

# alzheimer's disease

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LOOK FORWARD



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This booklet has been reviewed by Alzheimer's Australia



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Alzheimer's disease is a disease that affects 1 in 10 people over the age of 65, 12 million people globally with numbers expected to grow as our population ages.

The causes are still unknown although research has picked up in recent years, and it's ranked as the 4th most important health issue.

As yet there is still no cure.

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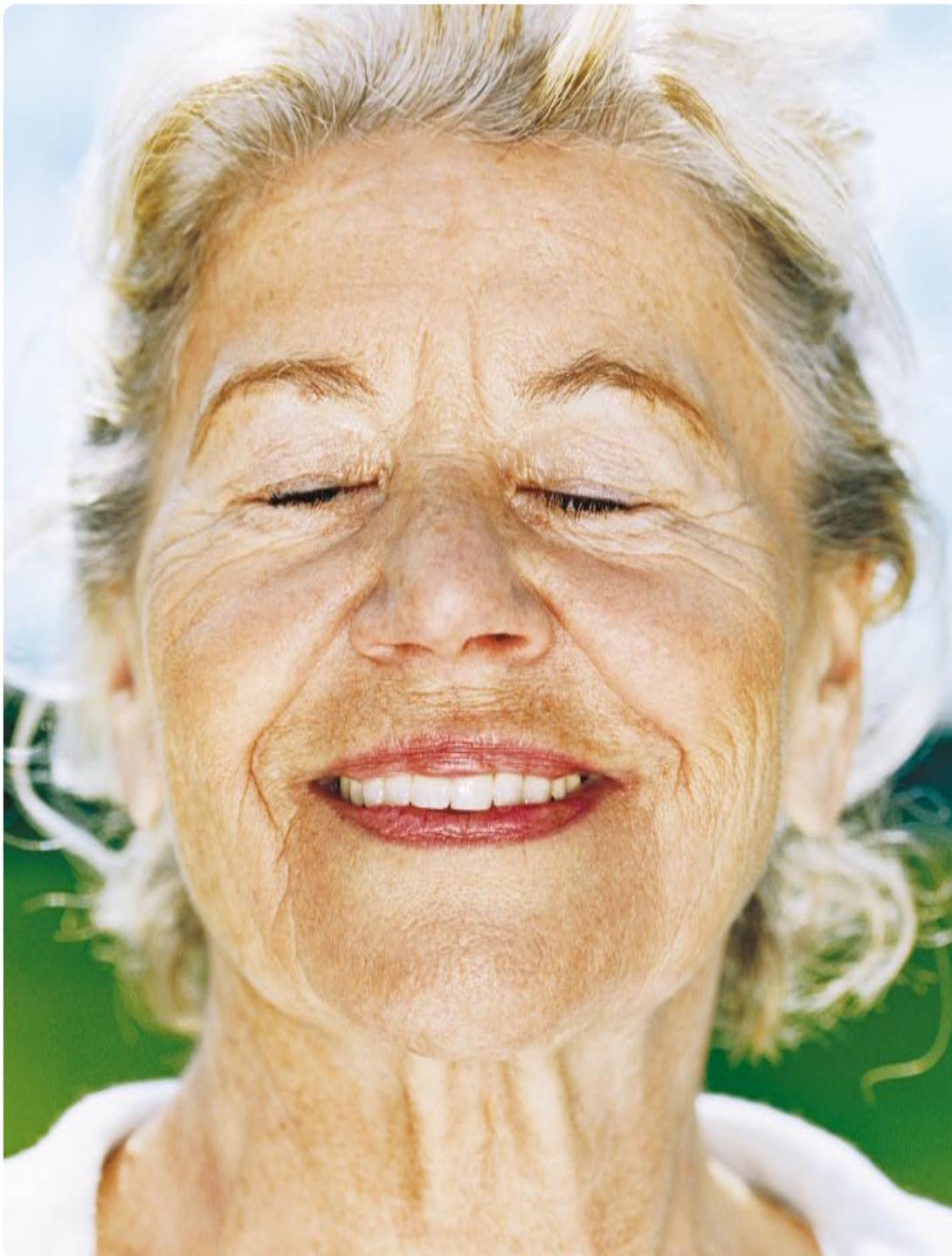
## Nearly a century ago

In 1902, German neurologist Alois Alzheimer observed the condition of a 51 year-old woman as 'unusually agitated, with periods of memory loss and impaired speech.' After five years of watching her gradual deterioration and eventual death, the doctor autopsied her brain. What he found was highly unusual: her brain was 'entangled and plaque-coated... with deposits of a peculiar substance in the cerebral cortex.'

At the time in 1907 neither he nor his colleagues knew what caused the misshapen portions of her brain. But soon after, the medical community began referring to middle-aged behaviour symptoms similar to what the woman exhibited as 'dementia of the Alzheimer's type.'

It wasn't until the 1960s that scientists discovered a link between a common condition of 'senility' in many elderly people and this 'Alzheimer's diagnosis'. Finally Alzheimer's disease became the subject of scientific inquiry with a number of wild goose chase theories along the way. By the 1980's and with the advent of nuclear medicine, more experiments provided greater insights into the realm of brain chemistry.

Today we study Alzheimer's disease with more skill and scientific apparatus than ever before – but we still cannot fully explain what causes these deadly plaques and tangles nor the debilitating effect they have on the brain.



# understanding alzheimer's disease

From the moment you hear the diagnosis of Alzheimer's disease, it's time to prepare for changes and challenges in every aspect of daily life. Thanks to proper early diagnosis, care and medication, it is now possible for those affected to experience a significant difference in their quality of life. Support networks and information resources can benefit both people with Alzheimer's disease and their families and carers.

**Preparing yourself for living with Alzheimer's disease means looking forward.**

This is the first in a series of three Look Forward chapters. Together they will give you a concise yet complete look at how Alzheimer's disease affects those diagnosed, as well as their families and carers. Use this book as an introduction to learn more about the disease and available support through groups, associations and the community. Resources are listed in the back of each chapter, as well as helpful references for published and online material.



# what is alzheimer's disease?

## The race is on for a cure

Over the last few years, increased research and new pharmaceutical developments are beginning to make a difference. While there's still no cure, the symptoms can be better managed with various drug treatments.

According to a November 2002 report from online health resource, CNN.com/health, "Medication helps lessen symptoms such as agitation and anxiety and can improve sleep and participation in activities. New medications for improving cognitive performance and treating related symptoms of Alzheimer's are continuously being tested."

NOTE: In Australia, there are currently four available medications to manage mild to moderate Alzheimer's disease: Aricept® (donepezil), Exelon® (rivastigmine) Reminyl® (galantamine) and Ebixa® (memantine).

There are also several antipsychotic medications used to control behaviour concerns in patients with Alzheimer's disease.

The symptoms of Alzheimer's disease do not appear suddenly. Damage to the brain occurs slowly and subtly and can take years before symptoms enable a diagnosis. As there are no specific tests for Alzheimer's disease, it is important to note any changes in mental functions and mention them to your doctor.

Alzheimer's disease is a brain disorder that causes a decline in mental abilities. Beginning with memory loss, over years it affects reasoning, speech and eventually most physical functions.

The disease occurs most frequently in those over age 65, although it is increasingly diagnosed in people in their 40's and 50's.<sup>1</sup>

It affects men and women, with a slightly higher incidence in women. As a progressively degenerative condition, it affects each person differently and can last for years before associated conditions become life-threatening.

## what happens in the brain?

Alzheimer's disease has been described as eroding the 'glue' we have in our brains to allow information to 'stick' with us. This impairs how new information is processed – like recent experiences or events – and prevents the brain from storing it. It's not unusual for someone with Alzheimer's disease to talk about 'old' memories in great detail yet not be able to remember what day it is today.

While the incidence of this happens sporadically at first, it eventually takes over as though a 'mental wall' has gone up preventing information from coming in or, as speech or cognitive functions diminish, going out.

Technically, of the one hundred billion nerve cells (neurones) in an average human brain, each is responsible for 15,000 connections (synapses) to store, process and retrieve information. Alzheimer's disease destroys cells in the parts of the brain that control memory and other key functions such as reasoning and language.<sup>2</sup> Unfortunately when brain cells die, they are not replaced.

The destruction of these brain cells begins in the hippocampus in the temporal lobes (at either side of the head, in from the ear) and show up through brain scans as less dense areas of brain matter. As the disease progresses, there is evidence of brown, spherical plaques floating between neurones and black, stringy tangles choking those neurones making it impossible to relay 'messages' through areas of the brain. Levels of glucose, the brain's energy source, begin to drop and deprive cells of essential nutrients. This ultimately shrinks the entire brain.

Unfortunately, these telltale physical signs can only be seen post-mortem in autopsy when a definitive diagnosis can be made. Until then, each patient lives with the label of 'probable Alzheimer's disease' from onset to death.

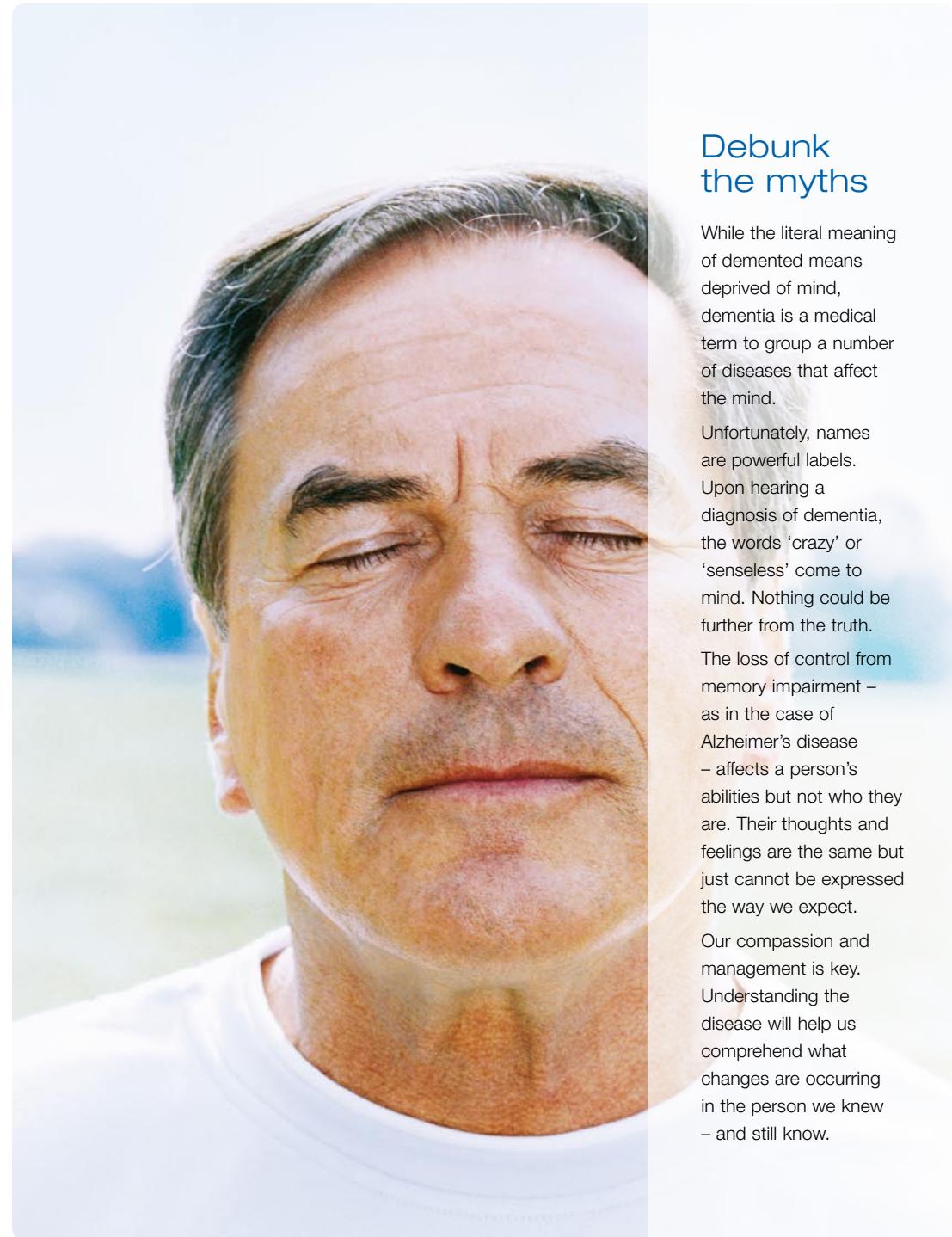
## Debunk the myths

While the literal meaning of demented means deprived of mind, dementia is a medical term to group a number of diseases that affect the mind.

