



Australian Government
Department of Veterans' Affairs

Living with Dementia



*A guide for
veterans, their
families and carers*



It helps when:

I'm comfortable

I can take my time

People listen and value me

I can enjoy the present, and

Reminisce about my past



Living with Dementia

A guide for veterans, their families and carers

The Department of Veterans' Affairs (DVA) expresses its appreciation to the following people for their valuable contributions, research and professional guidance in the development of this second edition of *Living with Dementia – A Guide for Veterans, their Families and Carers*.

- Alzheimer's Australia.



- Dr Graeme Killer, Principal Medical Adviser DVA.
- Dr Glenda Powell, Geriatrician.
- Carers, families and people living with dementia.
- Individuals appearing in photographs.

This book replaces an earlier publication, *Dementia – A Practical Guide for Carers* written in 1995 by Mr Stephen Medza of DVA, which has been widely acclaimed in assisting the carers of people with dementia. This book builds on the success of that guide.

Inquiries about this book should be forwarded to:

Social Health Policy Section
Department of Veterans' Affairs
PO Box 21
WODEN ACT 2606

Copies of this book can be obtained by phoning DVA on
133 254 (metropolitan callers)
or 1800 555 254 (non-metropolitan callers),
or by visiting the DVA website at www.dva.gov.au

© Commonwealth of Australia 2006
ISBN 0 642 47681 0

This work is copyright. Apart from any use as permitted under the Copyright Act 1968, no part may be reproduced by any process without prior written permission from the Commonwealth. Requests and inquiries concerning reproduction and rights should be addressed to the Commonwealth Copyright Administration, Attorney General's Department, Robert Garran Offices, National Circuit, Barton ACT 2600 or posted at <http://www.ag.gov.au/cca>

Disclaimer

The persons depicted in photographs have given their consent for the photographs to be used. All photographs are for illustrative purposes only and do not imply that individuals depicted have dementia.

Published by the Department of Veterans' Affairs, Canberra, May 2006. P00605

Contents

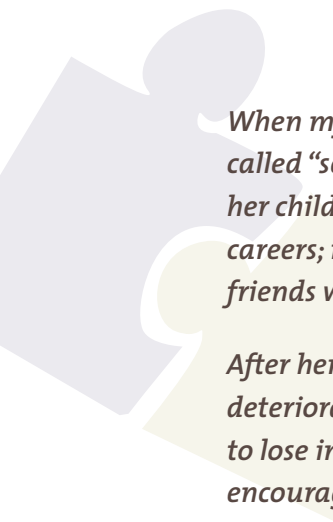
DEMENTIA	1
What is dementia?	2
Younger onset dementia	3
Younger veterans	4
If you suspect dementia	4
What are the early signs of dementia?	5
Treatment for dementia	6
Dementia risk reduction: the importance of a healthy lifestyle	7
LOOKING AFTER YOURSELF –	
If you have been diagnosed with dementia	9
Look after your health	10
Look after your feelings	11
Managing memory loss	11
Consider your driving safety	12
PRACTICAL ASPECTS OF CARING	13
Dementia and the environment	15
Communication	16
Activities	18
Driving	18
Hygiene	20
Nutrition	21
Intimacy and sexual issues	22
Continence	22
Sleeping	24
Wandering	25
Aggression	26
Hallucinations, delusions and paranoia	26
Depression	27

LOOKING AFTER YOURSELF –	
If you are caring for someone with dementia	29
Take time for yourself	30
Share your feelings	32
Ask for help	32
RESIDENTIAL CARE	33
Finding out about residential care	35
Choosing a residential facility	36
What will it cost?	38
Adjusting to the move	38
PLANNING AHEAD	39
Legal, medical and financial planning	40
Power of Attorney	40
Wills	41
Decisions about medical treatment	42
Guardianship	42
WHO CAN HELP?	43
Useful contacts	53
Useful publications	54
Appendix 1	60
Different forms and causes of dementia	60
Evaluation form	63



Dementia





When my mother first started to show signs of what our family called “senile dementia” she was living alone in Melbourne. Both her children had moved away from Melbourne to pursue their careers; my sister overseas and I to Canberra, but she had good friends who visited frequently.

After her seventieth birthday there was a fairly rapid deterioration in her ability to organise herself and she seemed to lose interest in doing things. For a while she struggled on with encouragement from her daughters to keep as active as possible, but gradually she seemed to retire within herself. Her friends were marvellous, reaching out to keep her in their world, collecting her for functions, taking her to church, to meetings, to Anzac Day and other commemorations and giving her their love.

As her condition deteriorated, I became more concerned, but there was little I could do from Canberra. It was very frustrating and worrying.

What is dementia?

Dementia describes changes in the brain caused by a large group of illnesses that cause problems with memory, thinking and behaviour. These symptoms cause a progressive decline in a person’s ability to function. Dementia is a broad term to describe changes to memory, intellect, rationality, social skills and what would be considered normal emotional reactions.

Dementia can affect anybody, including those in their forties and fifties, but it is more common in people over the age of 65. Older people are more at risk of developing dementia, just as they are at more risk of developing such conditions as arthritis and heart disease. However dementia is not a natural part of ageing.

There are many different types of dementia and each has its own causes. Alzheimer's disease is the most common form representing between 50% and 70% of all cases. For detailed information about dementia, refer to Appendix 1: Different Forms and Causes of Dementia, on page 60.

Younger onset dementia

There had been ominous signs for quite some time. At first we just dismissed them as being caused by overwork, tiredness and stress. Never in our wildest dreams did we consider "dementia". He was, after all, only in his fifties.

Very soon after his diagnosis he lost his use of speech. He managed odd words but was never able to articulate a full thought. He was never able to share his fears, his wishes and his pain. Even so his courage always shone through with whatever insights he had. His wonderful warm deep chuckle comforting me and endearing him to all around.

Although most dementias affect older people, sometimes younger people are diagnosed with the condition. Dementia has been diagnosed in the 30 to 60 year age groups.

The term "younger onset dementia" is usually used to describe people under the age of 65 with any form of dementia.

People with younger onset dementia and their families, have a number of extra challenges because the dementia appears when most people are enjoying a full and independent lifestyle. When diagnosed they are likely to be:

- in full-time employment
- actively raising a family
- financially responsible for the family, and
- physically strong and healthy.

Younger veterans

DVA frequently uses the term “younger veterans”, primarily to distinguish between veterans of the Vietnam era and subsequent peacekeeping missions, from those of earlier conflicts. Many younger veterans are now in their early to late fifties, with some over 70 years of age.

The Vietnam Veteran’s Health Study (2000) examined a range of conditions including posttraumatic stress disorder (PTSD) in veterans. This study found that some health conditions were more common in veterans, suggesting a possible association with war service.

However, there is no evidence of any link between war service and dementia among veterans.

PTSD and depression were found to be higher in younger veterans. Some of the symptoms of severe depression such as confusion, poor memory, lack of ability to concentrate, decreased organisational capacity and disturbed sleep, are similar to those of dementia. Severe anxiety states can also mimic some aspects of dementia. However, with appropriate treatment these symptoms of depression and anxiety can be managed successfully.

If you suspect dementia

A correct diagnosis by a doctor is essential if you suspect dementia. This may involve giving a detailed history, answering questions about memory and mood, a physical and neurological investigation, blood tests and often a scan of the brain. The doctor may refer you to a specialist such as a neurologist, psychiatrist or geriatrician, or to an Aged Care Assessment Team (ACAT).

There are a number of treatable conditions that produce symptoms similar to dementia. These conditions may also make symptoms of a true, underlying dementia worse. **It is essential to get a medical diagnosis when symptoms first appear to ensure that a treatable condition is diagnosed and treated correctly.** If the symptoms are caused by dementia, an early diagnosis will mean early access to support, information and medication, if appropriate.

WHAT ARE THE EARLY SIGNS OF DEMENTIA?

The early signs of dementia can be very subtle and therefore not immediately obvious. Usually though, people seem to notice that there is a problem remembering recent events. 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 a home address and names of friends and family.

