** website identifies the locations of over 13,000 public toilet facilities across Australia. It includes information about each toilet facility such as opening hours and access for people with a disability. This information is available at **www.toiletmap.gov.au**

This is an interactive site with the ability to search for requested streets, parks, suburbs or towns and to show the location of public toilets in a selected area. People who do not have access to the Internet may obtain copies of specific maps by contacting the **National Continence Helpline** on **1800 330 066**.

Sleeping

Sleeping problems are common for people with dementia. Their sleeping habits may change so that they sleep during the day and stay awake at night. Some older people wake during the

night to use the toilet, but a person with dementia who is disorientated with the time may not return to bed. Many will need less sleep with advancing age and reduced activities.

Ideas

- It can be helpful to keep a diary to see if a pattern of behaviour is developing.
- Discuss sleeping problems with your doctor. Stopping or changing medications may be contributing to the problem. The doctor can also arrange a medical check-up to identify and treat any physical ailments, or any side-effects of medications.
- Depression can cause problems with sleeping. Ask your doctor if an assessment is necessary.
- Have set, regular times for bed.
- Make sure that the bedroom is comfortable – warm and adequately lit, and that the person is able to find the toilet at night. Consider using a night-light.
- Cut down on alcohol and caffeine.
- Try a light snack, a herbal tea or warm milk before bed.
- Encourage the person back to bed and reorientate in relation to the time.

Sexuality

Sexual behaviour may be affected by dementia just as many other behaviours are affected.

Older people do have sexual feelings and responses. Intimacy is a source of comfort and well-being for many elderly adults.

Both a decline and an increase in sexual activity can be equally disturbing for a partner of a person with dementia.

“We always had a close relationship and sex was very enjoyable. Now this is being affected. He sometimes looks at me when we are together as if he doesn’t recognise me or isn’t sure what to say. It’s upsetting to see him change like this. I try not to let him notice but it is not the same as it once was.”

People with dementia may develop inappropriate sexual behaviour for several reasons.

- They may be unaware that the behaviour is inappropriate in that setting.
- They may need to release tension or to relieve anxiety and contribute to general well-being.
- They may express a need for comfort if they are feeling isolated or insecure.

Sexuality can be a difficult issue to discuss but it is important and should

be dealt with frankly for the benefit of the person with dementia as well as the family and carer.

Discussing the matter with a counsellor can be helpful and is recommended.

Assistance can be provided by contacting the **National Dementia Helpline** on **1800 100 500**.



Living with a person with dementia

If behaviours become concerning

All behaviour is a response to circumstances, events, feelings and the environment. It is the same for the person with dementia. However, due to changes in brain function they may be unable to fully understand or communicate the reasons for the behaviour. Some factors that affect the person's behaviour are:

- the type of dementia
- the level of impairment
- past and present skills and abilities
- their personality
- the skills and motivation of people around them.

Within these factors are “triggers” which may set off a response in the person with dementia.

These behaviours are sometimes called “behaviours of concern” or “challenging behaviours”.

Behaviours can become concerning for a number of reasons:

- The health and safety of the person with dementia is affected.
- They cause stress for families and carers.
- The health and safety of other people is affected.

Problem-solving approach

When faced with behaviours of concern, some families and carers:

- ask for help from professionals
- talk it over with friends
- get information from books
- join a support group
- manage by themselves one day at a time, or
- do all of the above.

The **National Dementia Behaviour Advisory Service (NDBAS)** is a national telephone advisory service for families, carers and respite staff who are concerned about the behaviours of people with dementia. The service provides advice 24 hours a day, seven days a week and can be contacted on **1300 366 448**.

Managing a behaviour of concern is rarely simple. However, finding a successful solution to managing it may be helped by a problem-solving approach.

There are three steps to this problem-solving approach. The steps are as follows, and are demonstrated in the tables on the next page.

- 1. Defining the behaviour**
- 2. Looking for triggers**
- 3. Developing a plan**

Step 1 – Defining the behaviour

- What is the behaviour you are concerned about?
- What happens just before and after the behaviour?
- Who is affected?
- When does the behaviour occur?
- Where does it occur?
- How do you or others usually respond and what is the effect?
- Are there any strategies or tactics people have used which result in less of the behaviour?
- Is the behaviour causing a risk of harm to themselves or others? If it becomes an emergency call the police or ambulance. If not, talk to the doctor about your concerns.

Step 2 – Looking for triggers

Why might the problem be occurring?

- Physical health
- Communication
- Environment
- Task
- Past history

NDBAS can give you an understanding of each of these factors and how they may contribute to concerning behaviour.

Step 3 – Developing a plan

For suggestions of appropriate strategies, contact NDBAS or talk with the doctor.

The plan

- What are the strategies you will try?
- Try one strategy at a time to gauge the effectiveness. Try it for 3–4 weeks.
- Record the effect of the strategy. If the behaviour worsens, stop the strategy. Wait 3–4 weeks to compare the behaviour.
- Compare the behaviour now with how it was before strategies commenced. If the behaviour has reduced to a level that is acceptable, continue the current strategy.

Remember that no one strategy is going to work for any one problem. Each situation has to be assessed individually and strategies developed for that person with dementia.

If the concerning behaviour continues at a level which is unacceptable, talk to the doctor and/or seek assistance from the NDBAS before returning to Step 2 of the process.