Unfortunately, names are powerful labels. Upon hearing a diagnosis of dementia, the words 'crazy' or 'senseless' come to mind. Nothing could be further from the truth.

The loss of control from memory impairment – as in the case of Alzheimer's disease – affects a person's abilities but not who they are. Their thoughts and feelings are the same but just cannot be expressed the way we expect.

Our compassion and management is key. Understanding the disease will help us comprehend what changes are occurring in the person we knew – and still know.



## Various forms of dementia<sup>3</sup>

Dementia is a broad term that describes loss of memory, intellect, rationality, social skills and normal emotional reactions.

Alzheimer's disease is the most common form of dementia, accounting for 50 to 70% of cases. Different dementias, each with their own cause and effects, should be medically diagnosed, including:

**Vascular dementia** The second most common cause of dementia reflects problems with blood circulation to the brain from multiple strokes (infarcts).

**Parkinson's disease** A progressive central nervous system disorder, characterised by tremors, stiffness in limbs and joints, speech impediments, movement difficulty.

**Dementia with Lewy Bodies** Tiny spherical structures called Lewy Bodies form in the brain contributing to the death of brain cells. Symptoms vary: from hallucinations, stiffness, tremors or difficulty moving.

**Pick's disease** A rare disorder of the frontal part of the brain which can be difficult to diagnose yet shows up in personality, behaviour or language disturbances.

**Huntington's disease** An inherited brain disease which affects mind and body appearing in 7 out of 100,000 Australians between the ages of 30 and 50. Characterised by intellectual decline, personality change, psychiatric problems and involuntary movement of limbs or facial muscles.

**Alcohol related dementia/Korsakoff's Syndrome** Too much alcohol, particularly with a diet deficient in thiamine (Vitamin B1) can lead to irreversible brain damage.

**Creutzfeldt-Jacob disease** Also known as Mad Cow Disease, this extremely rare, fatal brain disorder is caused by a prion or protein particle. Occurrence = 1 in 1,000,000.

## causes are still unknown

Researchers are still exploring what causes this deterioration of brain cells. A certain degree of forgetfulness is considered 'normal' in old age due to a slight decline in brain function. However, where to draw the line between typical memory loss and the early onset of Alzheimer's disease continues to elude doctors.

Theories are constantly tested and challenged. There is currently scientific inclination to believe that there are strong links to genetic or hereditary factors. Yet relatives of those with Alzheimer's disease do not have a significantly higher risk of getting the disease.<sup>4</sup>

An exception to this comes from recent findings that show a single gene carried in four chromosomes is responsible in 5% of cases of Alzheimer's disease. Anyone carrying the gene will get the disease and pass it on to half of their children. The remaining 95% of cases however, have no clear cause. Most likely a combination of factors – genetic and environmental – influence the development of Alzheimer's disease.<sup>5</sup>



Memory plays tricks on all of us, but having trouble recalling recent events can be an early symptom of Alzheimer's disease. This can be subtle and go unnoticed or ignored for some time, especially since the degree of forgetfulness increases gradually.



# how do you detect alzheimer's disease?

## Look for the early signs

It helps to look for these common symptoms of early-stage Alzheimer's disease

- gaps in memory
- confusion
- problems with language
- disorientation of time or place
- poor or decreased judgement
- personality change
- apathy and withdrawal
- diminished ability to do everyday tasks.

Today there is about a 90% accuracy rate for diagnosis of Alzheimer's disease. A visit to your doctor to talk about symptoms is the first step.

## Memory signals you should know

It's important to distinguish between typical memory lapse and consistent or more pronounced loss of mental ability. For example, most people experience misplacing their car keys (some of us even chronically!), however, disease-related memory loss could prevent someone from knowing what the keys are used for – even temporarily.

Here are some good examples developed by Alzheimer's Australia of what is considered 'normal forgetfulness' compared to memory loss associated with dementia.

Description	Person with dementia	Older person
Events	May forget part or all of an event	Memory may sometimes be vague
Words or names for things or objects	Progressively forgets	Sometimes may forget. Words or names are on the tip of the tongue
Written and verbal directions	Increasingly unable to follow	Able to follow
Stories on TV, in movies or books	Progressively loses ability to follow	Able to follow
Stored knowledge	Over time loses known information such as historical or political information	Although recall may be slower, information is essentially retained
Everyday skills such as dressing and cooking	Progressively loses capacity to perform tasks	Retains ability, unless physically impaired

## talk first, test later

Your doctor or specialist will want to create a thorough case history before any diagnosis. This starts by talking to the person experiencing memory loss AND someone close to them in order to gather as many facts as possible (and avoid the risk of omission).

Strokes, depression, alcoholism, infections, hormone disorders, nutritional deficiencies and brain tumours can all cause similar symptoms to dementia. It is very important to seek medical advice early to treat any condition appropriately.

### Some of the information doctors may need for assessment include

- a general profile of lifestyle
- details of past illnesses
- whether any family members have experienced a nervous system disease
- what sort of medication (prescribed or self-administered) the patient takes.

### After consultation, further examinations may include

- blood pressure
- blood tests (to check for hormonal or vitamin imbalances or viral infections)
- general physical with particular attention to the nervous system
- mental performance tests for memory and problem-solving ability
- further tests like brain scans and possibly chest X-rays.

## Starting with the basics

Assessment always starts with a series of questions to see how the patient responds. The Mini-Mental State Examination (MMSE) was introduced in 1975 and has become one of the most popular and effective methods to detect problems from very early on. A follow-up MMSE is normally scheduled 3-6 months later.

### A sample of the questions include

What's today's date?

What day is it?

What is the season?

What building are we in?

I'll name 3 things.

Please repeat them back:  
street, banana, hammer.

Count backward from 100 by 7.

Can you repeat the things I mentioned a moment ago?

Write a complete, sensible sentence about anything at all.



## the stages

Alzheimer's disease and other dementias affect people differently. While doctors can 'best guess' the disease's progression, a great deal depends on an individual's age, medical and family history, physical/emotional condition and home environment.

From first diagnosis, it's important for the person with Alzheimer's disease as well as their carer, family and friends to be aware of current changes and the ones yet to come. While much is still not known, there are a growing number of resources for information and support when it comes to living with the disease. Make these part of your life to better understand and adjust to Alzheimer's disease.

No specific time frame defines each stage of the disease. While the medical community formally recognises seven stages, common acceptance defines three stages – Early, Moderate and Severe (or 1, 2, 3) with each stage having phases of noticeable decline.

Remember people with dementia have good and bad days. Some days a person will be clear-headed and alert while other days they may become more agitated, confused or angry. This is a normal part of the disease's progression. Take each day as it comes.

The following outline of typical behaviours and changes to expect in Stages 1, 2 and 3 of Alzheimer's disease is only an overview excerpted from the Alzheimer's Australia Help Sheet 'Progression of dementia'. More detail will follow in Look Forward chapters 2 and 3.

## early stage: the forgetful phase

Alzheimer's Australia has summarised these key traits which characterise Early Stage Alzheimer's disease which can last from 2 to 4 years. People tend to

- say the same things over and over
- get lost easily, even in places they know well
- lose interest in things they once enjoyed
- have trouble finding names for common items
- lose things more often than normal
- go through personality changes.

### Personality changes

The hardest part of facing the disease is knowing your abilities will diminish. Everyone experiences profound frustration, especially seeing skills slip away. Socially, people with Alzheimer's disease may withdraw; they show less energy and initiative. Emotionally, they may become more easily upset, anxious or angry. These symptoms can be triggered instantly and dramatically.

Irrational behaviour is an effect of the disease and not controllable. Degrees of this behaviour vary, but in early stages, it may look like carelessness – for example, putting a wallet in the refrigerator or leaving a car door open.

### Motor skill changes

Driving a car can become risky as the person becomes more vulnerable to mistakes in judgement or co-ordination. While most usual tasks can be performed, many involving a process – like preparing a meal or operating appliances – become too complex.

### Memory changes

Apart from forgetting things, impaired decision-making can affect everyone. Many ordinary decisions involving finances, directions, instructions or schedules simply become too complex. What may have been a regular route to the shops now is a totally unfamiliar journey.

## moderate stage: the confused phase

Alzheimer's Australia indicates that the second stage of Alzheimer's disease is often the one that lasts the longest – anywhere from 2 to 10 years. For that reason, carers become very familiar with how a person with Alzheimer's disease behaves during this time.

Those in this stage may

- become more confused about recent events
- experience difficulty with simple daily activities such as dressing
- argue more often than usual
- believe things are real when they are not
- pace about
- often require close supervision
- display anxiety or depression.

### Behavioural changes

Frustration increases and the person may react more severely to loss of abilities. Delusions may occur where the person believes things that are not real. Disturbed sleep and hallucinations may prevent a good night's rest. Wandering at night is likely.

Compulsive symptoms like repeating gestures or activities may occur as the person cannot hang onto a thought long enough to complete the task. The same repetition also shows up in speech when words or sounds are repeated or sentences are expressed in only a few, often confused words. Excessive demands – whether from a carer or the environment – can result in outbursts or severe withdrawal.

### Motor skill changes

Help with daily activities is essential. Co-ordination is limited so dressing, grooming or eating require more and more assistance. Over or under-eating is common if unmonitored, and the hazard of choking or inhaling food becomes a real possibility.

## final stage: severe dementia

Those in the final stage of Alzheimer's disease require constant around-the-clock care. The great majority of people who get Alzheimer's disease do not reach this third, or terminal, stage; they die of the normal diseases of age in the second stage.<sup>6</sup>

During the third stage, however, the person is unlikely to

- use or understand words
- recognise who they are in the mirror
- recognise family members
- care for themselves at all.