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 and mood changes.
- Unable to handle stress or noise, perhaps becoming agitated.
- Withdrawing socially.
- Losing drive and interest in things that used to provide joy and motivation.

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.
- Mundane conversations, repeated phrases, words, ideas.

Treatment for dementia

Dementia causes a number of behavioural and psychological symptoms that can often be treated without medication. There are many things that can be done to help ease these symptoms and provide comfort to the person with dementia, the families and carers.

Some people may respond to reassurance, a change in the environment or removal of something that is upsetting. Symptoms that may be treated using these methods include depression, anxiety, hallucinations and ideas of persecution, over-reaction to trivial events, agitation and disinhibited and aggressive behaviour.

It is important to pay attention to good general health, as this can improve the feeling of wellbeing.

Medication is currently available in Australia for use by people with dementia. These include drugs that may have a temporary effect in improving mental functioning and offer relief from some symptoms. A doctor or specialist will be able to provide relevant details on medication use.



Dementia risk reduction: the importance of a healthy lifestyle



People often ask if dementia can be prevented. While this has not yet been confirmed, some risk and protective factors have been identified, some of which are within our control. Risk factors, such as ageing and genetics, are beyond our control, but we can do something about the risk factors related to lifestyle.

The health of your brain is linked to general health and wellbeing. Dementia shares many of the same risk factors as heart disease and stroke,

including elevated blood pressure and cholesterol, and obesity. A healthy lifestyle helps to keep your brain healthy and may reduce your risk of developing dementia.

It is important to remember that while the following tips for a healthy brain may offer a reduction in the risk of dementia, they do not guarantee prevention of dementia for any one person. Advances in research may also suggest different risk reduction strategies in the future. For up to date information, phone the National Dementia Helpline on 1800 100 500.

TIPS FOR A HEALTHY BRAIN

- Eat a balanced diet low in saturated fat and high in protective foods such as fish, nuts, fruits and vegetables.
- Exercise regularly. *
- Have regular health checks with your doctor.
- Keep your brain active with puzzles, crosswords, games and reading.
- Participate in leisure and social activities such as sports, hobbies and social groups.
- Avoid injury to your head.
- Avoid excessive alcohol consumption, recreational drug use and smoking.

* It is important to consult a doctor before starting any exercise program, particularly if there are other illnesses or disabilities to consider.



Looking After Yourself –

If you have been diagnosed with dementia

Looking after yourself – If you have been diagnosed with dementia

If you have recently been diagnosed with dementia, you may be worried and anxious about the changes you have noticed.

You may feel angry, frustrated or upset about the changes in your life, but remember:

- you are still the same person
- you will have good days and bad days
- each person is affected differently and symptoms will vary, and
- you are not alone – there are people who understand what you are going through, and can help.

There are a number of ways to help you remain as independent as possible and continue to enjoy life for a long time to come.

Look after your health

Engaging in regular physical activity is good for both physical and mental health and has a number of benefits for people with dementia. It can assist in avoiding, delaying or reducing some of the mobility problems associated with dementia, as well as helping to slow the decline in mental capacity, communication and social participation.

Exercise helps to reduce stress and depression, which are commonly experienced by people with dementia. It can also reduce your risk of developing diseases such as cardiovascular disease, diabetes, osteoporosis, colon cancer and obesity.

It is recommended that you do 30 minutes of moderate physical activity, such as brisk walking or dancing, on most days of the week.

Excessive stress can be linked to reduced memory capacity and poor sleep. Both mental and physical exercises are very good ways of dealing with stress and its accompanying effects.

Nutrition is an essential part of good health. It underpins healthy growth and development, contributes to your general health and wellbeing and plays a key role in preventing disease and disability. For people with dementia it is important to maintain a healthy weight by balancing eating well with regular activity. A dietician or doctor can advise you about good nutrition.

Look after your feelings

The changes caused by dementia may bring about a range of different emotions. This is very common and it may help you to share them with someone you trust. You may like to join a support group and meet others who have dementia to share experiences and ideas for coping with the condition.

MANAGING MEMORY LOSS

Tips for managing memory loss

- **Keep a diary or notebook of important things to remember and try to keep it with you.**
- **Establish a regular daily or weekly routine, which can help reduce reliance on your memory.**
- **Put up a white board or pin board in a prominent place such as the kitchen. Use it to write important things to remember for the day or week.**
- **Keep a special spot for important items such as glasses, wallets, keys and medicines.**

Consider your driving safety

A diagnosis of dementia does not necessarily mean that you have to stop driving immediately. However, your illness will eventually affect your judgement and ability to drive safely.

In most States and Territories, drivers must tell their licensing authority of any condition that might affect their ability to drive. Dementia is one such medical condition that needs to be disclosed.

The licensing authority will provide you with a medical form to be completed by your doctor. Your doctor will assess whether it is safe for you to keep driving. If your doctor determines that dementia is affecting your ability to drive, then the licensing authority can place conditions on your licence. These conditions might be that you may only drive near your home or that you may only drive at certain times of the day. Regular medical and driving tests will be required.

Any changes in your abilities may mean you should stop driving to ensure your safety and the safety of others. Consider having a family member or friend drive with you at least monthly to monitor your driving skills and safety.

Giving up driving can be a very difficult thing to do, especially if your car is an important part of your independence. Many people find that there are benefits in no longer driving. The alternatives, such as walking, public transport or getting a lift with family or friends can be less stressful than driving, cost less and allow you to enjoy the scenery along the way.

Other tips for looking after yourself

- Give yourself more time to do things.
- If something is difficult, try to take a break for a while.
- If you are having trouble finding the right word to express your thoughts or understanding what people are saying, take your time and tell them that you have a problem with communication.



Practical Aspects of Caring

We have our ups and downs with Mum. "Can't find the toilet", so we removed the door. "Can't find my way around in the dark", so we placed a sensor light in the hall. Mum cannot use the phone, or make a cup of tea, or dress herself properly, but her health is excellent.

Mum has some reserve funds and with this we pay a lovely friend to take her out to various places such as the art gallery, concerts at the local club, and drives in the country. Mum enjoys a good week with three days at the day centre and two outing days with friends. We look after her on weekends. She still manages independent living in her own home, with our support.

Little things such as leaving the gas fire on through the winter were difficult at first. Mum kept turning the gas off, but we taped the knobs and after lots of talking the gas fire is now acceptable to her. We had to disconnect the gas stove and buy a microwave. We prepare Mum's meals and put them in the freezer and the respite care ladies come in every night, give her a meal and put her to bed.

Practical aspects of caring

Dementia progresses differently in each person. Initially there may be only slight changes in personality and behaviour. The person may be less motivated to do things that previously interested them, or reluctant to part from familiar surroundings or routines. In addition, their abilities may change from day to day, or even within the same day.

These changes will become more noticeable over time. Concentration, understanding and the ability to reason may deteriorate. People with dementia may suffer confusion, distress, mood changes and aggression as they struggle with the frustrations of everyday life.

As the condition progresses, some abilities will remain. The sense of touch and hearing are not affected by dementia.

Following are some practical ideas for caring. Many of them are tips from families and carers, and people with dementia.

Dementia and the environment

Buildings and environments have a significant effect on a person with dementia. People with dementia function best in structured, quiet and uncluttered surroundings. A person's home, because it is familiar, can usually provide a far greater level of environmental support than the newest or best designed residential facility.

Sometimes the layout, appliances and amenities of the home may need to be modified to make them usable or safer for a person with dementia. The aim of any home modification is to allow the person with dementia to maintain independence and remain living at home for as long as possible. Modifications should only be made in response to specific problems or to encourage independence or participation. It is important to change as little as possible and to retain familiar items, unless they present a problem, or are an obstacle to the person's independent functioning.

Changes will occur in a person's abilities and will require on-going assessments. Consideration also needs to be given to the gradual ageing process that may affect vision, hearing and mobility.