Living with a person with dementia

Wandering

This may occur for various reasons:

- becoming lost or disoriented
- looking for people or places from the past
- enjoyment of walking
- discomfort such as tight clothes or wanting to find a toilet
- physical changes which have occurred in the brain that may cause a feeling of restlessness and anxiety
- being bored, restless or upset.

Ideas

- Look for a pattern to the wandering. Is it aimless wandering, agitated pacing, or wandering away?
- Look for a reason. Is the person disoriented or confused? Does he or she believe there is something they have to do?
- Exercise such as walking may help if the person is bored.
- Take the person for regular visits to favourite places.
- If the person is seeking something or someone from their past or feels they have a task to perform, then alternative activities to meet these needs could be planned.

Precautions to take

- Try a lock on the gate and make the garden a safe spot.
- Make sure the person always has identification with them.
- Advise neighbours about the wandering, and ask them to let you know if they notice him or her wandering.
- Have a recent photograph to give to the police in case the person gets lost.

Alzheimer's Australia has developed the following Help Cards to assist people with dementia, their families and carers. Contact the **National Dementia Helpline** on **1800 100 500** for these cards, which are free of charge.

- **Card for people with early stage dementia** who may need help and understanding at certain times – for example, in shops or on public transport.
- **Identification card.** This card shows a person's name and address as well as contact details for an emergency situation.
- **Companion card.** This card assists family members and carers by briefly explaining dementia and the way it can affect a person's behaviour.



Repetitive talk and actions

People with dementia may repeat actions and may constantly ask questions or say the same things. Families and carers can find repetitive actions and talk very frustrating.

Causes can include forgetting they have just asked a question, anxiety, forgetting the answer, insecurity, and being confused by people, places or events.

Ideas

- Have the doctor check for a medical condition or medication side effects.
- Distract the person with other enjoyable activities.
- Avoid reminding the person that they have asked the questions.
- Use memory aids for people who can read, such as a daily schedule.
- Try giving a different response or turning the questions into a discussion.
- If the person has lost the ability it may be best not to discuss plans until necessary.
- Try to understand why the person is repeating the question or behaviour. Responding to the underlying behaviour might help.
- Use respite care to give yourself a regular break.

Aggressive behaviour

A person with dementia in some circumstances may be verbally abusive or become aggressive to the point of physical violence. This may occur when the person is misunderstood or provoked.

Attempts to physically restrain an aggressive person may produce a violent response. Causes can include reactions to humiliating situations or people, frustration at not being able to complete a task, fear of unfamiliar surroundings or situations and reactions to the behaviour of others.

Ideas to prevent the behaviour

- Have the doctor check for a medical condition or medication side effects.
- Avoid putting the person in situations that may produce anxiety, fear or disorientation.
- Try to prepare the person by explaining what is going to happen or where you are going.
- Try to avoid arguments. It can be better to agree with what the person says or does and then try distraction or humour or provide friendly help.
- Try to use encouragement, praise and affection rather than criticism, anger or frustration.
- Be aware of any warning signs that the person is becoming agitated.
- Ensure your own protection; leave the room or house and go to a safe place until the outburst is over.

Living with a person with dementia

Ideas to respond to the behaviour

- Do not try to restrain the person. Avoid approaching until the person has settled down; stay out of reach.
- Try to avoid making the situation worse by shouting, abusing or touching the person.
- Try reacting in a calm voice or with reassuring words.
- Give the person time to settle down.
- Avoid punishment after the event. The person is unlikely to remember what happened and the punishment won't have a helpful effect.
- Try to remember that it is the illness and not the person causing the behaviour.
- Seek assistance from a professional such as a doctor or a counsellor if you feel the need to respond with aggression.

Ideas

- Check that the suspicions are incorrect.
- Try not to take false accusations personally. These accusations are associated with the brain damage and are not able to be controlled by the person with dementia.
- Try to keep the environment as familiar as possible.
- If possible keep a spare set of things that are often mislaid, such as keys or a wallet or purse.
- Distractions may help.
- Try to learn the person's favourite hiding places.
- Try to identify any pattern to the behaviour, such as accusations about a particular person, or the time of day it usually occurs. This may give some clues about why it happens – and what to do about it.

Suspicions and accusations

As the person with dementia becomes increasingly forgetful or confused, he or she may misplace or lose possessions or be unable to recognise familiar people or objects.

Others may be accused of stealing their money or other possessions. Other accusations can be linked to personal relationships such as the claim that their partner is being unfaithful. They may become confused and accuse their partner of being someone else.

Hallucinations

Having hallucinations means seeing or hearing things that are not there. Hallucinations can make the person frightened or agitated. Sometimes people with dementia may misinterpret or misidentify people or objects and this is not hallucinations.

Some hallucinations may be ignored if they are harmless and do not cause the person to be distressed. They may reflect underlying feelings. Try to identify what these might be.

Ideas

- Have vision and hearing checked.
- Have the doctor check for a medical condition or medication side effects.
- Ensure that rooms are well lit and there are no shadows that can be mistaken for objects.
- If the person seems frightened, quietly reassure them.
- Encourage the person to explain what they are seeing or hearing, and discuss this with them.

control and they are possibly quite frightened by it. They need your reassurance even though it may not appear that way.