Care during this stage has significant limitations. With little likelihood of communicating with or even recognising family members and carers, the person needs constant vigilance and help with most functions.

Outside care is a realistic option. While the carer may want to keep the person at home, it's essential to recognise just how much help and work is required.



## Starting with the basics

The adjustment to caring for someone with Alzheimer's disease takes empathy and support from family and friends. A carer must be open to share initial feelings and look for constructive ways to cope with both practical and emotional issues. Make a point to discuss the diagnosis with the family as soon as possible, emphasising this is an irreversible disease not a temporary psychological condition.

As every stage of Alzheimer's disease has increased demands, the carer cannot be expected to shoulder all aspects of care – especially transport, meals, medical appointments and exercise. It's never too early to put legal matters in order as the implications of Alzheimer's disease will have an effect on finances, medical care and housing.

The Alzheimer's association in your State or Territory will help you determine a manageable course of action. The second chapter in this series, Managing Alzheimer's disease, takes a closer look at care issues and makes specific suggestions for dealing with each stage.



## Profile of caring

### Sara and Tom

Sara and Tom were big movie fans but agreed they weren't what they used to be. Yet it came as some surprise when Tom couldn't even seem to remember films he had just seen when discussing them with friends.

This made Sara think about other examples of Tom's forgetfulness. She remembered how alarmed she was when reminding him of their grandson's birthday – he said "Who?" Or when he had trouble folding a letter to put in an envelope – and gave up. Or when one morning she announced plans for a noon luncheon and at 11:30 he asked about lunch.

Sara knew since they were both in their 70's it was normal to be getting more forgetful. But certain aspects of Tom's behaviour made her want to talk to their doctor. Could his medications cause side effects? Was he hiding some pain he wouldn't talk about?

On Tom's next visit to his doctor (to check his arthritis and medication), Sara was welcomed to the consultation. She was extremely tactful describing Tom's forgetfulness. Taking the hint, their doctor asked Tom many questions – some health related, most not. They realised Tom shouldn't be stumped by questions like "Do you still have your dog?" or "What colour is your car?"

Their doctor suggested ways to 'signpost' Tom's memory lapses or hardships in daily tasks – keep a diary and leave notes around the house. They were asked to keep a clearly written calendar of upcoming events or appointments.

While their doctor gently suggested he was 'exploring the possibility of early-stage Alzheimer's disease' he recommended Tom have a series of blood and brain tests. This, he explained, was more to rule out any other forms of disease rather than confirm the likelihood of Alzheimer's disease.

Two weeks later, Sara and Tom returned to their doctor. After discussion, Tom was referred to a neurologist who could more specifically suggest a course of action. The neurologist put Tom on a course of drug therapy with cholinesterase inhibitors to help inhibit the breakdown of essential brain chemicals and hence slowing down the progression of the disease. Another visit within two months was scheduled to check on Tom's condition and see if Sara had noted any significant changes.

# what family and friends can do

When a family member is diagnosed with Alzheimer's disease, someone will usually take on the responsibilities of looking after them. Practical and emotional support at this stage and in the future are essential. Daily routines will become less and less predictable. Commitment of your time and patience will become more and more demanding.

If you become the primary carer, it's important to make time for yourself. Stress levels, if left unchecked, can result in running yourself down or contribute to depression. With so many demands and responsibilities, plan your day to allow time for yourself. Call on friends and family to help whenever possible.

There's more detail on how to do this in chapter 2: Managing Alzheimer's disease.

## begin adjustments early

While signs of the disease may affect you gradually, it helps to adopt safe and secure practices around the home as soon as possible. This will avoid drastic changes later that can upset or confuse. Above all, familiarity and routine play a significant role in keeping emotional balance for both of you. A few guidelines, which will be explored in more detail include:

- **Familiar surroundings** Keep the home environment the same as much as possible. Avoid re-arranging furnishings or changing décor. If a household move is planned, do it as early after the diagnosis as possible to allow time for the person to adjust to the new home.

## How to decide if driving is unsafe

When someone is diagnosed with Alzheimer's disease, monitor their skills regularly to avoid the dangers of driving.

How is the person's sight? Good peripheral and distance vision are important.

Is reaction time prompt to avert accidents, especially due to another car?

Is decision-making ability intact to calmly decide the right course of action in an emergency?

Are there signs of physical clumsiness that would slow driving responses?

Is the person still alert to what's going on in general?

*Extracted from Triad, a newsletter for Alzheimer's disease care*



- **Daily routine** Regular times for routine activities should continue. If activities have been haphazard, it's wise to adopt a routine now. Waking up, dressing, breakfast, exercise, lunch, dinner, bathing all become essential rituals to look forward to that can have a calming, reassuring effect.
- **Simplicity** Keep the home free of clutter or excess which can be disturbing. Also think about removing hazards through the home like door mats or throw rugs and inessential small furnishings.
- **Speak to be understood** Start simplifying conversations, too. This helps a person with Alzheimer's disease to understand basic information clearly. When asking questions, phrase them to allow for "Yes" and "No" answers. When offering choices, keep them straightforward and limited to two. When giving instructions, focus on one thing at a time.
- **Eliminate disturbing effects** It's surprising how many people with Alzheimer's disease become intolerant of familiar sounds. Certain doorbell or telephone tones can agitate them, as can loud television or radio programmes, traffic noise or barking dogs. Where possible, try to avoid these noises or find alternatives.
- **Continue hobbies and home help** For as long as possible, allow the person to continue with their normal role at home and pursue their interests. Down the track, incorporate simplified tasks in their day like stacking papers or folding laundry. Be aware if certain activities become frustrating or taxing.

## coping with changed behaviour

In progressive stages of the disease, the changed behaviour of a person with dementia can be stressful and upsetting. Coping with changed behaviours can be very difficult and is a matter of trial and error. Always remember that the behaviour is out of the person's control and is not deliberate.

Sometimes it's easier just to ignore what is happening. For example, if a frying pan repeatedly appears in the fridge, there's little point complaining about it. With other behaviours it is possible to work out strategies to help you cope.

## Explaining the diagnostics

You may find it difficult to explain a diagnosis of Alzheimer's disease to your friends and family. One option is to write a letter (or email) which gives the same information to everyone. The example below is written in a straightforward style and gives the key points that you might like to include. Then when you're contacted, you can fill in the details as appropriate.

If you prefer to explain in person or over the phone, the information included in the letter is still a good starting point for this conversation.

Dear <person's name>,

I'm writing to let you know we've had some very serious news about [name]. S/He has just been diagnosed with Alzheimer's disease - and while still in early stages, I thought you might want to know.

You may want to include some background about what prompted medical attention

We first noticed [person] had trouble remembering a few things and sometimes acted strangely. But it wasn't until s/he <describe a non-embarrassing incident here> that we decided to see the doctor.

Describe briefly what the visits entailed, whether there were any tests or procedures, and what you plan to do in the short-term

After seeing a specialist and returning to our doctor, we found out that while there's still no cure, we can help control the symptoms over the coming years. We'll try medication and make the best of our usual activities while we can. We'll just take it one day at a time.

Let them know you would welcome hearing from them. Mention someone who is already showing support - especially for you as a carer

I know you have a lot going on but it would be wonderful if you have a chance to visit or call. <my sister, Denise> will be here every Tuesday afternoon to help me out with little things and spend time with [Dad/Mum/name].

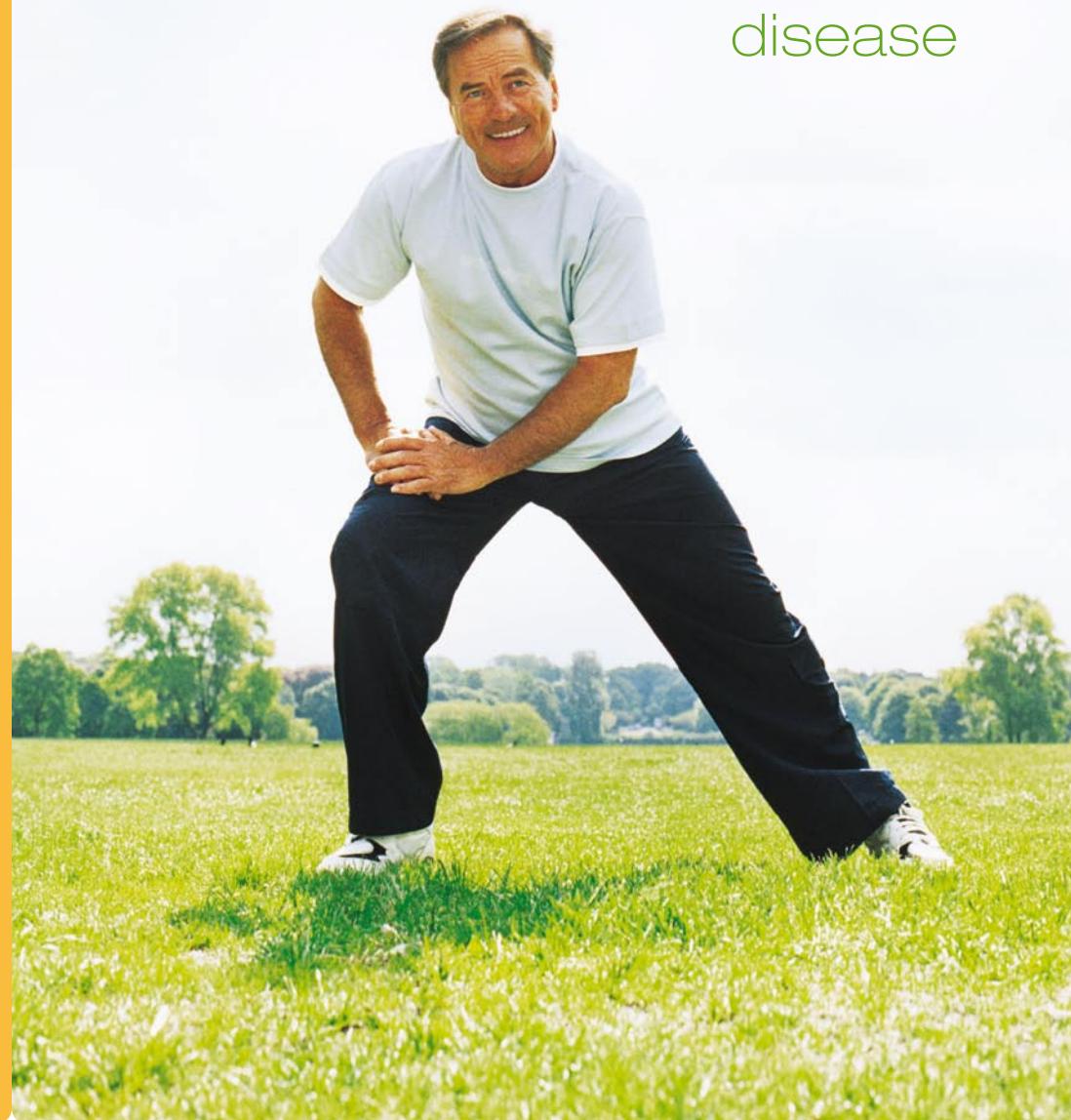
Mention you're looking into support services or groups and ask for recommendations

I'm busy finding out more about Alzheimer's disease and have already had contact with [the Carers Association and Alzheimer's Association <state>]. If you know of any other groups or services I should call, please let me know.