THE BEST LIVING ENVIRONMENT FOR A PERSON WITH DEMENTIA SHOULD

- **be familiar**
- **help the person to know where they are or find where they want to go**
- **encourage participation in tasks and activities rather than promoting passivity and dependence**
- **promote confidence and self-esteem by helping people to succeed rather than fail with everyday tasks**
- **reinforce the person's sense of identity by stimulating their memory**
- **be physically and psychologically comfortable with good lighting, a comfortable temperature, the right level of stimulation and minimal stress, and**
- **promote safety by making caring tasks safer and easier for families and carers by achieving a balance between safety, security and independence.**

TIPS TO HELP MAKE A SAFE ENVIRONMENT

- Remove loose mats, power cords and extension leads from the floors.
- Night-lights in the hallway and in the toilet may help to find 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 checked regularly.
- Check safety in the front and backyards. 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 are very common among carers.

The Department of Veterans' Affairs Rehabilitation Appliances Program (RAP) can assist with aids and home modifications that may be needed.

Communication

Losing the ability to communicate can be one of the most frustrating problems for a person with dementia. Some changes in communication 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.



TIPS FOR CARING

- Do not rush. Always allow plenty of time.
- Keep sentences short and simple. Focus on one idea at a time.
- Speak in soft, unhurried tones.
- Try to avoid conversations that include a lot of questions that need to be answered.
- Ask questions that require yes or no answers or a simple choice of two possible alternative answers.
- Consider using hand and facial gestures to help get your message across.
- Maintain eye contact and use positive, non-verbal communication, like smiling and leaning forward.
- Use visual cues like photographs, pictures and objects.
- Try to avoid background noise such as the television or a radio.
- When several people are present, encourage the use of nametags to help with recognition.

Activities

Most people with dementia will need some assistance to participate in leisure and other types of activities. It is important that they are involved in activities that promote their self-esteem and maintain the skills that they still have.

TIPS FOR CARING

- **Make use of abilities that are retained.** For example, the person with dementia may be able to help around the house by washing up, folding linen or working in the garden.
- **Make activities simple and unhurried.**
- **Avoid activities that increase the stress levels of the person.**
- **People with dementia will have some times in the day when they function better.** 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 recorded messages and books.**
- **Sensory experiences, such as massage, stroking an animal or brushing hair can be enjoyable for people whose abilities have deteriorated.**

Driving

Many families and 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 ability to drive safely.

Some people will recognise their declining ability and be prepared, or even relieved, to be rid of the responsibility of driving. Unfortunately, others may not recognise they can no longer drive safely or may

simply forget that they are not allowed to drive anymore. Some people find giving up driving one of the hardest things to do, as their car may be an important part of their independence. 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 such medical condition that needs to be disclosed.

The licensing authority will provide the driver with a medical form to be completed by their doctor. The doctor will assess whether the person is medically fit to drive. The licensing authority will then decide if the driver can continue driving or have conditions placed on their licence. These conditions can include only driving near their home or only driving at certain times of the day. Regular medical and driving tests might be required.

TIPS FOR CARING

- **Ensure a family member or friend drives with the person with dementia at least monthly to monitor their driving and safety.**
- **Help drivers to evaluate their own skills. “A Guide for Older Drivers” contains a comprehensive self-assessment questionnaire and is available from your State or Territory licensing authority.**
- **Encourage the person to talk to their doctor about their driving.**
- **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.**

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 families and carers and a person with dementia.

TIPS FOR CARING

- 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, handrails 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 do it yourself.
- It is not always necessary to shower or bathe daily. Frequent washing can compromise the skin of elderly people.



Nutrition

The type of food we eat affects our health and quality of life. The nutritional requirements for people with dementia are the same as for people not affected by dementia.

Dietary guidelines for older Australians recommend:

- **enjoying a wide variety of nutritious foods**
- **eating at least three meals a day**
- **drinking plenty of water**
- **eating plenty of fruit and vegetables (including legumes)**
- **eating plenty of cereals, bread and pasta**
- **eating a diet low in saturated fats**
- **choosing foods low in salt and use salt sparingly**
- **including foods high in calcium, and**
- **using added sugar in moderation.**

For people with dementia maintaining good nutrition can present extra challenges. They may:

- **suffer from a loss of appetite**
- **develop an insatiable appetite or a craving for sweets**
- **forget how to chew or swallow**
- **suffer from a dry mouth or mouth discomfort, and**
- **not recognise the food or drink given.**

TIPS FOR CARING

- **Meals should be used as 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.**
- **Do not use complicated table settings.**
- **Assist with the cutting of food but avoid assisting the person to eat unless absolutely necessary.**
- **Allow time for the memory to respond to food.**
- **Serve only one plate of food at a time.**
- **Reduce distractions at mealtime.**
- **If the person is not eating, investigate possible causes such as depression or problems with gums, teeth or dentures.**

Intimacy and sexual issues

The need for closeness is a very important and natural part of everyone's lives. People with dementia continue to need caring, safe relationships and touch. Basic intimacy needs do not disappear just because the person has dementia.

Some people with dementia may experience an increased interest in sex while others may show no interest at all. Sometimes inhibitions are lost and the person may make inappropriate advances to others or undress or fondle themselves in public.

TIPS FOR CARING

- If sexually inappropriate behaviour occurs, remain calm and don't take offence.
- Look for reasons behind the inappropriate behaviour. For example, the person may be removing their clothes because they want to go to sleep or to the bathroom.
- Try to redirect the person to another activity such as their favourite food or a walk outside. If in public, take them to a quiet area and dress them again if necessary.
- Find ways to include different forms of touch in the everyday routine so that the person receives physical contact – massage, holding hands and embracing are ways of continuing to provide a loving touch.

Continence

Continence is the ability to control bladder and/or bowel function. Incontinence is the loss of this ability, which is often very distressing for those affected, and their carers. There are many things that can be done to ensure maximum comfort and dignity.

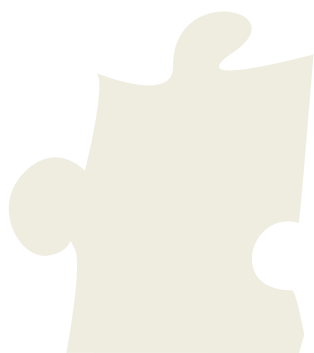
Make sure that a medical assessment is carried out to rule out treatable causes such as constipation, urinary tract infection or diabetes.

Changes in the brain that occur with dementia can interfere with a person's ability to:

- recognise the need to go to the toilet
- be able to wait until it is appropriate to go to the toilet
- find the toilet
- recognise the toilet, and
- use the toilet properly.

TIPS FOR CARING

- Be sure that the person is drinking enough fluids throughout the day (5-8 glasses daily) to keep the bladder healthy and prevent urinary tract infections. (Jelly, ice cream or custard may be substituted).
- Consider limiting caffeine intake as it can irritate the bladder and increase the need to urinate.
- Encourage using the toilet before and after meals, before bed and on waking.
- Use clothes that can be easily removed such as an 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, and absorbent sheets and waterproof underlays on chairs and the bed will help to reduce laundry. Incontinence pads are available through the Department of Veterans' Affairs Rehabilitation Appliances Program (RAP).
- The National Toilet Map may help you plan ahead for toilet breaks when travelling. Visit www.toiletmap.gov.au



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. Many will need less sleep as they do less during the day.

TIPS FOR CARING

- It can be helpful to keep a diary to see if a pattern of behaviour is developing.
- Plan activities during the day so that the person avoids sleeping for long periods.
- Make sure that the bedroom is comfortable, warm and adequately lit.
- Ensure the person is able to find the toilet at night. Consider using a night-light.
- Have set, regular times for bed.
- Try a light snack, herbal tea or warm milk before bed.
- Provide soothing music or read to the person before bed.
- Cut down on alcohol and caffeine during the day.
- 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.

Wandering

Wandering is quite common among people with dementia and can be very worrying for families and carers concerned about their safety and wellbeing.