The **National Dementia Behaviour Advisory Service (NDBAS)** is a national telephone advisory service for families, carers and respite staff who are concerned about the behaviours of people with dementia. **The service provides advice 24 hours a day, seven days a week and can be contacted on 1300 366 448.**

Over-reactions

You may find that a person with dementia may sometimes over-react to a trivial setback or a minor criticism. They may become very agitated or stubborn, scream, shout, make unreasonable accusations or laugh or cry uncontrollably.

This tendency to over-react is part of the disease.

Coping with this behaviour can be very difficult and is often a matter of trial and error. Remember that the behaviour is not deliberate; it is out of the person's

Topic 7

Preparing for residential care

In this topic

- Reasons for residential care
- Residential care: options for people with dementia
- Arranging an assessment
- The importance of planning and preparation
- Planning for the possible move
- Residential care decision-making checklist
- Residents' rights and responsibilities
- Mixed feelings

A time may come when the person with dementia could need to move into a residential care facility.

If or when this actually happens may depend on your circumstances, the services available, your health and the health of the person with dementia.

These decisions can be difficult and it can be a very emotional time.

Planning for the changes and involving the person concerned may make this a little easier.

“The progression of the dementia has required my mother to be admitted to a nursing home. Even as this brings some sorrow I don’t feel guilty as I was able to give my mother six years of comparative comfort and, in the early stages, some happiness.

“Being able to let go – this is an on-going problem for the carer – to let go for day care, let go for respite care and later let go for nursing home placement. Do not feel guilty as you allow the person to be helped by other people in these areas.”

Reasons for residential care

There are many reasons why people with dementia may move to a residential care facility. Some of them are:

The health of the person with dementia

- Doubly incontinent
- Unable to get out of bed

The behaviour of the person with dementia

- Aggression
- Can’t find his or her way from room to room
- Often lost or wandering

The health of family members and carers

- General health problems
- Newly diagnosed illness
- Accidents or operations

The well-being of family members or carers

- Breakdown caused by the 24-hour per day caring role
- Physically unable to keep doing the work
- Competing family demands

Housing is not suitable**Services needed are no longer available in the local community****The amount of service needed is not possible****Residential care: options for people with dementia**

Most people with dementia live in the community. However residential care is available as an option for people who cannot live at home and who have been assessed by an Aged Care Assessment Team (ACAT) as needing this type of care.

There are two broad types of care facilities – low-level and high-level care.

Low level care facilities (formerly known as hostels) generally provide accommodation and personal care, such as help with dressing and showering, together with occasional nursing care.

High-level care facilities (formerly known as nursing homes) care for people with a greater degree of frailty, who often need continuous nursing care.

Specific dementia units are designed especially for people with dementia and can be classed as either low-level or high-level depending on the level of care needed. Not all people with dementia require a specific dementia unit.

While the Australian Government provides substantial funding to residential facilities to assist with the costs associated with providing care, most residents will also pay a number of fees and charges to their residential aged care home.

The types of fees and charges payable are prescribed by the Government. These fall into two categories:

- daily care fees
- accommodation payments.

The amount you can be asked to pay depends on your income and assets.

For more information regarding fees and charges contact the **Aged Care and Community Care Information Line** on **1800 500 853**.



Arranging an assessment

Before a person can enter a residential care facility an Aged Care Assessment Team (ACAT) must assess them for eligibility. ACATs are teams of health professionals, such as doctors, nurses or social workers, which provide information, advice and assistance to older people who are having difficulty living at home.

They will visit people in their homes or in hospital and ask a series of questions about the person's lifestyle and health needs. After the assessment they will discuss the results with you so that together you can decide on the right type of residential facility to best suit the needs of the person with dementia.

ACAT assessments are free and approvals for residential care are valid for 12 months from the date the ACAT member signs the assessment form.

“Since Christmas my husband has been going into respite care for up to nine weeks per year. Though assessed for full-time nursing home care we have not taken up this option yet but there are not many beds available in the area and long waiting lists.

“My children are divided in acceptance of their father going into permanent care, although he's almost 83 and only shuffles about. Ultimately the decision will have to be mine; I acknowledge this but it is a hard decision to make.”

The importance of planning and preparation

As dementia progresses the level of care becomes even more intensive and demands on the time of families and carers increase.

The care of the person with dementia usually becomes increasingly shared between family, carers and the service organisations. For many reasons, the balance of care may move to the person with dementia needing to be cared for in an aged care home.

Many families and carers find this decision very difficult.

- The situation may have been developed quickly and they haven't prepared for the possibility.
- There may be conflict about it within the family.
- There is concern that the care for their vulnerable family member may not be good enough.
- Within the community there is often a negative view of aged care homes.
- They feel that they will be seen as not caring and that they may be “dumping” the person with dementia.
- They may have made promises to the person that can longer be kept.
- They may compare themselves to other families who seem to cope better, either now, or in “the good old days” or in the old country.



Preparing for residential care

These difficulties are very real for families and carers. If you are facing difficulties, it might help to discuss what is actually happening and what is possible.

Preparation and planning for the time when permanent care is a serious consideration will help to make the transition easier for families, carers and the person with dementia. Options can be considered, comparisons drawn and decisions can be made unhurriedly.

The most difficult situations are when this placement occurs unexpectedly because of a crisis. The feelings of loss, the shock and the grief become very difficult to deal with. These emotional responses can be stronger if you don't have time to prepare and adjust.