Include your details and a warm sign-off

You can still reach us at [address, phone]. We truly hope you're well and look forward to hearing from you.

## managing alzheimer's disease





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# a time of changes

When Alzheimer's disease begins to have greater impact on daily care, prepare yourself by having people to turn to and receive constructive relief.

If you are looking after someone with Alzheimer's disease, you need help and support to be an effective carer. Very few people are able to make the adjustment from their full-time responsibilities without the help of other family members or services available in the community.

This chapter explores the progression of Alzheimer's disease and explains how to deal with changing behaviour. You will find suggestions on sharing care and ways to deal with many day-to-day situations. We have also provided up-to-date resources to help you take the next steps in building your own important network of support.



## the 3 Ps of managing Alzheimer's disease: planning, patience, perseverance

As with most of life's events, everything goes more smoothly with planning. Nowhere is this more true than with a diagnosis of Alzheimer's disease. No matter what your role is – the person with Alzheimer's disease, a primary carer or family member – practical matters should be put into place as soon as possible.

### Planning

Two critical areas of planning are practical and financial assistance.

The impact of Alzheimer's disease is such that care is not a matter of convenience; it will become a requirement. Family members, particularly the spouse or adult children, will be called upon to provide supervision and everyday assistance for the person with the condition. Where a couple relies on one another for every aspect of care and support, they will have to broaden their 'care network' if one of them is diagnosed with Alzheimer's disease.

It is important to sort out financial obligations as early as possible and forecast what changes lie ahead. Out-of-home commitments may be seriously limited, so jobs and other relationships can become strained.

### Patience

Living with Alzheimer's disease is a time of adjustment. While the disease may go on for years, no two days will be the same. Seeing a friend or family member 'lose themselves' is distressing to say the least. Caring for that person puts super-human demands on everyday life and calls for remarkable patience and understanding.

Understanding how others respond to the diagnosis is equally challenging; people avoid what they don't understand. Helping them understand the disease (and the person it affects) will become an everyday event. People may think that Alzheimer's disease, given that it is a form of dementia, is something 'to steer clear of' and that anything they might do will not make a difference. In fact, the opposite is true; every effort to help and provide compassion is valuable at this time.

### Perseverance

If you are the carer, understand that your continued help and optimism makes an important difference to the comfort of the person with Alzheimer's disease. This shouldn't mean total sacrifice of yourself. Counselling for grief, guilt and all the accompanying feelings of helplessness is important at this time, as is support from family and friends.

## adapting to behaviour changes



## When changing behaviour impacts lives

When certain behaviours appear – like forgetfulness, anxiety, angry or tearful outbursts or compulsive/repetitive actions – it is important to note when they happened and, if possible, what may have provoked the behaviour.

A daily journal (provided at the end of this booklet) will help both you and your doctor keep track of what is happening. The result may be to evaluate medication or make suggestions on adapting your lifestyle or environment. Remember, in no way should these be taken as instructions on how to run your life. Rather, suggestions from an impartial source (one who does not deal with round-the-clock care as you do) provide sound insights on how to manage the person and plan your day as a carer.

## Challenges and choices: simplifying life

A difficult (and frustrating) aspect of daily care is the constant surprise at what awaits. Changes day-to-day are rarely positive. Sometimes suddenly diminished abilities, like not knowing how to put on clothing or forgetting what towels are for, can cause chaos.

When the time comes to supervise personal functions like dress, hygiene, meals or even sleep, a carer is constantly tested. Although traditional communication becomes difficult, acting with loving-kindness will always say more than words can express. Staying positive and reinforcing small victories will help everyone face the challenge of each day.

Try to focus on realistic expectations and respect limitations. Why create challenges that can't be met when everyone could be satisfied achieving smaller goals?

The same is true as Alzheimer's disease progresses. Take every moment as it comes. Downsize agendas, activities and anything that calls for prolonged attention. In other words, simplify. Everyday tasks, conversations and hobbies can continue, just at a slightly different level. Most people with dementia welcome ways to express themselves in social situations with friends and family.

## Communicating effectively<sup>7</sup>

Here are a few talking and listening tips to help achieve meaningful conversations with someone with Alzheimer's disease.

### 1. Gain attention

Many elderly people have diminished vision or hearing anyway so it's a good idea to greet them by name or use a gentle touch when speaking to them. When addressing a person with Alzheimer's disease, wait until they have finished a task or activity before interrupting.

### 2. Eliminate background noise

Help the person focus on your conversation by removing any distractions like TV, music or other voices. Often they cannot tolerate the cacophony of many voices at once and find it disturbing.

### 3. Use nonverbal cues

Body language and facial expressions are helpful to gain and keep attention or illustrate a point. Smiles, a touch on the arm and direct eye contact are also reassuring.

### 4. Maintain a calm tone

Your tone of voice speaks volumes; slow, relaxed speaking is much easier to understand. If you're normally a quick talker, learn to bring down the pace.

### 5. Listen actively

Take the time to listen to what someone is trying to say even if the words aren't quite right. Make a conscious effort at listening carefully and patiently. You'll often gain good insights.

### 6. Encourage expression & answers

Make sure you are understood and avoid complex, abstract sentences. Introduce a topic in general then move into more specific details. Express questions in a way that a simple "yes" or "no" will answer. Try to avoid certain expressions which could be taken literally and cause confusion (like "hop into the bath").

### 7. Distract as needed

When a person with Alzheimer's disease tends to repeat things, offer a distraction such as an activity, snack or walk outside. This is a more natural way to bring up a new topic rather than asking them to "stop it". Distractions work to calm anxious episodes as well.

### 8. Provide reminders

Notes, calendars and diaries are very useful to prompt a person with Alzheimer's disease for as long as they can use them. Be aware that announcing plans for the future (more than a week ahead) is NOT a good idea as it can provoke anxiety or repeated inquiries about the event.

### 9. Help with problems

Offer solutions with everything you say. Instead of testing memory with "Do you remember everyone's name", offer introductions like "Here are Claire and Ben with their son, Brian".

### 10. Accept silence

Non verbal communication becomes more important as the ability to handle language declines. Silence is not necessarily a sign of anger or depression; it may simply be difficult to initiate conversation. Remember, silence can be calming. Accept it.

While customary ways of relating to the world are affected with Alzheimer's disease, the need to relate is stronger than ever. People need to learn a new set of skills in caring for or communicating with a person with dementia. Expect trial and error. Reflect on what works well and what to avoid.

## Dealing with emotional behaviour

### Anger

The degrees of anger, from cranky to abusive, range in people with Alzheimer's disease. They tend to lash out at small irritations while trying to cope with larger issues. Try not to let their anger provoke yours.

**Suggestions** Try to understand feelings in order to cope with them. Know that a person's anger may look like it's directed at you, but is more a reaction to their own shortcomings. It usually helps to ignore anger rather than confront it.

### Anxiety

Stress can show up as anxious behaviour, as in repeated gestures or repetitive questions. Nothing can drive a carer up a wall more than hearing (or seeing) the same thing hundreds of times a day.

**Suggestions** Look for causes behind the question. Asking "What time is it?" every few minutes means the person is bored and needs distraction. People with Alzheimer's disease are often aware they're losing touch with the familiar. Be reassuring. Once a carer finds ways to unlock the 'true meaning' of questions, the more likely they are to find the patience to answer them.

### Agitation

People may become more confused, restless, insecure or prone to outbursts late in the afternoon or early evening. This behaviour is often called 'Sun-downing'.

**Suggestions** As energy levels tend to drop in the afternoon, encourage an after-lunch rest time. Having afternoon tea or snacks like fruit, yogurt or muffins can boost the system. Try using lavender essential oils or fragrance to help bring about emotional calmness.

## Dealing with emotional behaviour

### Abuse

Outbursts, expletives or screaming fits can occur when the person feels overwhelmed or inadequate. Again, this is not behaviour he or she can control. It is the disease's removal of inhibitions or protocols.

**Suggestions** Calming an abusive person can be difficult, but a distraction like a favourite video, TV programme, music or activity may help. Carers must take care not to give in to their own rage. Many people with dementia experience abuse (verbal or worse) by frustrated carers. Support and relief are essential.

### Fear

Any new or unfamiliar activity can prompt fear that results in reactions like crying, hiding or anger. Sudden or startling changes can trigger fears and even catastrophic reactions (severe outbursts).

**Suggestions** Find the source of the problem and steer clear of it. A walk or drive may take the person's mind off the problem. Remember, rational explanations are not usually the answer. People with Alzheimer's disease often respond to physical soothing, like stroking an arm or gentle massage.



## What happened to Ronald Reagan?<sup>8</sup>

A few years after leaving his second term in the White House, Ronald Reagan's memory lapses became too pronounced to ignore. While it was likely he was developing Alzheimer's disease during office, there was not enough decline in his function to warrant a public announcement until 1994.

Did Alzheimer's disease affect Reagan's functioning as president? With so many people and resources available to help him through his everyday demands, we can never be sure how disease affected his obligations of office. However, during a regular medical check-up late in his second term, he joked with his doctor "I have three things to tell you today. The first is that I seem to be having a little problem with my memory. I cannot remember the other two".

In July 2000, the daughter of this powerful man, who in 1982 declared November National Alzheimer's Month, appeared before the world's largest assembly of professionals dedicated to combating the disease. Her father was in the final stages of the disease. He had stopped talking and had trouble walking. Six years had passed since his official diagnosis. Yet despite accelerated research and more awareness, doctors and scientists were still grappling with how to find the cause and a cure.

Despite living with Alzheimer's disease, Ronald Reagan saw his 92nd birthday (9 January 2003) and 50th wedding anniversary among loving, supportive friends and family. Clearly, good care can make an enormous difference.



# adapting to lifestyle changes

Life doesn't stop when dementia starts. It's important to encourage the person with Alzheimer's disease to continue to take part in social activities for as long as possible.

## Recreation: going places, doing things

Finding the right social and recreational activities to share is a matter of your own judgment. Spending time together at sporting events, going to concerts, the theatre, or visiting museums and galleries are all pursuits you can continue to enjoy. Outdoor hobbies like walking, fishing, swimming or bird-watching may help rejuvenate both body and mind. Or you may prefer to just visit friends.

If the person you are caring for has incidences of anxiety or fear, reassure them about where they are and what they're doing. These reactions are often short-lived and just a momentary lapse in awareness. Given that these lapses are likely to increase over time, take care not to become involved with activities where a hazardous outcome could take place (for example boating or bicycling).