People may wander for a number of reasons. They may feel disoriented in a new environment or they may just forget where they were going or why. Wandering can also be a way of using up excess energy or the result of boredom or of being upset.

TIPS FOR CARING

- It can help to look for a reason for the wandering.
- Talk to the person's doctor about whether any illness or pain, or the side effects of medication might be triggering wandering.
- Increased exercise, such as walking, may help reduce the desire to wander.
- Provide diversional activities, such as music or gardening.
- Remove cues associated with going out, like house keys and money.
- Place stop signs at exit doors or black strips across doorways.
- Install bells and buzzers that sound when external doors are opened and lock gates. Move keys to the door locks where the person will not think to look for them.
- Make sure that the person carries some form of identification in case they get lost. An identity bracelet with a name, address and telephone number or a Medic Alert bracelet is useful. It may be helpful to sew a nametag into garments the person wears regularly.



Aggression

Some people with dementia may exhibit physical and verbal aggressive behaviours such as hitting and excessive swearing.

TIPS FOR CARING

- Exercise may help reduce some outbursts.
- Try to anticipate the person's needs to avoid frustrating them.
- Always explain what you are going to do in case they feel threatened by your actions.
- A familiar routine and a calm environment may help avoid some behaviours of concern.
- If behaviour becomes aggressive, it is usually best not to make physical contact. It may be better to leave them alone.
- Speak in a calm, reassuring voice.
Do not be drawn into an argument.
- Do not punish them for their behaviour.

Hallucinations, delusions and paranoia

Brain changes in dementia can cause the person to suffer altered experiences. Hallucinations are sensory experiences that cannot be verified by anyone else. Typically the person sees or hears something that is not there and this can be frightening for them.

Delusions are ideas not based on reality, but which the person with dementia believes to be true. Common delusions include ideas that people are stealing from them or are intending to harm them.

Paranoia is characterised by unrealistic beliefs. These are usually beliefs of either persecution or grandeur. Sometimes the person may become very suspicious, accusing others of stealing, hiding their belongings or accusing their partner of being unfaithful. They may also believe that they possess superhuman powers.

TIPS FOR CARING

- Do not argue. It is better to acknowledge that the delusions and hallucinations frighten the person. Allow them to discuss their concerns.
- Investigate suspicions to check their accuracy.
- Try activities that may distract them.
- Try to maintain a familiar environment, including consistent routines, and if possible, familiar carers.
- Medication can sometimes help to control delusions and hallucinations in people with dementia.
- Arrange for a medical check-up to eliminate the presence of other physical or psychiatric problems and to check the effects of medication.

Depression

Depression is a feeling of extreme sadness and is very common among people with dementia. Some of the typical signs of depression are a loss of interest in activities that were previously enjoyed, lack of energy, poor sleep and feeling worthless.

It can be difficult to tell the difference between dementia and depression, as many of the symptoms are alike. However, treating depression can make significant improvements so it is very important that it is investigated and treated.



TIPS FOR CARING

- **Be positive.** Frequent praise will help the person feel better.
- **Be realistic** about what the person can do.
- **Try to keep to a daily routine.**
- **Limit the amount of noise and activity in the environment.** This may help avoid over-stimulation.
- **Discuss the person's symptoms with their doctor.**
- **Medication such as anti-depressants may be prescribed.** These can be very helpful, but can have side effects for people with dementia. These should be discussed with the doctor before treatment commences.



Looking After Yourself –

If you are caring for someone with dementia

Looking after yourself – If you are caring for someone with dementia

My father's Alzheimer's disease was in the early stages and was not diagnosed or obvious to outsiders. Many of my mother's friends and acquaintances thought it was my mother, not her husband, who had a health problem.

My sister and I found this hurtful, frustrating and confusing. My mother sometimes questioned whether in fact there was anything wrong with her husband and whether his odd behaviour and poor short-term memory was in her imagination. My mother also wondered if she was the one who had something wrong and whether she also had Alzheimer's disease. My mother was extremely distraught and stressed. As well as this, adverse comments by others did nothing to allay my mother's fears, or support her in her daily trauma of coping at home alone with my father.

Caring for someone with dementia can be very demanding. Burnout due to stress, combined with physical exhaustion, can happen to even the most dedicated families and carers.

It is important to remember and acknowledge that you have needs and that you can take positive steps to meet them. You will only be able to continue caring effectively if you take care of yourself.

Take time for yourself

It is important for yourself, and the person you are caring for, to have regular breaks and participate in activities that you enjoy. This will help you to relax and recharge and for the person with dementia it can mean new faces and activities to look forward to.

One way to do this is to arrange regular respite care for the person with dementia. Respite care provides a substitute carer to relieve the regular carer on a planned basis or in an emergency. It gives the



regular carer a chance for a rest. Where possible it is a good idea to plan respite care well in advance to help families and carers get the substitute care when and where they need it.

Respite care may be provided in different ways depending on the individual situation. Care may be provided:

- in a residential care facility
- in your home
- in community based day programs such as day clubs.

Some families and carers find it difficult to take breaks or use respite services. Some feel guilty leaving the person with dementia in someone else's care, or perhaps the person does not want to be without you, even for a short time. If you are finding it difficult to take a break, talk to someone about your feelings.

Share your feelings

It can help to share your feelings. Chat to a trusted friend, relative, counsellor or your doctor. You can join a support group and meet other families and carers and share your experiences. Many people find comfort and practical assistance by attending these groups with others who know what it is like to care for a person with dementia. Alzheimer's Australia can link you to a support group in your local area.

Ask for help

It is difficult to be a carer 24 hours a day, 7 days a week without help. Family and friends may be able to assist you if you let them know how to help. Many community organisations can help families and carers by arranging a break from caring, or providing information and advice about support services in your local area.





Residential Care



I chose a two-bed room for my mother to share. I thought that the stimulation from having company would outweigh the loss of privacy and independence. The atmosphere was more like a hospital than a home, but the company from my mother's roommate and her extensive family were a boon and a blessing for both of us. When I was unable to visit I knew that she would not be alone, and when I was there I had others to talk to. On Sunday afternoons when there were no organised activities, I would take my picnic thermos and some cakes and we would share our afternoon tea with other residents present in the lounge.

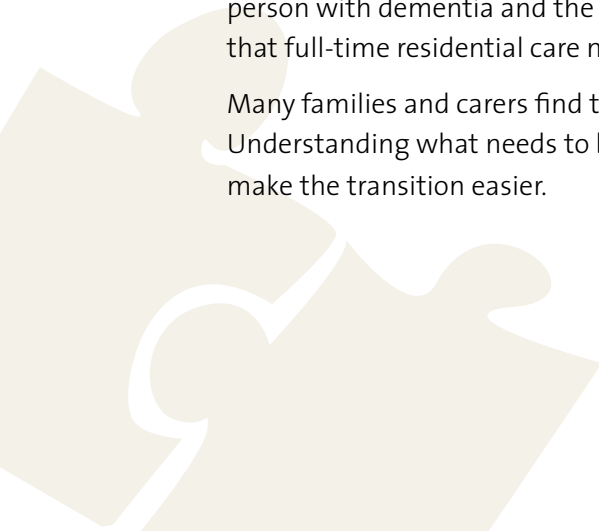
Over the next four years there were many sad moments as my mother's powers of speech, mobility and, ultimately, recognition faded. No one could tell me in advance what to expect because the progressive loss of capabilities is different for each person.

For my mother, it seemed to happen in stages, with shorter and longer plateaus in between. Sunday afternoon drives became Sunday afternoon walks in the garden, and in turn became Sunday afternoons by her bedside.

Residential care

As dementia progresses, caring usually becomes more intensive and the demands on families and carers increase. The health of the person with dementia and the wellbeing of the carer often mean that full-time residential care needs to be considered.

Many families and carers find this a difficult decision to make. Understanding what needs to be done and where to go for help can make the transition easier.