Planning for the possible move

A move to a residential facility will take the person into unfamiliar situations that can be confusing and frightening.

People with dementia can be disturbed by the change. However, with careful planning, sensitive handling of the transition, and supportive staff attitudes and behaviours, they generally adjust over time.

When residential care is being considered, planning that involves the family, carers and health care workers

is important to make the transition as smooth as possible.

In planning the move families and carers can explore questions such as:

- What residential facility is available?
- What lies ahead and how can I prepare the person with dementia and myself for it?
- What information will help me to make decisions?
- Where do I go to get the advice or information I need?
- How can I make sure that he or she will be receiving the best possible care?
- How will I know when the time is right?
- How can I continue to care when he or she goes into a residential facility?

Assistance is available to families and carers to answer these and other questions. If you have been through the assessment process you will have had an opportunity to discuss your concerns with the ACAT. Other people who may offer advice and support are families and carers who have already been through the process, support group members, counsellors at Alzheimer's Australia and Carers Australia and residential care staff.

"I know very well that I will have to face up to permanent care for my wife. I have already planned this with the appropriate people."

Preparing for residential care

Residential care decision-making checklist

The ACAT will probably suggest that you look at a number of facilities. Take time to consider how each one will meet the needs of the person with dementia. Take a checklist like the one below with you each time you visit a residential facility.

When you are looking at a residential facility, here are some items you may like to consider:

- What is the attitude of managers and workers – do they listen to you and ask for information?
- Does it feel like a friendly, welcoming place?
- Is there somewhere to sit privately?
- Is it OK for you to come to help with eating or showering?
- Are you satisfied with day-to-day care issues such as food, access to bathroom, temperature control?
- Can the person have his or her own doctor?
- Are you satisfied with medical services and specialist services?
- What is the medication policy?
- What procedures are in place in the event of a fire?
- Is there at least one person on duty at all times?
- Has the fee structure been fully explained – are there extra costs?
- What are the individual resident's rights – own belongings, pets, mail, religious beliefs?
- Are you satisfied with visiting times, access for family members?
- Can outings, overnight stays and holidays with family members be easily arranged?
- Do other residents appear well cared for?
- Does anyone speak the language of the person with dementia?
- Are other services, such as hairdressing and massage, provided?
- Is there assistance for you and the person with dementia in preparing for the move?
- Will you be asked for suggestions and comments?
- Is there a policy for having your concerns looked into?
- Are surroundings such as buildings, grounds and individual rooms suitable?
- What training have staff had?
- Can you join a committee of residents and relatives?

Most residential aged care homes have waiting lists and how long you will have to wait varies from home to home.



Residents' rights and responsibilities

The rights and responsibilities of all residents of residential care facilities are the same in every facility. To ensure the protection of these rights and responsibilities, they have been included in the legislation that all Australian Government funded residential care facilities must abide by as a Charter of Residents' Rights and Responsibilities. You can get a copy of the Charter from the residential facility you are helping the person move into, and it should be displayed prominently within all residential care facilities.

An advocacy service in each state and territory provides information, support and advice regarding rights and responsibilities in residential facilities. Contact the **Aged and Community Care Information Line** on **1800 500 853** for details of the organisations in your state or territory.

“My mother, Gwen, is 86 and in fine health. Her blood pressure is 120/80, her only serious hospital admissions were for childbirth (no complications) and, up until recently, she was a pack-a-day smoker for about 60 years. As a former quiz show champion in the 1960s, Gwen can still tell all about the life story of Elizabeth of Glamis when I present her with a rose of that name.

“Yet, Gwen needs full-time care. In her mind, she still lives in Bondi and her sons and husband (or is it her brothers and father?) will be home soon and she needs to get their dinner on. Or it's 1944, she's at work at Tooth's Kent Brewery, and worried she's not up to the job.

“Gwen has severe and worsening dementia. She now permanently resides in a dementia-specific facility that has a policy of no restraints and avoids medications that sedate the residents. What's lacking in medication is provided for with activities, smiles, laughter and outings. Even a visit to the snow is under consideration.

“Every Friday I visit and play bingo with Gwen and a dozen or so other 'residents'. Gwen nods off while I play and if we win I wake her and say 'Call out bingo Mum!' and she responds 'Why?'

Preparing for residential care

“Occasionally, she’ll come out with comments like ‘34, I don’t like 34’ or ‘That’s a nice number, I’ve always liked 28’. Of course I agree with her, because I know she was great at mental arithmetic, so the concept of ‘nice numbers’ stems from a lifetime of account keeping without the benefit of even a hand held calculator.

“We don’t know why or when her dementia started. Looking back, one can see the signs were there earlier than we first thought.

“When I look around at bingo, the course of this illness is extremely diverse. Some of the other residents can seem very lucid, but within weeks they seem to decline to incoherency and immobility

“Leon. With his jaunty tweed trilby and a stylish walking stick, he’s always late for bingo because he needs to ensure he is properly attired for the day. Slipping seamlessly from Russian to English, he’s prone to aggression if things don’t go well. I give him a wide berth but love his style.