*(The Alzheimer's Australia Help Sheet 'Activities' provides information on planning and providing activities for people with dementia.)*

## Developing positive coping strategies<sup>9</sup>

The more you know about the disease, particularly in the early stages, the more able you are to prepare for the future. Consider integrating the following Coping Strategies and Actions early to better adapt to living with Alzheimer's disease:

Coping Strategy	Action
Acceptance	Read accurate information. Discuss the facts with the person with Alzheimer's disease. Accept that a family member has the disease. Let the person with Alzheimer's disease be involved in making decisions. Accept the 'good days, bad days' nature of the disease and respond accordingly.
Sharing with others	Let the person with Alzheimer's disease help decide which family/friends will hear the diagnosis. Anticipate reactions and responses.
Use technology	Incorporate modern devices to assist daily living like more smoke detectors, beeping key chains, electronic organisers, pocket tape recorders, email and the Internet.
Positive sense of self	Focus on strengths of the person with Alzheimer's disease. Develop a list of accomplishments over their life; read it often.
Role replacement	Continue tasks and roles as long as able. Create alternative, meaningful roles. Support each success and tolerate failure.
Be proactive	Encourage the person with Alzheimer's disease to plan all aspects of the future and think ahead. Anticipate specific functional changes; ie. driving, living arrangements, etc. Adapt to changing needs as Alzheimer's disease progresses. Find out what is offered in the community for activities, learning and resources. Reinforce the familiar; create routines and follow schedules.

## Nutrition

It is vital that meals be monitored for someone with Alzheimer's disease, especially when they were accustomed to cooking for themselves or their family. As faculties diminish, planning or shopping for well-balanced meals is difficult, not to mention preparing them. Even when meals are provided in advance, leaving foods too long or failing to heat them properly risks bacterial contamination. On the other hand, having a pantry full of ready-to-eat 'junk food' (sweets are a common craving) can lead to malnourishment.

The carer should take responsibility for nutritious meals. An alternative to daily preparation is to take part in 'Seniors Meals' community programmes. Aside from good food, these offer a chance at socialising and altering the routine for those individuals who can cope with the experience.

In some instances, unusual eating habits or preferences develop. Eating too much, too little, too slowly, too quickly or even compulsively (like only one food) is not unusual. It is sensible to encourage a proper diet, but sometimes it may help to go along with harmless preferences.

Dehydration is an issue for many older people with or without dementia, so encourage drinking plenty of water. Take care to avoid or limit alcohol for someone with Alzheimer's disease as many problems may be exaggerated through overuse. Some patterns of destructive behaviour may be alcohol-related rather than symptoms of the disease. Talk to your doctor about ways to check or deal with the hazards of heavy drinking.

## Continence

Incontinence is the loss of control of bladder and/or bowel function that is triggered by signals from the brain. In people with Alzheimer's disease, changes in the brain can interfere with a person's ability to:

- recognise the need and be able to wait to go to the toilet
- find and recognise the toilet
- use the toilet properly.

Seek your doctor's advice to rule out medical complications. Remain calm and patient; there are ways to alleviate the problem or make it less stressful.

For more information, contact the National Continence Helpline on 1800 330 066, Monday to Friday, 8am to 8pm (EST).

## Children and Alzheimer's disease

In continuing relations with people with dementia, some of the most resilient, forgiving people are children. Being introduced to Alzheimer's disease once symptoms cannot be ignored makes it easier for them to accept the changes ahead.

Children may feel sad or afraid about a family member's changes in behaviour or personality – especially if they're close to that grandparent or relative. Let them know these feelings are normal and educate them about the disease. Encourage them to ask questions and answer them honestly or seek answers together. Help children or teens avoid worry or guilt by keeping communication open. Give them a chance to express their feelings – even if those feelings include embarrassment, resentment or frustration.

Children and family can continue a constructive relationship with the person with Alzheimer's disease by

- looking at old family photographs together
- creating a memory book for the person with Alzheimer's disease
- charting a family tree
- keeping a journal together.

Ask your local librarian for age-appropriate children's/adolescent books. There are a number of excellent titles available as storybooks, as well as non-fiction.

## Profile of caring

### How Carol juggled her work, son and mum

Many people find themselves sacrificing jobs and their personal lives to become committed carers. Alzheimer's disease disrupts schedules and poses totally unpredictable demands.

Such was the case of Carol – a Sydney single mum with a teenage son and a full-time bank-teller job. When her mother began showing signs of self-neglect and forgetfulness, Carol rearranged her schedule to spend weekends with mum who lived three hours down the coast.

At some point the bank branch manager noticed the strain on Carol. Fortunately they were both willing to discuss the situation. While there was little her boss could do to help Carol with her son's commitment to high school, she did suggest Carol take a temporary transfer to a branch in her mother's town. It would allow her to continue work while being able to stay with her mum to monitor the signs of dementia and care for her more closely.

The result was both positive and practical. Carol found short-term tenants for her home while her son stayed with family friends for the remainder of the school year. She was surprised and pleased that her son took the train most weekends to help her with his grandma. Eventually, a suitable residential care facility was found and Carol moved back to Sydney but was able to visit regularly.

## Wives and daughters

A study surveyed 252 female carers; 103 of whom were wives of men with Alzheimer's disease, 149 were daughters with a parent with Alzheimer's disease.

The study found that the daughters were significantly more likely to become clinically depressed. This may be a result of several factors.

First, in marrying, a spouse commits to caring for her partner 'in sickness and in health,' but a daughter never signs up to care for her parents.

Second, a daughter may have other family responsibilities and relationships that suffer as a result of the time and stress involved in caring for her parent.<sup>10</sup>



## care for the carer

Learning to manage strange behaviour, demanding schedules and solve new problems is challenging to most individuals. As the carer of someone with Alzheimer's disease, you will discover a new capacity in yourself to be creative, resourceful and resilient. It's a job no one applies for, yet there is often little choice but to accept it.

Maintaining your own well-being is vital to providing good care. Physical and mental exhaustion are not uncommon among carers. Find time for yourself with activities and relationships apart from the person you look after. Family and friends can become your greatest allies for this relief.

## Relaxation and renewal ideas

Everyone has ups and downs, highs and lows, but carers of people with Alzheimer's disease do tend to experience them more than usual, given the unpredictability of the illness.

It's important to get away from the everyday demands of full-time care. Find ways to physically, emotionally and spiritually revitalise yourself regularly in your schedule. Think beyond shopping or visiting friends, as both of these everyday activities will not take you sufficiently away from your concerns.

You'll see from the following list that many suggested activities are in groups or classes. This can help you find a new network of people who do not regard you as 'the carer' and instead appreciate you from a different perspective. Don't be wary of learning something new. Acquiring a new skill or interest is like making a new friend, one you'll grow to cherish for what they give to you.

Find out about these activities from your local papers or library notice board:

yoga	sewing groups	pet training
tai chi	craft classes	photography clubs
swimming	cooking classes	choir
aqua aerobics	gardening clubs	musical tuition
exercise classes	book groups	
library visits	foreign language	

## Counselling

Seek counselling and support groups as a carer. Not only will this give you the opportunity to spend time with others in similar situations, you'll also find helpful approaches to coping with daily situations.

While group counselling is a social situation, realise that it does not take the place of social outings with friends. It is meant to be constructive, sharing and co-operative. You may find it preferable to seek individual counselling on personal matters like your own fears, frustrations or grief. Speak to your doctor for referrals or contact your local Alzheimer's association.

## Community services available for the carer

Find out about groups and associations to help you with advice and activities as early in the disease as possible.

Your Shire or town may have community listings of support groups or Senior Centres published in your local newspaper.

Australia-wide, resources abound (with a wealth of information on the Internet) to help you at every stage and with many issues.

The following resources may be able to help. As with any search to find the right answer, it helps to start in the right place.

### Alzheimer's Australia (in each State and Territory)

These organisations are set up as central resources for many support functions: Call **Dementia Helpline** 1800 639 331 or visit [www.alzheimers.org.au](http://www.alzheimers.org.au)

**Social workers** identify and organise help, including possible financial solutions. **Home health care organisations** like HACCC (Home and Community Care) provide nursing services, medical/social workers and therapists. **Home health aides** also provide assistance with personal care.

**Out-of-home services** include adult day care centres, mental health services, transport and nursing homes.

**Carer relief programmes** are often community-based with a central state organisation to contact about services available in your area. They are usually listed as Carers Resource Centre, Carer Respite Centre or as a Carers Association of your state.

**Centrelink** can advise you about Carer Allowance (or Payment) and also whether you are eligible for Disability Support Pension or financial assistance for housing, pharmaceuticals or mobility allowances.

**Financial and Legal Planning** should be looked after by the family solicitor, the Law Society, Legal Aid or Office of the Public Advocate.

## At home help

### Care for a person with dementia

When you feel you need specialised help (or have limited support from friends or family), consider a paid helper for part-time relief.

See CentreLink for information on Carer Allowance to help with the cost of home help. Home care agencies will recommend people suitable for the help you need. In some cases, this may require special qualifications – like hiring a nursing assistant as opposed to a companion. Or you may wish to advertise for help and screen applicants yourself. This allows greater flexibility to negotiate rates, days and the type of help required.

### Housework

To spend constructive time with the person you are caring for, it makes sense to assign more mundane tasks to outside help. Hiring someone to clean is one good way to free your precious time and attention. Having ironing done out of home may be an advantage for time as well as safety. Consider also using the internet for grocery shopping with home delivery. If you don't have a computer, every local library in Australia now has an Internet-connected computer and will help you use it.

## Home safety

As Alzheimer's disease progresses, both you (the carer) and friends or family who help out, should be aware of potential everyday hazards.

### Floors/stairs

Keep areas free of clutter, loose rugs or non-essential furnishings. Avoid polished floors and ensure stairs or steps are well-lit with stable handrails.

### Exits

As the likelihood of wandering increases (especially at night), secure all doors. Chimes or alarms installed to signal open doors are excellent alerts. Choose secure locks and avoid blocking doors with furniture in the event of fire. Windows, too, should be fitted with locking devices.

### Identification

In case of wandering, a wristband or necklace with name and contact details is helpful. These are available at most pharmacies. Alzheimer's Australia can also provide identification cards.

### Kitchen

While most of us have at some time forgotten something on the stove, this is more common for those with Alzheimer's disease. It's wise not to expect them to cook, chop vegetables or operate appliances reliably. In some cases, safety locks on stove fixtures and cupboards can prevent dangerous situations. (Alzheimer's Australia's Help Sheet 'The Kitchen' provides useful advice on how to make the kitchen safer.)

### Bathroom

Most home accidents happen in the bathroom. Slippery floors, hot water or broken glass can cause minor mishaps as well as serious injury. Avoid sliding rugs, glass jars or bottles, medications or things that could harm left in open cabinets. Install a maximum water temperature thermostat to help prevent scalds and burns.

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planning  
ahead with  
alzheimer's  
disease



# courage to face the future

As Alzheimer's disease progresses it is crucial to plan ahead and have practical strategies to manage living with the illness. By making plans early, the person with dementia may be able to participate and ensure that their wishes are carried out. This should include arrangements for financial and legal obligations.

This last chapter of the Look Forward booklet that examines options through to the later stages of Alzheimer's disease. You will also find a number of questions and answers that span the topics of all three chapters.

We hope you have received practical, supportive information with all the Look Forward materials. They are intended as a starting point to help you find out more about the disease so that you can be better prepared for its course. Share this information with family and friends and look further into the resources listed at the back of each chapter.