Finding out about residential care

Assessment

An assessment and approval for residential care from an Aged Care Assessment Team (ACAT) is required before you can start looking for residential care. They will help to assess the level of care the person with dementia will need, and provide information about appropriate facilities.

Types of residential facilities

Residential facilities are classified as offering either low level or high level care.

Low level care

These facilities provide assistance with some daily living activities such as eating, dressing, bathing, medication and some nursing.

High level care

These facilities provide 24-hour nursing care.

Some residential facilities provide both low and high level care so that people can stay in the same facility when the level of care they need changes.

Dementia-specific facilities

These facilities have specially trained staff and physical environments that have been designed to meet the needs of people with dementia. Not all people with dementia require a dementia-specific facility. People with special care needs, such as those who may not be accommodated safely in general residential facilities, are best suited to these facilities.

Dementia-specific facilities may provide low or high level care. There are a limited number of dementia-specific facilities, especially in rural areas.



Choosing a residential facility

Most residential facilities have waiting lists. How long you will have to wait for a vacancy varies between facilities. The ACAT will probably suggest you look at a number of facilities.

Take time to consider how each one will meet the needs of the person you are caring for. Decide on what factors are important to you before you go, and take a checklist of questions and a friend or relative with you when you visit each facility. Following is a suggested list of things to consider.

	YES	NO
1. Are the staff friendly and welcoming?	<input type="checkbox"/>	<input type="checkbox"/>
2. Did the staff receive and answer your questions positively?	<input type="checkbox"/>	<input type="checkbox"/>
3. Is the overnight staffing arrangements appropriate to the needs of the person with dementia?	<input type="checkbox"/>	<input type="checkbox"/>
4. Do staff appear to treat residents and their visitors with respect?	<input type="checkbox"/>	<input type="checkbox"/>
5. Is the facility a comfortable temperature?	<input type="checkbox"/>	<input type="checkbox"/>
6. Is the facility clean and comfortable?	<input type="checkbox"/>	<input type="checkbox"/>
7. Is there appropriate lighting and ventilation?	<input type="checkbox"/>	<input type="checkbox"/>
8. Are there secure and interesting outdoor areas?	<input type="checkbox"/>	<input type="checkbox"/>
9. Are there areas for families to get together?	<input type="checkbox"/>	<input type="checkbox"/>
10. Is family involvement encouraged, e.g. sharing of meals, celebrations?	<input type="checkbox"/>	<input type="checkbox"/>
11. Can family and friends be involved in care?	<input type="checkbox"/>	<input type="checkbox"/>
12. Do people in the facility appear relaxed and at home?	<input type="checkbox"/>	<input type="checkbox"/>
13. Are specific cultural backgrounds and beliefs respected?	<input type="checkbox"/>	<input type="checkbox"/>
14. Does the facility observe major commemorative events, e.g. Anzac Day?	<input type="checkbox"/>	<input type="checkbox"/>
15. Are there single rooms available?	<input type="checkbox"/>	<input type="checkbox"/>
16. Will the person have their own bathroom and toilet facilities?	<input type="checkbox"/>	<input type="checkbox"/>
17. Does each bedroom give the person some privacy?	<input type="checkbox"/>	<input type="checkbox"/>
18. Do residents have some of their personal, special belongings nearby?	<input type="checkbox"/>	<input type="checkbox"/>
19. Are there provisions for married couples?	<input type="checkbox"/>	<input type="checkbox"/>
20. Are there quiet areas available?	<input type="checkbox"/>	<input type="checkbox"/>
21. Would it be clear to the resident where to go if they needed help?	<input type="checkbox"/>	<input type="checkbox"/>
22. Is the facility equipped to manage specific health concerns, e.g. pain management?	<input type="checkbox"/>	<input type="checkbox"/>
23. Is there a residents or relatives committee?	<input type="checkbox"/>	<input type="checkbox"/>

What will it cost?

Residential facilities will be able to provide information about the range of fees and charges. The costs of residential care can be complex, so it is important to gather as much information as possible.

Adjusting to the move

The move into residential care is often very emotional for the person affected by dementia and their family and carers. People with dementia can find change very difficult. Careful planning and sensitive handling of the move can greatly help during this time of transition.

Families and carers may also have mixed feelings as a result of the move including relief, guilt or sadness. Daily activities and responsibilities will also have changed for family members and carers who carried most of the caring role.

Individuals need to find their own level of comfort in terms of caring for a relative or friend once they have moved into residential care. There are no rules to say how much anyone must be involved – it's a personal choice.



Planning Ahead



Legal, medical and financial planning

Even though dementia affects everyone differently, sooner or later the person's abilities will decline and they may become unable to make their own decisions about their financial, medical and legal affairs. Most people would like to have these issues managed by people that they trust, usually family or carers.

Planning ahead can make it easier for everyone, as it ensures that an individual's wishes are understood and observed. This requires the person with dementia to be legally competent – that is, able to understand the implications of what is being discussed, agreed and signed. It is also important to make sure that a trusted family member or carer knows where the legal documents are kept once this process has been completed.

To obtain advice on planning ahead, consult your geriatrician or psychiatrist. They may advise you to speak with a solicitor, the Law Society or Law Institute, a local community legal centre or Legal Aid in your State or Territory. The Public Advocate or Public Guardian can also be contacted for advice about decision making involving someone with dementia.

Power of Attorney

A Power of Attorney is a formal document appointing another person to act for someone in relation to their financial and personal affairs.

There are two types of Powers of Attorney, a general Power of Attorney and an enduring Power of Attorney. A general Power of Attorney is only valid while the person granting the power is legally competent. An enduring Power of Attorney remains valid after the person granting the power loses competence and continues until either it is revoked or the grantor's death.

A Power of Attorney can only be made while a person has the capacity to understand the significance of their actions in signing

the document. It is advisable that the issues surrounding the appointment of a person pursuant to an enduring Power of Attorney are considered. This should be done as soon as possible after diagnosis if there is no enduring Power of Attorney in place.

The law and practice in relation to enduring Powers of Attorney varies between the States and Territories, so always seek advice before granting an enduring Power of Attorney.

Wills

A will sets out how the estate of a deceased person should be administered and distributed. It is important to keep wills up-to-date. A will is only valid if the person making the will has capacity to give instructions for the will. If the person does not have that capacity the will can be declared invalid.



Decisions about medical treatment

If a person with dementia loses the legal capacity to make decisions about their medical treatment someone else will need to make these decisions. If somebody has not been appointed to make these decisions the Guardian Boards or Tribunals (see below) will appoint somebody. The person with dementia may not know this person.

An enduring Power of Attorney covering health matters enables a person to be appointed as a substitute decision-maker for medical decisions.

An advance directive is a written document expressing wishes about medical treatment. Although the advance directive will give those responsible for the treatment an indication of the person's wishes, the directive does not bind those treating the person to follow these wishes. Different names may be used in some States and Territories for advance directives, but the function of the documents is similar.

Guardianship

In each State and Territory there is a Guardianship Board or Tribunal that can appoint a guardian or administrator to look after the affairs of a person who is no longer able make decisions for themselves.

The Guardianship Board or Tribunal will appoint a guardian or administrator for a person where no other person has been previously appointed. Making an application to appoint a guardian or administrator should be considered if for example a person previously appointed:

- cannot or does not wish to look after the other person's affairs, or
- there is conflict in the family about the person's best interests.

You can contact a local Guardianship Board to discuss any concerns and find out how to make an application for the appointment of a guardian or administrator.



Who Can Help?

Who can help?

Department of Veterans' Affairs

DVA 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 and war widows/widowers have access to appropriate services, and
- work with community agencies to develop programs to meet the needs of veterans and war widows/widowers and their dependants.

DVA has fact sheets available on over 300 topics of relevance to veterans and war widows/widowers, their dependants, families and carers. Visit www.dva.gov.au

To contact DVA phone 133 254 (metropolitan) or 1800 555 254 (non-metropolitan)

Alzheimer's Australia

Alzheimer's Australia provides information, counselling and support for people with all forms of dementia and their families and carers.