“Then there’s Peter, a handsome Greek who loves to flirt and feign incompetence to get my attention. Once when I told him I had two young children he declared ‘Why only two!’ and, raising his fist in the air, ‘I give my wife seven children!’ I was

impressed with this display of macho self-confidence but it was tamed slightly by his age, his wheelchair and the checked woollen knee rug. And of, course, his dementia.

“While causing each of them to obviously suffer and deteriorate, dementia still opens a window on some incredibly interesting people. It’s a view finder that focuses on someone’s personality, their history, their idiosyncrasies but not the sorts of information we normally see as essential. I feel very honoured to sit at Friday bingo and watch these wonderful revelations, while they are unable to tell me their name much less a pin number.

“Every week when I visit Gwen, I first remind her who am, that we’re going to play bingo, that she won’t be late for work and, of course, she’ll be home in time to cook the boys’ tea. I’m grateful we have this time together and dementia has let me get to know her so well. I’m grateful that the care she receives, rather than demeaning her, is wonderfully nurturing and respectful of these people and their diversity. It has given my mother such worth in a world where she no longer can function.”

Mixed feelings

Families and carers often feel up and down emotions. For example they can feel happy that the person with dementia will be looked after in the best place for him or her, but sad and lonely at their own loss.

This can feel like a rollercoaster ride when you are not able to predict how you might feel each day. You may cry or laugh, feel angry, sad or just feel numb. These feelings can take all your energy and leave you quite drained.

Here are some feelings that families and carers have experienced:

- Relief that the person is getting the needed care
- Worry that they might not be looked after
- Pride in the job they've done
- Upset at feeling a failure (“ I could have coped better”)
- A sense of freedom
- Guilty because you had promised to always look after the person yourself
- Lonely, just missing the person with dementia and missing his or her company
- Lost – the person with dementia filled all your day
- Worried that if something happens to you, who will care about the person with dementia
- Guilty that you feel relieved
- Angry that no services were available
- Sad because it is such a loss in your life
- Sad because it is a step closer to the end of life for the person with dementia
- Grateful for those who helped

If you would like to discuss your feelings you can contact:

- The **National Dementia Helpline** on **1800 100 500**
- The **National Carer Counselling Program** by contacting the **Commonwealth Carer Resource Centres** on **1800 242 636**

“It is OK at times for me to feel depressed and overwhelmed.”

“Let yourself go at times by crying, screaming or whatever helps.”

Topic 8

Moving on



In this topic

- Caring about – when not caring for – the person with dementia
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- When the person with dementia dies
- Loss and grief
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Caring about – when not caring for – the person with dementia

This topic is to help you when the person with dementia is no longer with you, through being cared for somewhere else or because they have passed away.

As the person with dementia changes you lose the person you know. While this is happening you have to deal with your emotions as well as caring for the person.

Everybody has different reactions. This topic may assist you to deal with your reactions and the reactions of those around you.

There is a section to help you to think about the future and how you might plan for this so you can move on with your life.

When the person with dementia moves to a residential facility

When the person with dementia is being cared for in a residential facility it is important for you to still feel involved in his or her life. You should talk about this with the manager so that care for the resident is a partnership and your involvement is welcomed.

Here are some issues you might want to discuss:

- visits
- outings
- access to medical doctor, records
- recognition of your input and suggestions
- systems in place to have any concerns looked into.

“When my husband went into the nursing home I was told all sorts of things but it depends on whether you’re at the stage of accepting this advice. However, I read where a doctor said ‘Leave the care to the nursing home and enjoy your visits’. I have found this the best advice yet. I pop in every day, or when I choose, never for more than an hour. I vary my times morning and afternoon and don’t go when I am tired.”

“I find that taking my husband out of the nursing home, if only for an hour or two, he enjoys it and so do I. I usually take him to feed the ducks and he enjoys that.”

“Once he settles into the home, have regular visits to create a family home atmosphere. Go for a drive, and have picnics or go to the movies.”

“When my wife first went to live in a residential care facility, I had a real knot in my stomach most of the time. Now I know she is being well cared for, the carers are exceptional. The hard thing for me now is getting used to living on my own. It takes a lot of getting used to, but you just have to adjust.”



When the person with dementia dies

You may grieve again when the person with dementia dies. You may not wish for the person to go on living – you may be grieving for the person you once knew who has now finally gone.

How you grieve, what you do, how long you are sad, when you stop crying – there are no rules; we all deal with this in our own way.

“When Mum died she had been living in the nursing home for two years. For the last six months, she had become very frail and couldn’t get out of bed. When they called us and told us she had passed away peacefully in her sleep, it was still a shock. I don’t know why, but I suppose Mary my sister and I felt that we had finally lost our mother. Two years later we still have a cry occasionally, on Mother’s Day, at Christmas and at some other totally unexpected times.”

Funerals

When a death occurs the doctor must sign a medical certificate confirming the death. If the death occurs in aged care home or hospital the manager will arrange for the doctor to issue the certificate.

Funeral directors arrange the funeral and take care of all details including the necessary legal requirements. Many

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funeral directors have schemes where you can discuss funeral arrangements while the person can still participate in the discussion. This is a matter of personal choice.

Loss and grief

It can be difficult to prepare yourself for the time when the person is no longer with you but, by thinking about how you might feel and doing some planning, you can make this a little easier.

Here is some information that might help you to deal with and understand your reactions and the reactions of those around you.