## advanced stages of illness

As Alzheimer's disease progresses, many basic motor skills can be affected since areas of the brain can no longer send signals for functions like balance or muscular control.

Some examples of loss of coordination in advanced stages of the illness include

- problems getting out of bed or up from a chair
- jerking muscles or tremors
- frequent stumbling or falling
- general muscle weakness
- repetitive motions like rocking or swaying
- involuntary motions like tapping or swatting
- difficulty swallowing
- inability to perform purposeful movements
- loss of continence.

Any of these signs should be reported to your doctor as some could be symptoms of other illnesses, or caused by certain diets or medications. Also keep in mind that as a person loses the ability to walk, talk or swallow, they become more at risk from complications like pneumonia or malnutrition.

Caring for an individual with more advanced stages of Alzheimer's disease takes around the clock vigilance and support. To achieve this, outside help or residential placement may become necessary.



# selecting a residential care facility

Many considerations go into deciding when to place the person with dementia into a care facility and then finding the right residence. Thanks to a greater public interest in looking after our ageing population, most nursing homes and aged care facilities are now more modern and home-like.

Among many important questions, the first ones to ask yourself are

1. Is care needed that is beyond your capacity to provide?
2. Does the care facility provide what you need?
3. Will you and others be able to stay in contact easily?

## Is external care needed?

Making the decision to find an alternative to caring for a person at home can be a difficult one.

Keeping in mind that each situation is unique, when the list of personal needs outweighs the capabilities of the carer or family to provide them, outside care may need to be considered.

Alzheimer's disease affects each person differently and safety issues need to be considered in every care environment. Symptoms such as memory loss, confusion and disorientation are usually present, and limited mobility and coordination may be additional factors affecting safety. Some people with dementia may become disoriented and get lost in unfamiliar or even previously familiar places.

A long-term care facility clearly has specific advantages, especially for those needing close, around-the-clock supervision. Having the daily care needs looked after by a residential facility can also help the person with dementia to continue meaningful relationships with their family and friends.

## Evaluate care facilities

Choosing a residential facility is a very difficult thing to do. For many people, atmosphere is certainly the most important factor. This means looking beyond the lobby at how residents live, socialise and function day-to-day. Take into account how individual needs are met and how flexible the facility can be. Activities for those who enjoy them can provide purpose and pleasure, and may reduce aggressive behaviours.

A programme and staff that offers organised, individualised activities such as music, games, exercise, dancing, gardening or group excursions is more likely to keep residents intellectually enriched.

Ongoing contact with friends and family shouldn't be limited to visiting hours or confinement to the facility. Ask about opportunities to take your family member on outings or visits.

Many facilities have an active volunteer network to take residents on excursions or shopping, which can truly help their sense of independence and control. Even a regular visit to or by a hairdresser or barber can be uplifting.

Clearly, competent medical supervision is also important, particularly having counsellors on staff to help with behavioural symptoms. Ask about the medication policy and review any admissions agreement thoroughly before signing.

There is a lot of information available to assist you in choosing a residential facility – contact Alzheimer's Australia to find out more.

## Involve others

If possible, visit a few facilities with the person living with Alzheimer's disease while they are still cognisant of most personal issues and their likes and dislikes. If they can be involved with the selection well in advance of placement, the prospect of leaving home may not feel as daunting when the time comes. Remember to be clear on visiting frequency or outings together.

Family members should also be advised or invited to take part in the selection. Keep an open forum on all matters, especially arrangements for holidays or special occasions as well as ongoing visits.

Taking up new residence should not keep anyone from visiting. Accessibility is an important issue, as are visiting schedules. After all, no matter how comfortable or capable a facility is, nothing can replace the meaning of a familiar face. A trip of more than 10 to 20 minutes may prevent many people from making the effort.

## Later stages of dementia

People with dementia differ in the rate that their abilities deteriorate. But because dementia is a progressive disease, their abilities will decline.

If someone is in the later stages of dementia and becomes seriously ill, there may be discussion about whether to try to actively treat their illness. Giving or withholding treatment, such as resuscitation, is a serious decision and not an easy one to make. Discuss the options with both family members and staff of the residence. Planning can make a considerable difference to how an emergency is handled.

## In home help

In many instances, hiring nursing care at home is an option to alleviate demands on the carer. A qualified professional visiting on a regular basis can assist with meals, bathing, exercise and companionship.

This type of help can assist any transition period when considering outside residential placement. While expense for home-care varies, some assistance is available from private health funds. Or you can contact your local Aged Care Assessment Team to see if you qualify for assistance.

Look up Nurses/Nursing Services as well as Aged Persons Support in your Yellow Pages® directory and speak to your local Seniors Centre.

## Emotions

Often carers of people with dementia need help in dealing with their range of emotions when considering residential care.

The person with Alzheimer's disease may also feel frightened or angry about what lies ahead. Even though each person is affected in their own way, it helps to talk about feelings – especially loss, anxiety or guilt.

Finding reassurance is vital to avoiding depression or grief. That reassurance can come from friends, family members and counsellors or clergy.

## Coping with grief

Grief is an emotional response to loss. When a person develops dementia, the carer is faced with the loss of the person they used to know and the loss of a relationship. People caring for partners are also likely to experience grief at the loss of the future planned together. Grief is an individual feeling and people will feel grief differently at different times. Talking about your feelings with friends, family and professionals can be helpful.



## Look around you

Your first impressions of the facility are important. Consider these aspects of care when evaluating a residential facility

### Physical

- does it feel like a home more than an institution?
- a facility that reflects a caring atmosphere is easy to see
- is the security satisfactory?
- is there freedom to move around?
- are there adequate medical facilities on site?
- are there routine medical and dental checks, or is that left to the family to arrange?

### Social

- what interaction do residents have with one another?
- find out what activities are available apart from a TV room
- what are the dining arrangements?
- do outside groups or organisations take an interest in the facility?

### Individual

- apart from individual medical care, how much allowance is there for personal needs?
- consider everything from religious rituals to family outings when you assess a facility and the staff
- ask how they handle behaviour problems
- visit the care facility at least two or three times before making a final decision
- let your instincts play a part in your evaluation
- would you live there?
- do the staff welcome your inquiries?

Finally, find out what proportion of residents have Alzheimer's disease. You are looking for assurance that the staff are trained and experienced in caring for someone with dementia.

## Profile of caring

### Deciding when it is time

For two years, Joan watched and coped with the steady decline of her mother, Vivian, as she bravely confronted Alzheimer's disease. Joan was the only one of three children who still lived locally and although she had a busy family life of her own, she took on the ever-increasing responsibilities of looking in on her mum daily.

While her visits helped in functional ways (checking on her mum's food, helping her dress, making sure her TV programme guide or glasses or medications were within reach), Joan knew she was losing any emotional connection. These hurried visits became more about basic necessities – necessities which required more than an hour every morning.

Fortunately, she knew to speak to her mother about alternative living arrangements early on. They had both agreed, along with the rest of Vivian's children, that an Aged Care facility would be the best option when the time came.

The difficult question now facing them was: When was it time? On one hand, Vivian was still able to function independently to a degree. On the other, there were several occasions when her actions could have seriously jeopardised her well-being. There were increasing incidences of leaving the taps on until the bathtub overflowed; not replacing her phone on the handset so that incoming calls couldn't get through; leaving her space heater on all night too close to furnishings, or leaving food out all day.

Clearly there was no way to continue the way things were. Joan could see that her mum was starting to need ongoing supervision.

However, when she contacted facilities in the area, she discovered they had waiting lists of several years! While they had agreed to place their mother into a residential facility much earlier, they hadn't done anything about it.

Fortunately a local Seniors Centre and friends were able to help with referrals for in-home services until a residential placement became available. Thanks to regular medical care, Vivian's condition remained stable and she was able to live in her own home for a further 18 months before moving into a care facility.



## visiting

Visiting can sometimes be difficult, especially as the abilities of the person with dementia decline. However, there are ways to make visits meaningful.

While the person with Alzheimer's disease is still able, take them out for a drive, or lunch or afternoon tea. A change of scenery can take their mind off daily aggravations and frustrations.

Even a walk around the grounds (or escorting a wheelchair) can have a calming effect.

If confined to their room or bed, consider if you're able to

- help with personal grooming
- recite new, favourite poems or read the newspaper aloud
- bring friends for a musical/song recital
- pen letters (aloud) with them
- play favourite CDs
- draw something with them
- create a montage of magazine pictures
- play games that they have enjoyed in the past
- bring a pet for a visit (if allowed).

### Stay in touch

Encourage friends or more distant family members to stay in touch with cards or notes. In many cases, thanks to diminished memory, each time the person looks at a card (or has it brought to their attention by staff), it's like getting a new greeting!

# financial and legal issues



Early after diagnosis, discuss the responsibilities for financial and legal matters. The potential loss of income by a carer, extra expenses during care and the eventuality of placement in a residential facility all have cost implications.

Moreover, at a certain stage of the disease, the person with dementia may be deemed legally incompetent to transfer authority over property or assets, even if they are required to help pay for care. Power-of-attorney arrangements should be discussed with a lawyer to entitle a designated person to take specific authority. Some lawyers specialise in care for older people and the issues surrounding control over their affairs.

Should the Family Court have to rule in a case where no power-of-attorney is specified, a trustee or conservator will be appointed. This can require a fair amount of paperwork as well as court appearances, so it is prudent to take matters into your own hands while all individuals are able. It might also be useful to itemise all valuables, bank accounts, insurance policies and investments to know where you stand financially. The Alzheimer's Australia Help Sheet 'Early planning' is a useful guide to these topics with suggestions on who to call or contact for more information.





# conclusion

## Some doctors write with optimism about facing Alzheimer's disease today

'The old hopelessness has become outdated. Researchers are increasingly confident that within the next decade combinations of currently available medications, new drugs in development and the broad array of non-drug therapies and carer support will turn the disease into a reasonably manageable chronic condition, similar to diabetes or asthma.'<sup>11</sup>

With so many medical and scientific resources at work on the disease, there is reason for hope. And with more and more information available about care and coping, there is reason to persevere.

There is still much we need to learn about Alzheimer's disease. A number of research based resource centres have been established in Australia to support medical research which seeks the causes, and develops treatments and cures for Alzheimer's disease and other neurological disorders.

Examination of the brain after death is the only way to confirm the diagnosis during life. Making the decision to donate a brain after death is very personal and difficult, but it offers the donor the opportunity to help similarly affected people. This is particularly important for those in whom Alzheimer's disease may have a hereditary or familial association. If you or a close relative have such a disease, this program may then be very relevant for a child or grandchild at risk of developing the disease.

In time, these donations will help those affected and those not yet affected. To find out more consult your doctor or contact the Dementia Helpline on 1800 639 331.



# frequently asked questions and answers

**Q I see gradual changes in my mother's behaviour and am not sure if this is just a sign of ageing or early Alzheimer's disease. Should I have her go through tests?**

A There are no conclusive blood or behaviour tests to determine the onset of Alzheimer's disease, but a doctor, after a preliminary visit, may refer a patient on for specialised examination with a geriatrician or neurologist. See details in the Look Forward chapter 1 for the difference in memory-loss associated with ageing versus possible Alzheimer's disease.