Alzheimer's Australia produces a large number of Help Sheets on a variety of dementia related topics. Help Sheets can be obtained by phoning the National Dementia Helpline on 1800 100 500 or by visiting Alzheimer's Australia at www.alzheimers.org.au

To contact the National Dementia Helpline phone 1800 100 500

Aged Care Assessment Teams

Aged Care Assessment Teams (ACAT) are made up of nurses, doctors, social workers and other health professionals who provide assistance to older people in determining their needs for home based support or residential care.

All people requiring residential care must be assessed by an ACAT before applying to an Australian Government funded care facility.

You can contact your closest ACAT by phoning the number listed in the 'Age Page' of your telephone directory, or the National Dementia Helpline on 1800 100 500. Your doctor or hospital can also help you to contact an ACAT.

Aged Care Complaints Resolution Scheme

The Aged Care Complaints Resolution Scheme is a Government service that seeks to resolve complaints about the health, safety and/or welfare of people receiving aged care. For further information phone 1800 550 552.

Allied health services

A range of allied health services is available to eligible veterans and war widows/widowers under DVA health care arrangements. These include services from physiotherapists, chiropractors, osteopaths, podiatrists, speech pathologists, social workers, optometrists, occupational therapists, psychologists and dieticians. Your clinical need must be assessed for you to receive any of these services and you also must obtain a referral from either your Local Medical Officer (LMO), general practitioner, medical specialist, your hospital doctor, a hospital discharge planner or a provider of the same treatment type.

For more information about these services phone DVA on 133 254 (metropolitan) or 1800 555 254 (non-metropolitan).



Carers Australia

Carers Australia works in each State and Territory to bring the needs, views and concerns of carers to the attention of the wider community including government, policy makers, health professionals and service providers. Carers can phone Carers Australia in their State or Territory on 1800 242 636 or visit www.carersaustralia.com.au

Carer Resource Centres

Carer Resource Centres are part of Carers Australia in each State and Territory and provide families and carers with information and referral to the range of community services and government assistance available to support them in their caring role. You can phone your local Carer Resource Centre on 1800 242 636 or visit www.carersaustralia.com.au

Carer Respite Centre

A Carer Respite Centre is an Australian Government funded agency that keeps updated records of all available respite beds. It also provides information and coordination on a full range of services. This includes respite programs funded by the Australian Government, State Governments, non-profit organisations, private agencies and the wider community. You can phone your local Carer Respite Centre on 1800 059 059.

Commonwealth Carelink Centres

Commonwealth Carelink Centres around Australia provide information about the range of community care programs and services available to help people stay in their own homes. Phone 1800 052 222 or visit www.commcarelink.health.gov.au

Commonwealth Department of Health and Ageing

The Commonwealth Department of Health and Ageing has an Aged and Community Care Information Line. For more information on any aspect of aged care you can phone 1800 500 853 or you can visit the Department's web site at www.health.gov.au

Community nursing

Community nursing services are available to eligible veterans and war widows/widowers to meet their assessed clinical nursing and/or personal care needs. A referral is required from a general practitioner, Local Medical Officer, treating doctor or specialist in hospital, hospital discharge planner or a Veterans' Home Care assessment agency. Services are provided by a contracted community-nursing organisation in the person's home. Community nursing helps restore or maintain the optimal level of health and independence of the individual.

Contracted community nursing organisations use a mix of registered, enrolled nurses and nursing support staff, as clinically appropriate, in the delivery of clinical nursing care. The community-nursing organisation bills DVA directly for its services.

For more information about these services phone DVA on 133 254 (metropolitan) or 1800 555 254 (non-metropolitan).

Continence Foundation of Australia

Practical advice and information is available for people with bowel/bladder problems and their carers from the Continence Foundation of Australia. Phone the National Continence Helpline on 1800 330 066 or visit www.contfound.org.au

The National Public Toilet Map shows the location of more than 14,000 public and private toilet facilities across Australia. It can be used to help plan both short and long trips. You can visit www.toiletmap.gov.au

General practitioners

Only a doctor can diagnose dementia. Your local doctor is often the first person you will talk to about your concerns and is available to undertake an assessment of your health needs. You may be referred to a specialist, such as a geriatrician, neuropsychologist or psychiatrist, depending on your doctor's assessment.

HomeFront

HomeFront is a falls and accident prevention program aimed at assisting veterans and war widows/widowers to continue living independently in their own homes. All DVA Gold and White Card holders are eligible for an annual free home assessment to identify hazards in and around the home. Following the assessment, some financial assistance will be provided towards recommended items or home modifications. Phone HomeFront on 1800 801 945.

Home Maintenance Helpline

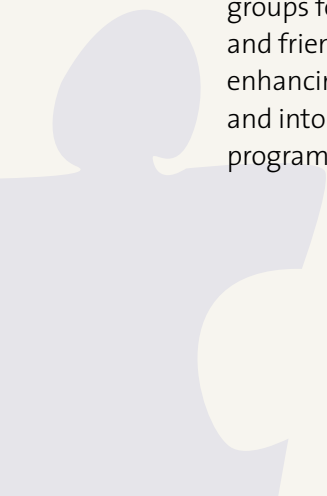
The Home Maintenance Helpline is a telephone advice and referral service to assist with property maintenance advice and referral to reliable, efficient tradespeople. This service is available to all veterans and war widows/widowers, not just those with Gold and White Cards. Where possible the Helpline will link you with Government subsidised services. Phone the Veteran's Home Maintenance Helpline on 1800 801 945.

Independent Living Centre

The Independent Living Centre in each State and Territory offers a number of services designed to promote safe living. Information is available about a number of products including smoke detectors, hot water services, temperature regulators, monitoring services and many others. Advice is also available about home modifications and home design. Phone numbers for Independent Living Centres can be obtained from the phone book, or by phoning the National Dementia Helpline on 1800 100 500.

Living with Memory Loss Program

Living with Memory Loss program consists of information and support groups for people living with early stage dementia and their family and friends. The program has a positive focus on maintaining and enhancing skills and abilities and exploring ways of managing now and into the future. For information about the *Living with Memory Loss* program phone the National Dementia Helpline on 1800 100 500.



National Dementia Behaviour Advisory Service

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 confidential, comprehensive advice 24 hours a day, 7 days a week. Phone them on 1300 366 448.

Rehabilitation Appliances Program

The aim of DVA's Rehabilitation Appliances Program (RAP) is to restore or maintain an individual's independence and minimise the effect of disabilities. Providing aids for daily life, surgical appliances, and home modifications where clinically prescribed, can assist people to remain living in their own home. Phone DVA on 133 254 (metropolitan) or 1800 555 254 (non-metropolitan).

Retirement Service Centres

The Department of Veterans' Affairs, Centrelink and the Australian Taxation Office have established combined Retirement Service Centres which provide a "one-stop-shop" to members of the veteran community, the aged and pre-retirees. Sites have been established at:

- Camberwell, Victoria
- Chatswood, New South Wales, and
- Launceston, Tasmania.

Phone DVA on 133 254 (metropolitan) or 1800 555 254 (non-metropolitan).

You can also phone Centrelink on 13 27 17. Centrelink provides financial assistance for people with illness and disabilities, and their carers. You may be eligible for some payments and concessions from Centrelink.



Standards and Accreditation

The Aged Care Standards and Accreditation Agency is an independent body responsible for managing the accreditation and ongoing supervision of Australian Government-funded aged care facilities. The agency has offices in all state capitals. You can phone the national office on 02 9633 2099 or visit www.accreditation.aust.com

Veterans' Affairs Financial Information Service

The Veterans' Affairs Financial Information Service (VAFIS) provides a free service designed to give the veteran community information about financial and related matters. VAFIS staff can provide information about investments, superannuation, the Pensions Loans Scheme, lump sum advances, and basic taxation issues. Phone DVA on 133 254 (metropolitan) or 1800 555 254 (non-metropolitan).