People have different reactions

These reactions are influenced by our experiences, capabilities, coping mechanisms, personality and emotions. The same event, such as the death of a spouse, produces different responses in different people.

Do not expect those around you, such as family members or friends, to behave or feel as you do. We all react differently to bad news. You will react in your own way depending on:

- the person that you are
- the experiences that you have had in your life
- the help and support you have
- what else is happening in your life

- what your relationship has been with the person with dementia.

Typical reactions

The first reaction is often **shock**. You may feel numbness and be stunned. Some people report this reaction when first told of the diagnosis or the death. They say they were not able to take in much of what they were being told. They needed to come back later when they were more likely to understand what was being said.

Disbelief and **denial** can accompany shock. *It can't be true! Why him/her? There must be a mistake!* can be typical reactions. For some people this reaction will soon pass, especially if the event, such as confirmation of dementia, or death, was expected. For others it may take longer and caring and supportive friends or family may help them.

Anger and **resistance** may come next. As the loss becomes real, anger can surface. This could be anger at the situation that can't be changed or it could be anger at others such as the medical profession for not diagnosing dementia sooner or it could be anger at the person for "deserting" the relationship. The grieving person may have a strong need to talk about these feelings and express his or her anger. Most people who have the opportunity to talk about their anger feel helped by the experience. Comments such as *Don't cry, Be brave* or *Pull yourself together* are not helpful.

Despair can happen as the person begins to accept that the loss is permanent. Despair can include sadness for what could have been or for what has been lost. They may yearn to have the person back or to turn back the clock.

It may have been felt around the time of placement in a residential facility. People often believe that if they had tried harder, or done more, this placement wouldn't be happening. Some family members and carers may feel guilt at this time.

Gradually the person is able to resolve or adjust to the situation and think about the future. Lost energy is regained and they become more interested in the outside world.

Many families and carers report that, while the strong emotions may decrease over time, they are often reminded of the past by events such as birthdays and anniversaries. The grief never completely leaves them.

Be yourself

We all react to the losses in our lives in our own way. A man who usually doesn't cry or show emotion may not get emotional and cry when his wife dies. A very private person may wish to grieve privately and present a calm exterior with other people.

Accept assistance

Family, friends, ministers of religion and others may offer practical assistance. Accepting assistance can help you to

express your feelings, reflect, talk together with family and friends and help each other to understand and adjust to the losses.

Give yourself time

Each person chooses his or her own time to grieve and adjust to the changes in their life. There is no right time, only right times for each individual.

Talk about your thoughts and feelings

Many people like to talk about the pre-dementia person or the person they have lost. This can be healthy; it helps to sharpen memories and to remember the good times and bad. The memories help come to terms with the situation as is.

Spend time with your memories.

You may want to write a diary, a story or a poem.

Professional help

You may find it helpful to talk to a trained professional. If you get worried that you just can't seem to come to terms with the loss, seek professional assistance. Your doctor, Alzheimer's Australia, or your Commonwealth Carers Resource Centre may be able to help.

Physical reactions

If, after several months, you are not sleeping, not eating properly, sad much of the time or not grooming, these are signs that your grief is affecting you.

Discuss this with your doctor

The future

When the person with dementia is no longer with you, what will you have to do?

What will you need help with?

Will it be practical, everyday things?

- I can't look after this big house. Should I move to somewhere smaller?
- I need assistance with financial affairs. What will be my income, benefits?

How will I adjust to my new life?

- I will need to look around for new friends or start to see old friends again.
- I might try a course at the local TAFE.
- I would like to help other families and carers; I will contact Alzheimer's Australia or Carers Australia.

Do I need help with personal needs?

- I can't seem to get interested in anything.
- I somehow feel that I'm not important any more
- I'd like to become a more sociable person. I feel very lonely.



Taking action

There are usually decisions that you can take, actions you can start and plans you can make that will help you in the future.

Getting started is the hard part.

Planning ahead is helped if you know what you want. As your thoughts about the future become clear, planning will be easier. It may help if you think of your plan as having three parts:

1. **Those things you can do immediately or very soon**
2. **Those things you can do over the next few months**
3. **Those things you can do in the future**

Make yourself a “to-do” list for each of these categories

| Now | Soon | Future |
|-----|------|--------|
|-----|------|--------|

Choose one of the things on your “now” list – and do it!