**Q While my husband copes with the disease rather well most of the time, some days nothing seems to go right. Does something trigger this?**

A Dementia affects each person differently and problems can also vary from day to day. In early stages, some days may appear to be totally 'normal' with few outward signs of the disease. As dementia progresses, activities and interaction can help keep the person grounded in routine and recognition. Whilst it is difficult to anticipate behaviours, distress is often caused by a disruption to regular patterns or some other unexpected disturbance (excessive noise, commotion, crowds). Keep a level tone and try to calm the person whenever they're distressed or irritable.

**Q Even after she was diagnosed with Alzheimer's disease, my mother and I always enjoyed going out to eat at our local club on Fridays. Recently however, she gets upset during dinner or even before we sit down. Should I stop taking her out?**

A The familiarity of the event is probably cherished by your mother, but circumstances might make it feel less familiar, thus strange or threatening. Friday nights may be too busy to enjoy a quiet dinner out. Consider changing the day or eat at an earlier hour. Try to select the same table each visit. Be reassuring about the outing before you leave and throughout the dinner, perhaps planning on a favourite food or dessert.

**Q Recently I discovered my father takes all spoons from the kitchen and stashes them in his bedside drawer. Yet he claims he has no idea how they got there. He also puts used tea bags in the microwave. What can I do about this behaviour?**

A Not much. As the disease progresses, people not only show signs of memory loss but also have trouble with associative functions – namely, remembering the purpose or place for a lot of everyday things. There is no way (or good reason) to 'correct' these behaviours and as long as they are not injurious to health or safety, it's better to try to tolerate them.

**Q I'm worried about my husband when he wanders through the house. Already he has tried to use cleaning products on his cereal and turned the oven on without realising it. While I try to watch him most of the time, I'm afraid he could hurt himself.**

A Speak to Alzheimer's Australia or an Independent Living Centre about ways to curb household dangers. See if your library or bookstore can provide a copy of the recent book, 'The Complete Guide to Alzheimer's Proofing Your Home' (Mark Warner, c. 2000, Purdue University Press, USA, 362.196831 WAR). Also see Home Safety suggestions covered in chapter 2.

**Q What can I do when my wife shouts and argues?**

A This behaviour is not the person responding: it is the disease. Take care not to react with anger or frustration – it is likely they are trying to express these same feelings and will not benefit from your outbursts. Ignore the behaviour or distract a person by changing the subject, or leave the room. In all cases, speak with respect and dignity. Sometimes the only help to offer is love and acceptance. (see 'Dealing with Emotional Behaviours' in Look Forward chapter 2.)

**Q Do people with Alzheimer's disease have different nutritional needs?**

A Eating preferences can develop during the disease, especially a tendency to favour certain foods like sweets or junk food. A well-balanced diet, with care taken to provide plenty of water, is important. People with dementia who live on their own are vulnerable to malnutrition if left to their own devices for meals. Their eating habits should be monitored. Consult a doctor or a dietician. A range of publications on nutrition is also available.

**Q Our family has a hard time visiting our uncle lately. He doesn't speak; he just stares at us. We're uncomfortable and puzzled. Would it matter if we stopped visiting?**

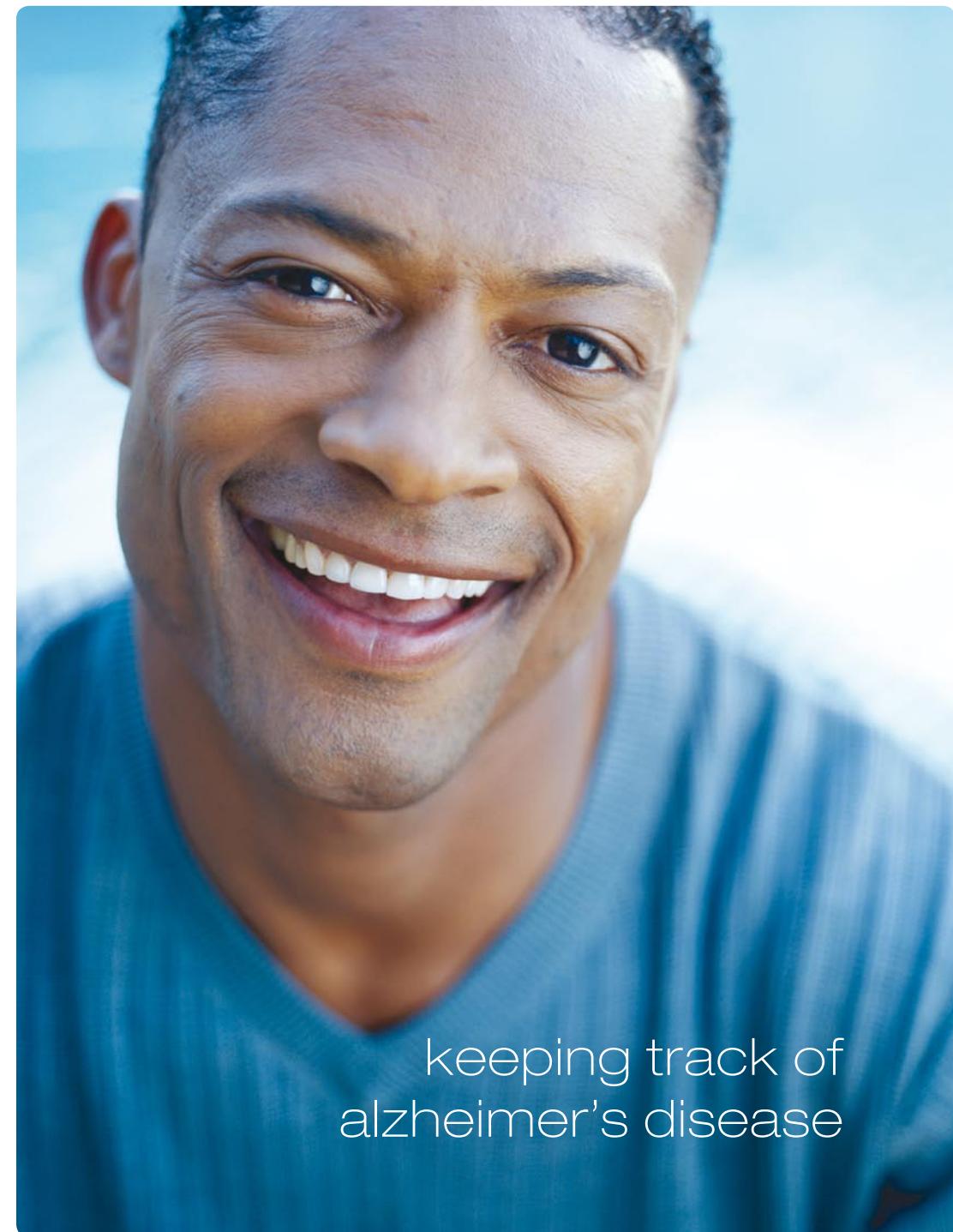
A People often distance themselves from what they do not understand. Your uncle may be unable to show it, but he still is a family member who deserves care, affection and attention. On some level he experiences your visits even if he is unable to respond to them. Reach out with a touch, a kiss or a warm embrace. Sit with him even if there is no meaningful exchange. While we cannot be sure how much a person experiences, we know that the person within is still there.

**Q My father is doing a fine job looking after my mother with Alzheimer's disease, but lately he looks and acts differently. I think the responsibility is too much for him. What can I do?**

A An elderly spouse may feel a fierce pride and devotion in looking after their partner. It's a way of showing they are much needed and still capable of independent living. It is, however, important to look for signs of carer stress in any age person looking after someone with Alzheimer's disease. This type of stress can appear as weight change, chronic fatigue (sleeplessness), withdrawal or depression and various health complaints. Looking after a carer is important for all friends and family involved. Contact Carers Australia or Alzheimer's Australia for more information.

**Q My husband recently moved to a nursing home after I spent years looking after him. Although I visit frequently, how can I fill the gap of not having him here?**

A Adjustments are not easy when care arrangements change. Look for ways to bring new activities into your life and make time for friends and other family. Clearly, there is a gap as long as you let one remain. Your aim is now to fill it with fulfilling activities, many of which can help you remember good times with your husband.





# keeping track

When you are caring for a person with Alzheimer's disease, it can be helpful to keep track of the changes which may occur over time.

This journal lets you record their ability to perform a range of tasks so that you can compare their current capabilities with their performance in the past – ideally this would be done every 6 months.

It is recommended that 2-3 months after diagnosis, the person with dementia revisit their specialist or GP for an assessment and to review ongoing treatment.

We have also provided space for you to record any concerns, note ways you've been dealing with unusual behaviour or jot down anything else you'd like to discuss with your GP or specialist.

We hope you will find this helpful.





# Checklist

Complete this checklist 6 months after the previous one.  
To effectively monitor this person you should compare these results to the first “benchmark” checklist.

Record whether your friend or relative has improved, stayed the same or become worse over the last 6 months.

## Date

How is this person at...	Much Better	Better	Not Much Change	Worse	Much Worse
Remembering the names of family and friends					
Being able to keep track of a conversation					
Remembering his/her address and telephone number					
Remembering what day and month it is					
Remembering where things are usually kept					
Remembering things that happened when he/she was young					
Knowing how to work familiar appliances around the house					
Handling agitation or restlessness					
Coping with sad or depressed mood					
Dressing and undressing him/her self					
Keeping face, hair and clothes neat					
Able to feed self, eg. appropriate meal times, cleaning up after meals					
Handling money for shopping					
Handling other, everyday situations, eg. knowing how much food to buy, knowing how long between visits from family and friends					
Overall effort and involvement by caregiver	Much Less	Less	Not Much Change	More	Much More

# Notes

This space can be used to record details such as questions you’d like to ask your specialist, unusual developments or effective ways of handling behavioural changes.

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# references and resources

In creating this booklet, every effort has been made to work from current information on Alzheimer's disease. While research into this area is dynamic with new theories and discoveries every day, most data and information is widely agreed upon.

The following sources were valuable for their authoritative documentation

## Online resources

[www.alzheimers.org.au](http://www.alzheimers.org.au)

Alzheimer's Australia  
State-by-state links are available  
on this website for contacts  
across Australia

[www.alzheimers.org.nz](http://www.alzheimers.org.nz)

Alzheimer's Association New Zealand

[www.alzheimers.org.uk](http://www.alzheimers.org.uk)

Alzheimer's Association UK

[www.alz.org](http://www.alz.org)

Alzheimer's Association America

[www.alzheimer-info.net/  
alzheimers\\_canada](http://www.alzheimer-info.net/alzheimers_canada)

Alzheimer's Association Canada

[www.med.web.plus.com](http://www.med.web.plus.com)

[www.carers.asn.au](http://www.carers.asn.au)

Carers Australia

[www.dasinternational.org](http://www.dasinternational.org)

A site by and for people  
with dementia

[www.merckmedicus.com](http://www.merckmedicus.com)

Merck Medicus Medical Internet

[www.quorndon-mag.org.uk](http://www.quorndon-mag.org.uk)

The Quorndon magazine

[CCN.com/health](http://CCN.com/health)

[www.seniorlink.com.au](http://www.seniorlink.com.au)

Senior-friendly online  
Computer Learning Centre

## Books

Many books are now available that portray Alzheimer's disease with empathy and insights for both the person with dementia, their families and carers instead of mere clinical facts on the disease. Check your bookshop and library – especially under the Call Numbers 616.83. To browse book titles on the internet, visit [www.amazon.com](http://www.amazon.com) which offers hundreds of books for sale (new and used) on Alzheimer's as well as magazine subscriptions. A range of books to borrow is also available in Alzheimer Australia libraries.