Veterans' Home Care

The Veterans' Home Care (VHC) program provides a range of home care services for eligible veterans and war widows/widowers. A VHC assessment agency will assess the need for home care services and based on that assessment, services such as domestic assistance, personal care, limited home and garden maintenance and respite care may be provided. The VHC assessment agency may also provide referrals, with the person's consent, to other government programs and community agencies that are best placed to meet specific needs. Phone VHC on 1300 550 450.

• Respite care

Veterans' Home Care is the first point of contact for members of the veteran community requiring respite care.

DVA provides in-home respite and emergency respite care and approval for residential respite care through the VHC program. Approval, based on assessed need by VHC, should be obtained to access respite care. An Aged Care Assessment Team assessment and approval is also required before a person can access residential respite care in an approved facility. VHC staff will then discuss respite options and assist in determining the best balance between in-home and residential respite.

- **Eligibility for DVA respite care**

All veterans of the Australian defence forces who hold Gold and White Cards, and their war widows/widowers may receive respite care, funded through DVA, where approved by a VHC assessment agency. Commonwealth and Allied veterans who have a White Card may be eligible for respite care, but only where it relates to their war caused disabilities.

Partners and carers may benefit from in-home respite care through Veterans' Home Care if they are caring for an eligible veteran or war widow/widower.

- **Financial Assistance for DVA respite care**

In any one financial year, DVA may pay for up to 28 days (196 hours) of in-home or residential respite care, or a combination of both. Seven hours in-home respite is equivalent to one day in a residential respite facility. Any additional costs, such as pharmaceutical items, telephone calls or additional days of respite care will have to be met by the veteran or war widow/widower.

- **Respite in a residential care facility**

Any person, not just a veteran or war widow/widower, who has been assessed by an Aged Care Assessment Team as requiring respite care in a residential facility, can access up to 63 days respite care per financial year. DVA will pay the basic daily care for up to 28 of the 63 days when the person entering residential respite care is a Gold or White Card holder. After 28 days, the veteran or war widow/widower is responsible for paying the basic daily care fee.

- **Australian former prisoners of war and Victoria Cross veterans**

DVA pays the basic daily care fee for up to 63 days (or such further period as is permitted under the *Residential Care Subsidy Principles*) for former prisoners of war and Victoria Cross veterans who receive respite care in an approved residential facility.

- **In-home respite care**

In-home respite care can be arranged for a few hours on a regular basis or for several days at a time. It can be used by veterans and war widows/widowers who care for another person, as well as the carers of eligible veterans and war widows/widowers.

- **Emergency short-term home relief**

Emergency short-term home relief (ESTHR) is respite care provided to veterans and war widows/widowers. ESTHR offers episodes of up to three days (72 hours) of continuous emergency care, such as when the carer is suddenly or unexpectedly unable to continue providing care. Funding of ESTHR is separate from, and does not affect, the 28-day in-home or residential respite. A cap of nine days (216 hours) in any financial year applies to ESTHR.

If ESTHR is needed outside business hours, local Commonwealth Carer Respite Centres provide an after-hours emergency telephone service that links carers to local emergency respite services. Phone 1800 059 059.

Vietnam Veterans Counselling Services

The Vietnam Veterans Counselling Service (VVCS) provides free and confidential counselling and group program services for veterans and their families and promotes community awareness and understanding of the problems they face. Veterans of all conflicts and peacekeeping missions and their immediate families, including war widows, are eligible. VVCS centres are located in each State and Territory capital and several regional centres. After hours telephone crisis counselling is available through the Veterans' Line on 1800 011 046.

Useful contacts

To phone Department of Veterans' Affairs:

☎ 133 254 (metropolitan)

☎ 1800 555 254 (non-metropolitan)

🌐 Or visit the DVA web site at www.dva.gov.au

New South Wales

Tower B, Centennial Plaza
280 Elizabeth Street
SURRY HILLS NSW 2010

Postal Address:

GPO Box 3994, SYDNEY NSW 2001

South Australia

Blackburn House
199 Grenfell Street
ADELAIDE SA 5000

Postal Address:

GPO Box 1652, ADELAIDE SA 5001

Tasmania

Montpelier Building
21 Kirksway Place
BATTERY POINT TAS 7004

Postal Address:

GPO Box 481E, HOBART TAS 7001

Western Australia

AMP Building,
140 St Georges Terrace (Cnr. William Street)
PERTH WA 6000

Postal Address:

GPO Box F352, PERTH WA 6001

Victoria

300 Latrobe Street
MELBOURNE VIC 3000

Postal Address:

GPO Box 87A, MELBOURNE VIC 3001

Queensland

259 Queen Street
BRISBANE QLD 4000

Postal Address :

GPO Box 651, BRISBANE QLD 4001



Useful publications

There are many books, information sheets and kits available for people with dementia, their carers and families. Some of these are listed below.

Free publications from the Department of Veterans' Affairs

Phone DVA on 133 254 (metropolitan) or 1800 555 254 (non-metropolitan) or visit the DVA web site at www.dva.gov.au

DVA fact sheets

DVA has fact sheets covering over 300 topics of relevance to veterans and war widows/widowers, their dependants, families and carers.

Planning Ahead: A guide to putting your affairs in order

This is an excellent guide to preparing for, and coping with, bereavement. It can help you and your family get your affairs in order and keep all your personal papers up-to-date in a safe place. The guide includes personal information sheets and checklists, which ensure that all relevant information is available when you need it. It also includes a book that lists the services that are available to help you, your family and friends.

You and Your Pension: A guide for service pensioners and for war widows and widowers who receive the income support supplement

This guide contains information about pensions, services and benefits, health, personal finances and lifestyle issues, and your rights and obligations. The guide is also available on audiocassette for people who have difficulty reading standard print.

Back to Basics: Handy hints for carers to help prevent back injuries

This book provides practical, user-friendly advice for carers to use in their daily routines. It shows the variety of transfers that carers can

use and explains how to undertake them to minimise the risk of injury to the person or carer. Many photographs and practical hints are included to demonstrate these techniques. It also provides an excellent overview of the range of products and aids available to assist carers.

Carers Booklet: Assistance for the Veteran Community

This booklet has been developed to assist carers. It provides information about specific services available through DVA as well as general information about services available in the community.

Choose Health: Be Active

This booklet shows simple ways to fit exercise into a daily routine and is designed to help the veteran community achieve sufficient physical activity for good health as they age. It includes information about finding suitable activities, getting started, overcoming setbacks and exercising with chronic health problems, together with a handy activity planner.

Discharge Planning Resource Kit

The DVA Discharge Planning Resource Kit provides discharge planners and other health professionals in hospitals, and day procedure centres, with up-to-date information about current DVA procedures and services, and best practice principles in discharge planning.

The Right Mix - Your Health and Alcohol

The Right Mix has something for anyone interested in a healthy lifestyle. A range of resources provides simple information about standard drinks, alcohol and medication, sleep and health conditions. You can find out how to start making changes if you want to, or where to go for help if you are concerned about your drinking.

Contact DVA for these resources or visit www.therightmix.gov.au

Free publications from Alzheimer's Australia

Help Sheets

Alzheimer's Australia produces a large number of Help Sheets about a variety of dementia related topics. These include those written especially for people with dementia, as well as Help Sheets for families and carers. Many of the Help Sheets are in community languages and some are available in audiocassette format. Help Sheets are free of charge to people with dementia, their families and carers and can be obtained by phoning the National Dementia Helpline on 1800 100 500 or visiting www.alzheimers.org.au

The Caring Experience

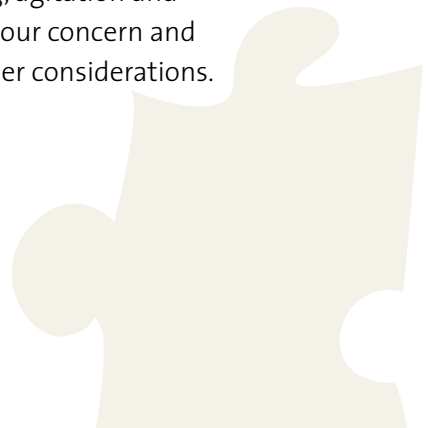
This book contains information that carers may need, and ideas they could use. The book is available from the Commonwealth Department of Health and Ageing by phoning your local Carer Resource Centre on 1800 242 636, or the National Dementia Helpline on 1800 100 500.