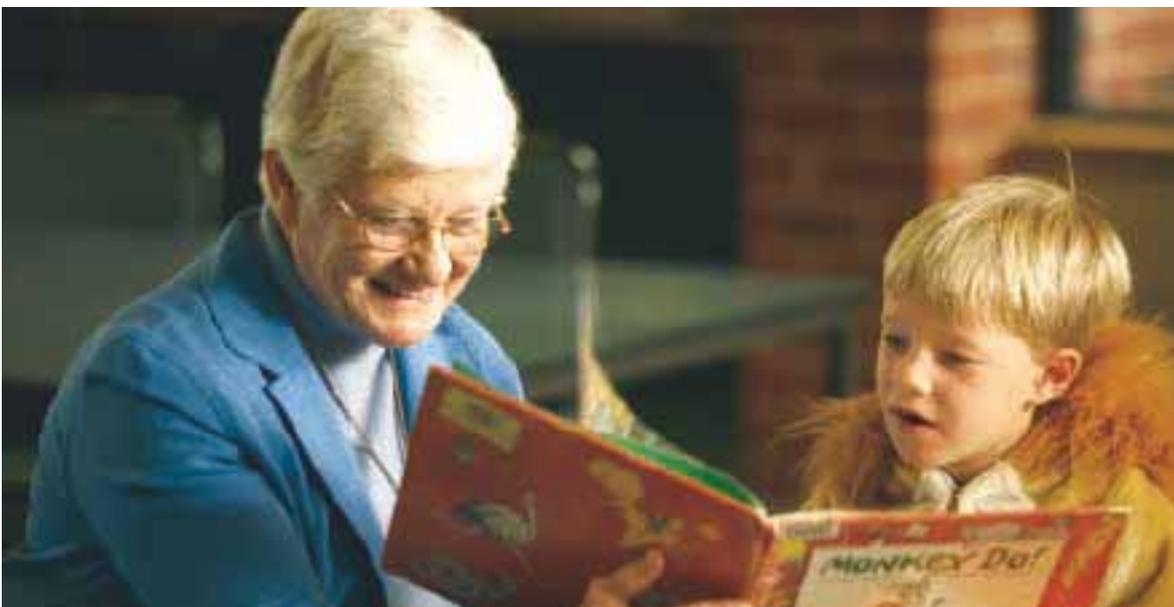
Try to set yourself some goals for the other items on your lists and stick to them.

Do what works for you. For example, it might help to put your list on the fridge or on your calendar as a reminder or try sharing your list with a friend.

It might help to imagine what your life may look like at that time. How would you like it to be?

What are your thoughts now? You could come back to these thoughts in the future and add others or change them.

How can you prepare for that life now?



Topic 9

Additional resources

In this topic

- Practical resources for families and carers
- Personal accounts of dementia written by carers
- Guides to caring
- Books written by people with dementia
- Books for children
- Videos and DVDs
- Useful websites

Many excellent publications, videos and DVDs are available about dementia and caring for someone with dementia.

Up-to-date information about books, videos and DVDs is available from Alzheimer's Australia in each state and territory. Local libraries may also be able to supply some of these books.

Practical resources for families and carers

Alzheimer's Australia Help Sheets

Alzheimer's Australia produces a range of Help Sheets containing advice, commonsense approaches and practical strategies. They cover the issues most

commonly raised by people with dementia and their families and carers.

The most commonly requested Help Sheets are available in a range of community languages.

Contact the **National Dementia Helpline** on **1800 100 500** for copies. Help Sheets can also be obtained by visiting www.alzheimers.org.au

Commonwealth Carer Resource Centres

The Commonwealth Carer Resource Centres in each state and territory provides families and carers with practical written information to support them in their caring role. There is a wide range of information and much of it is available in community languages.

A free **Carer Support Kit** is available in English and other languages. In addition to general information, it includes information on taking care of yourself, managing health care and medications and emergency care. A **Kit for Aboriginal and Torres Strait Islander people** is also available.

Contact the **Commonwealth Carer Resource Centre** on **1800 242 636**.

Personal accounts of dementia written by carers

Hazel's Journey by Sue Pieters-Hawke. Hazel Hawke's daughter tells the full

story of her mother's life in the past 10 years, including her fear and anger, her decision to go public and the gentle happiness in her life now.

A funny thing happened on the way to the nursing home by Jim O'Connor.

A true and touching account of a man caring for his wife who has dementia. The story contains pathos, humour and hope.

Elegy for Iris by John Bayley.

The author writes about his life with his wife Iris Murdoch. He attempts to uncover the real Iris, whose mysterious world took on darker shades as she descended into Alzheimer's disease.

The long good night: My father's journey into Alzheimer's

by Daphne Simpkins.

This is a memoir about love rather than an elegy about a disease. It gives caregivers cause for honest hope and its many other readers a wonderfully nuanced story of love and laughter amid the ruins of illness – a story that both illuminates the tragedy of Alzheimer's and powerfully transcends it.

Guides to caring

The 36-hour day by Nancy Mace and Peter Rabins.

A family guide to caring for a person with dementia. It covers all aspects of dementia: assessment, coping strategies, legal issues, residential options, carer health, children and teenagers, and research.

Understanding difficult behaviors by Anne Robinson.

This book offers practical suggestions for coping with Alzheimer's disease and related illnesses, including topics on resistance, wandering, agitation and incontinence. Each chapter covers a specific behaviour concern and includes possible causes, coping strategies and other considerations.

Dementia with dignity by Barbara Sherman.

Barbara Sherman is an Australian author who has been a carer herself. Written in a very readable style, the book explains dementia and its progressive effect. It also has suggestions for dealing with behavioural problems and for residential placement and beyond.

Learning to speak Alzheimer's by Joanne Koenig Coste.

Unveiling the "habilitation" approach, this book is designed to enable the person with Alzheimer's disease to maintain dignity and encourage use of remaining skills to support a sense of self-worth and independence. A practical, positive and compassionate read.

Additional resources

Books written by people with dementia

Who will I be when I die? by Christine Boden.

Christine was diagnosed with Alzheimer's disease at 46 and re-diagnosed with frontal lobe dementia when she was 49. This is the first book written by an Australian with dementia and offers a unique insight into her battle with dementia.

Dancing with dementia by Christine Bryden.