The following books are a few excellent choices:

**Courage to Care (A Caregiver's Guide Through Each Stage of Alzheimer's)**  
by Joanne Parrent, Alpha Books, Indianapolis, 2001.

A thorough, well-organised reference book filled with case excerpts, historical insights and stage-by-stage guidance on practical concerns.

**Alzheimer's: Answers to Hard Questions for Families**  
by James & Hilde Lindemann Nelson; Doubleday, NY, 1996.

Faces issues which confront most families – from moral dilemmas to productive planning – with many hypothetical scenarios at every stage of Alzheimer's disease. As professors and bioethicists in the US, the authors create unique yet universal accounts.

**Losing My Mind: An Intimate Look at Life with Alzheimer's**  
by Tom DeBaggio, Free Press, USA, 2002.

A moving, unusual memoir by a man facing his own daily struggle with the onset of Alzheimer's disease (diagnosed in 1999 at age 57) and how he shares his experience with it before it becomes too late. Remarkable, intimate writing from a patient's point of view, this book combines personal experiences with sobering facts about Alzheimer's disease.

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**The Forgetting – Alzheimer's Portrait of an Epidemic**  
by David Shenk, Doubleday, USA, 2001.

A compelling look at where Alzheimer's disease is headed and what's happening with medical research. The author shares vivid historical details (including Ronald Reagan's and Rita Hayworth's struggle with the disease) and poses thought-provoking questions about our ageing population and care issues we all must face.

**The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss in Later Life**  
Third Edition by Nancy L. Mace, et al, Johns Hopkins University Press, USA 1999.

Support and factual information to help families effectively care for relatives with dementing disorders and how family members can be affected.

**Alzheimer's Early Stages**

by Daniel Kuhn, Hunter House Publications, USA, 1999.

Medical facts and everyday issues presented in a thorough, well-organised style help make this an excellent reference book. Practical suggestions to give good care and take good care of yourself as a carer or family member.

**Take Me Home: Families Living with Alzheimer's**  
by Amanda Hampson, Rezolv In Print, Australia, 2000.

Looks at the family experience of Alzheimer's. Includes personal accounts of partners, children and grandchildren of people with Alzheimer's as well as extensive information about risk factors, research and treatments. Accessible, easy-to-read style.

**Dementia with Dignity: A Handbook for Carers**

by Barbara Sherman, McGraw-Hill Book Company, Australia, 1999.

The Australian author has been a dementia 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. This is the new edition of her book.

**Who Will I Be When I Die?**

by Christien Boden, Harper Collins Publishers, Australia, 1997.

Christine Boden 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 the disease and offers a unique insight into her battle with dementia.

### **Early Stage Dementia-Reassurance for Sufferers and Carers**

by L. West, Hodder, Sydney, 2001.

This book offers practical information on what a diagnosis entails, the treatments and help available. Drawing upon real life experiences, it provides not only comfort and insight, but also hope for those with early-stage dementia and their carers.

### **Periodicals**

#### **Australian Family Physician**

Vol 31 No 4 April 2002; Vol. 31 No 9 September 2002.

#### **Medicine Today**

Vol 3 No 9, September 02.

#### **New England Journal of Medicine**

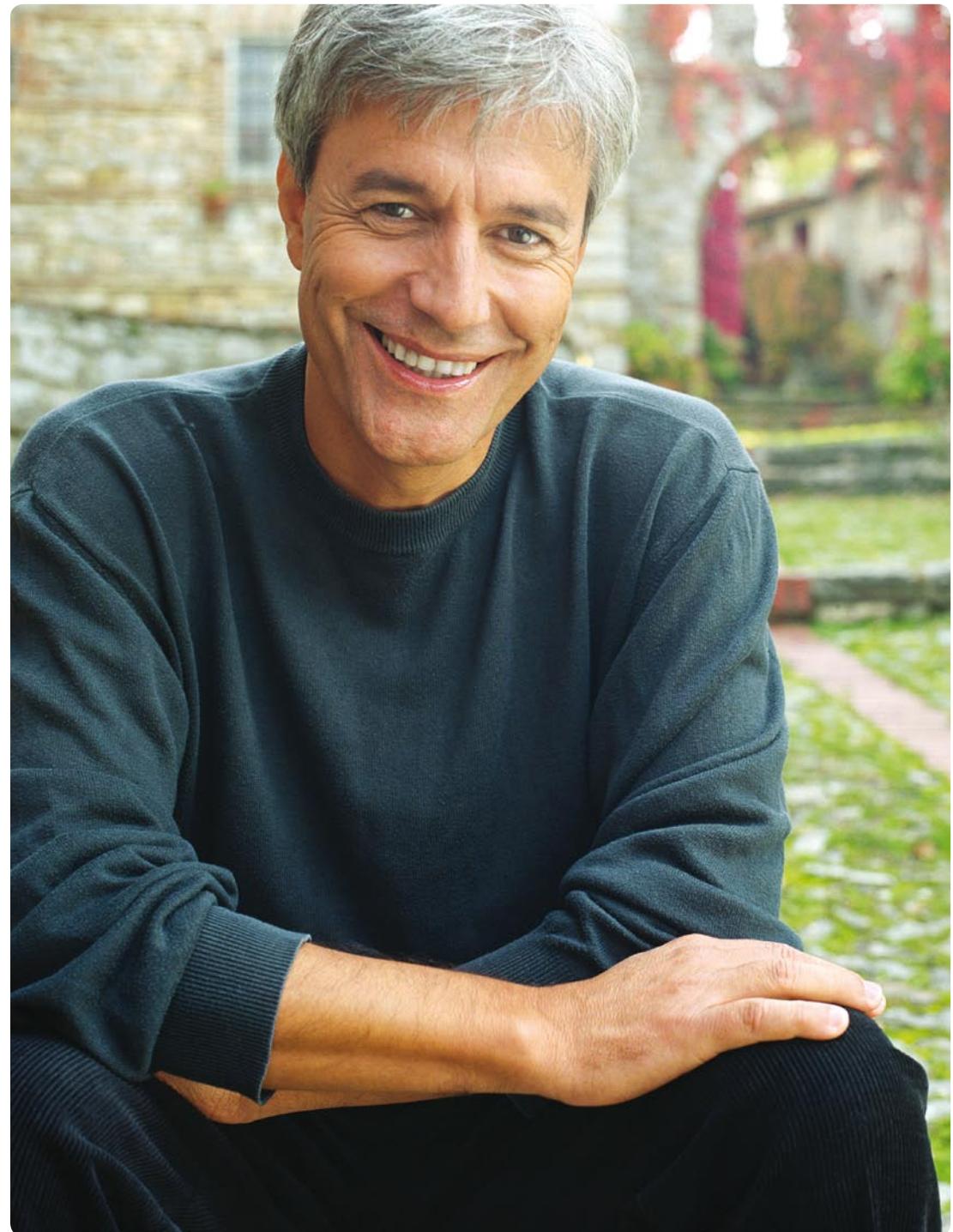
(various issues online)

[www.nejm.org](http://www.nejm.org)

### **Help sheets**

Alzheimer's Australia have nearly 100 Help Sheets, available free of charge to people with dementia, their families and carers.

These can be accessed through their web site [www.alzheimers.org.au](http://www.alzheimers.org.au) or by contacting the Dementia Helpline on 1800 639 331.





## glossary of terms

### apathy

lack of interest in information or activities; a common trait of Alzheimer's disease.

### brain scan

an image of the brain taken photo-electronically (by EEG, MRI, or CT) to help eliminate the possibility of tumours, stroke or other abnormality.

### cholinesterase inhibitors

recognised drug treatment to stabilise or slow down mental deterioration in dementia by inhibiting the breakdown of acetylcholine in the brain. Currently available as Aricept® (donepezil), Reminyl® (galantamine) and Exelon® (rivastigmine).

### delusions

imagined false beliefs or impressions; hallucinations.

### dementia

the loss of mental ability due to brain disease or injury; any of a large group of illnesses.

### disorientation

not knowing where you are or why you're there.

### genetic

storage system of trait information in our chromosomes.

### geriatrician

doctor specialising in illness or disease of the elderly; they also have expertise in arranging support for elderly people living at home.

### hereditary

transmitted from one generation to another, genetic constitution.

### hippocampus

part of the limbic system in the brain, believed to help process incoming sensory information, organisation of movement, spatial information.

### neurologist

doctor specialising in brain disorders and nervous system conditions.

### nuclear medicine

science of diagnosing and treating disease using radioisotopes.

### online

resources or information found on the internet.

### plaques

a coating made of beta-amyloid protein formed around nerve endings preventing them from sending messages through the brain.

### profile (health or lifestyle)

a summary of everyday activities, habits, nutrition and ailments to create a scenario of what influences your well-being

### support network

any resources to help people cope, learn and function effectively. Traditionally defined as family, friends and church, today's support networks are community centres, associations and online forums or chat-groups.

### tangles

a substance in neurones called Tau molecules which form tangles (like seaweed) which tend to strangle brain cells.

### www.

indicates website (internet) address; also called url.

## references

1. [www.cnn.com/health/condition.clinic/alzheimers.html](http://www.cnn.com/health/condition.clinic/alzheimers.html), 2002 Cable News Network LP, LLLP.
2. Alzheimer's Early Stages, Daniel Kuhn MSW; Hunter House Publishers; Alameda CA; 1999; pg 11.
3. "What is dementia?" Help Sheet, June 1999, Alzheimer's Association Australia.
4. Alzheimer's A Caregiver's Guide and Sourcebook, Howard Gruetzner, John Wiley & Sons Inc, USA, 1992, pg 48.
5. The Forgetting – The Alzheimer's Epidemic, David Shenk, Doubleday, USA, 2001.
6. Alzheimer's Disease – Everything you need to know, Frena Gray-Davidson, RGA Publishing Group, UK, 1998.
7. Excerpted from Improving Communications, Alzheimer's Early Stages, Daniel Kuhn, Hunter House Publishers, US, 1999.
8. The Forgetting, David Shenk, 2001 from 'Building Resilience through Coping and Adapting,'
9. The Person with Alzheimer's Disease, Phyllis Braudy Harris, Ed; Johns Hopkins University Press, US, 2002.
10. Courage to Care, Joanne Parrent, Alpha Publishing, 2001.
11. There's Still a Person in There (Epilogue), M. Castleman, D. Gallagher Thompson, M. Maythons, G.P. Putnam Sons, NY, 2000.





This booklet has been reviewed by Alzheimer's Australia



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