Books

Contact the National Dementia Helpline on 1800 100 500 for information about how to obtain any of the following books, videos or DVDs.

***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: A Handbook for Carers, by Barbara Sherman:

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.

A number of books are available that have been written by people with dementia, or by a family member who share their experiences of the illness, including the following.

Who Will I Be When I Die? by Christine Boden (Bryden): 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: Christine's latest 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.

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.

Hazel's Journey: A Personal Experience of Alzheimer's Disease, 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.

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.

***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.

***In Memory of Memories: Experiences of Living with Dementia*, by**

Robert Breckman (ed.): A collection of writings, first published in the UK Alzheimer's Society Newsletter, by people whose lives have been affected by dementia.

Living in the Labyrinth: A Personal Journey Through the Maze of

***Alzheimer's*, by Diana Friel McGowan:** 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.

***A Funny Thing Happened on the Way to the Nursing Home*, by Jim**

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

Useful videos/DVDs

Understanding Dementia (Video and DVD) Alzheimer's Australia 2005:

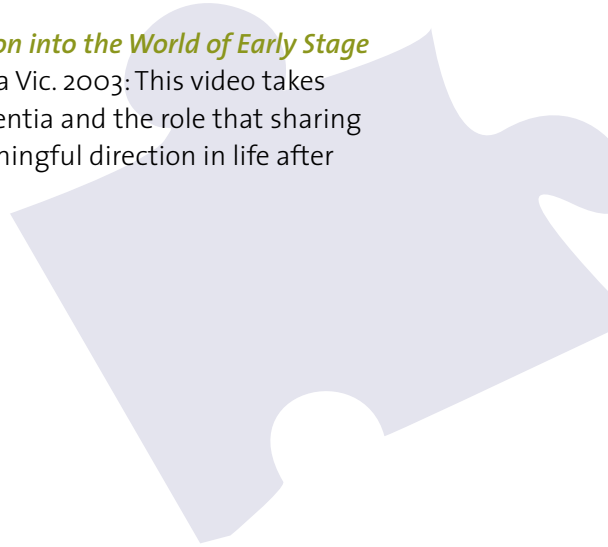
This is an introductory video/DVD in which medical professionals explain the causes and symptoms of dementia and people who are living with different stages of dementia show how it affects their lives. Strategies are given to help manage the changes that dementia brings and to ensure that those affected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

Alzheimer's: My Mom, Our Journey (DVD): Written, produced and

directed by Julie Meisner Eagle [2004]. Shot over the course of eighteen months, Julie chronicles her mother's life journey with younger onset dementia.

The Forgetting: a Portrait of Alzheimer's: Stories of Love, Courage and Hope (DVD). St Paul, Minneapolis: Twin Cities Public Television (TPT) 2003: 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 Q & A program hosted by David Hyde Pierce and an interview with the author of "The Forgetting" David Shenk.

Living with Memory Loss: An Exploration into the World of Early Stage Dementia (Video) Alzheimer's Australia Vic. 2003: 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.



Appendix 1

DIFFERENT FORMS AND CAUSES OF DEMENTIA

There are many different forms and causes of dementia. Some of the most common are:

Alzheimer's disease

Alzheimer's disease is the most common form of dementia representing between 50% and 70% of all cases. It is a progressive condition of the brain that results in impaired memory, thinking and behaviour. Memory of recent events is the first to be affected, but as the condition progresses, long-term memory is also lost.

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 in the area of the brain vital to memory and other mental functions eventually die and this means that information cannot be recalled or understood.

Risk factors for Alzheimer's disease are advancing age, family history and Down's syndrome.

Vascular dementia

Vascular dementia is a form of dementia caused by disorders of the blood vessels in the brain. It is the second most common cause of dementia. When arteries feeding the brain become narrowed or blocked, the blood flow to the brain is interrupted, resulting in a stroke and the death of a section of brain tissue.

Vascular dementia often causes problems with thinking, language, walking, bladder control and vision. High blood pressure, smoking, diabetes, high cholesterol and artery disease are risk factors.

Preventing additional strokes by treating underlying diseases, such as blood pressure, may halt the progression of vascular dementia.

Vascular dementia may appear similar to Alzheimer's disease. A mixture of Alzheimer's disease and vascular dementia is common.

Parkinson's disease

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

Dementia with Lewy bodies

The degeneration and death of nerve cells in the brain cause dementia with Lewy bodies. The name comes from the presence of abnormal lumps, called Lewy bodies, which develop inside nerve cells. It is thought that Lewy bodies 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 (similar to Parkinson's disease), and have more frequent falls. Their condition tends to fluctuate quite rapidly, often from hour to hour or day to day. Dementia with Lewy bodies is often mild at the outset and can occur by itself, or together with Alzheimer's or Parkinson's disease.

Fronto Temporal Lobar Degeneration (FTLD)

The frontal lobe is the part of the brain that governs mood, behaviour, judgement and self-control. FTLD is the name given to a group of dementias where there is degeneration in this part of the brain. Damage to these areas leads to alterations in personality and behaviour, and changes in the way a person feels and expresses emotion.

Language problems often occur early with FTLD and may range from limited speech to total loss of speech. Approximately 50% of people with FTLD have a family history of the condition.

Huntington's disease

Huntington's disease is an inherited, degenerative brain condition that affects the mind and body. It usually appears between the ages of 30 and 50 and symptoms typically start with mild personality changes. Huntington's disease is characterised by intellectual decline and irregular, involuntary movement of the limbs or facial muscles. Other symptoms include personality changes, memory disturbance, slurred speech, impaired judgement and psychiatric problems.

Dementia commonly develops in the later stages of this disease.

Alcohol related dementia (Korsakoff's syndrome)

The excessive consumption of alcohol over a period of years, particularly if associated with a diet deficient in thiamine (Vitamin B1), can lead to irreversible brain damage and alcohol related dementia. This dementia is preventable.

The National Health and Medical Research Council of Australia's recommendations for the safe use of alcohol are that men should drink no more than four standard drinks daily and women should drink no more than two standard drinks daily. Development of alcohol related dementia and Korsakoff's syndrome has not been reported in people drinking regularly at or below these levels.

The most vulnerable parts of the brain are those used for memory, planning, organising and learning. Taking thiamine appears to help prevent and improve this form of dementia as it can limit some of the toxic effects of alcohol. If drinking stops there may be some improvement. Your doctor can advise you about thiamine intake.

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, and
- exposure to certain toxins.



FEEDBACK ON

Living with Dementia

CONTENT

How useful did you find the information in this book?

- Very useful
- Fairly useful
- Useful
- No use at all

PRESENTATION

What do you think about the layout of the information?

- Excellent
- Good
- Fair
- Poor

READING

How easy is it to read the text?

- Very easy
- Easy
- Difficult
- Very difficult

IMPACT

Did you learn anything from reading this book?

- Yes – lots
- Yes – quite a lot
- Only a little
- No – nothing at all

Will you consult your doctor about your health?

- I already consult my doctor
- Yes I definitely will
- I will think about it
- No I definitely will not

Are you a veteran or war widow?

- Yes
- No

What is your age?

- Under 60
- 60-69
- 70-79
- 80-89
- 90 or over



Comments:

Fold along this line first

Delivery Address:
PO Box 21
WODEN ACT 2606

No stamp required
if posted in Australia



Living With Dementia
Book Evaluation Form
Reply Paid 21
WODEN ACT 2606

Fold along this line last — so your comments are covered, then seal with sticky tape

FEEDBACK ON

Living with Dementia





It helps when:

I'm comfortable

I can take my time

People listen and value me

I can enjoy the present, and

Reminisce about my past