Formerly Christine Boden (see *Who will I be when I die?*) her new book is a thoughtful exploration of how dementia challenges our ideas of personal identity and of the process of self-discovery it can bring about.

Living in the labyrinth by Diana McGowin. This autobiographical book tells of the author's struggle with the effects of Alzheimer's disease and offers the reader insight into the world of dementia.

Show me the way to go home by Larry Rose. Larry Rose records his experiences with Alzheimer's disease with humour and unquenchable spirit.

Losing my mind : An intimate look at life with Alzheimer's by Thomas DeBaggio.

Not only does the author have the ability to chart the mechanics and musings of his failing mind, he also turns an autobiography, a medical history and a book of meditations into a testament to the splendour of memory and a triumphant celebration of the human spirit.

Books for children

Smell of chocolate by Barbara McGuire. Produced by Alzheimer's Australia WA, this book is aimed at children aged six to nine. After a delightful story with cartoons about Ben and his adventures with his Grandfather Pog, the book includes a descriptive but simple Alzheimer's fact file that helps children understand more about the disease.

Wilfrid Gordon McDonald Partridge by Mem Fox.

Wilfrid is a small boy who lives next door to an old people's home. He likes all the people who live there, but his favourite person of all is Miss Nancy Alison Delacourt Cooper, because she has four names just as he does. So when Wilfrid discovers that Miss Nancy has lost her memory, it is only natural that he should set off to help her find it.

What's happening to Grandpa?

by Maria Shriver.

A realistic but reassuring glimpse into ways everyone in a family can help ease the burden of a grandparent with Alzheimer's disease. This book offers a personal insight into what our elderly loved ones have to offer, and will inspire children to find creative ways to keep these stories alive.

Videos and DVDs

Understanding dementia (VHS & DVD)
Alzheimer's Australia.

This is an introductory video/DVD in which medical professionals explain the causes and symptoms of dementia and people who are living with different stages of dementia show how it affects their lives. Strategies are given to help manage the changes that dementia brings and to ensure that those affected continue to enjoy quality of life.

Remember me ... Carers' reflections on dementia (VHS & DVD) Commonwealth Carer Respite Centre Southern Metropolitan Region and Alzheimer's Australia Vic.

A moving and powerful video that captures the stories of five carers as they reflect on their experiences of dementia. Narrated by Frances Hutson, a carer herself, carers describe their difficult journey, including their feelings of grief and loss and their strategies for coping. The carers discuss the importance of getting support and using available services and of re-evaluating life priorities and finding a way forward.

Living with memory loss (VHS & DVD)
Alzheimer's Australia Vic.

This video takes you into the world of early stage dementia and the role that sharing experiences can play in forging a meaningful direction in life after diagnosis of dementia.

Understanding memory changes: Normal ageing or dementia? (VHS & DVD)

Produced by Alzheimer's Australia Vic, this 30-minute production is based on an interview with Anne Unkenstein (co-author of *Remembering well*) in 2002. Topics include how memory works, early changes with dementia, strategies for dealing with memory loss and challenges for the family.

Understanding the brain & behaviour (VHS & DVD)

Presented by Dr Helen Creasey, geriatrician and neurologist, this valuable resource gives a clear explanation of sections of the brain and includes colour-coded 3D graphics as well as personal vignettes of people living with dementia to demonstrate behavioural changes. It also includes a supporting booklet that features discussion questions for small groups.

The Forgetting (DVD)

St Paul, Minneapolis: Twin Cities Public Television (TPT).

This documentary weaves together the intense real-world experiences of people with Alzheimer's disease and caregivers, the history and biology of Alzheimer's and the ongoing struggle to end the disease. Bonus features include a Q & A program hosted by David Hyde Pierce and an interview with the author of *The Forgetting*, David Shenk.

Additional resources

Complaints of a dutiful daughter (VHS)

With profound insight and a healthy dose of humour, this video chronicles the various stages of a mother's Alzheimer's disease and the evolution of a daughter's response to the illness. Suitable for social workers, any form of health studies and carer support groups.

Useful websites

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|---------------------------------|--|
| Department of Health and Ageing | www.health.gov.au |
| Alzheimer's Australia | www.alzheimers.org.au |
| Carers Australia | www.carersaustralia.com.au |
| Centrelink | www.centrelink.gov.au |
| Department of Veterans' Affairs | www.dva.gov.au |

Abbreviations and acronyms

| | |
|--------------|---|
| AA | Alzheimer's Australia |
| ACAS | Aged Care Assessment Services (Victoria only) |
| ACAT | Aged Care Assessment Team |
| CACP | Community Aged Care Packages |
| DVA | Department of Veterans' Affairs |
| EACH | Extended Aged Care at Home |
| FIS | Financial Information Service (Centrelink) |
| FTLD | Fronto Temporal Lobar Degeneration |
| GP | General Practitioner |
| HACC | Home and Community Care |
| NDBAS | National Dementia Behaviour Advisory Service |
| OT | Occupational Therapist |
| TIS | Telephone Interpreting Service |

Important contacts

| | |
|-------------------------------------|--------------|
| National Dementia Helpline | 1800 100 500 |
| Commonwealth Carelink Centres | 1800 052 222 |
| Commonwealth Carer Resource Centres | 1800 242 636 |
| Commonwealth Carer Respite Centres | 1800 059 059 |
