

Quality Dementia Care Series: Younger Onset Dementia a practical guide

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Foreword

“You’re too young for dementia” is often the reaction of health professionals, family and friends of people with dementia because society associates dementia with older adults. Advocacy on the many issues that impact on the lives of those with younger onset dementia has become an important part of the work of Alzheimer’s Australia in recent years.

The objective of this publication is to draw together information on younger onset dementia and provide practical information for those newly diagnosed as well as their families and carers.

Alzheimer’s Australia is grateful to Professor John Hodges and his team at FRONTIER, the Frontotemporal Dementia Research Group at the Prince of Wales Medical Research Institute for writing this publication and for doing such an excellent job.

The publication refers to many resources on the Alzheimer’s Australia website. I encourage the reader who wants to access these resources and useful links to other websites and recommended further reading to log on to www.alzheimers.org.au/youngeronseddementia.

The development of this publication has been made possible by funding provided by the Australian Government through the National Dementia Support Program administered by Alzheimer’s Australia. This program is one of a number of initiatives of the Australian Government under the Dementia Initiative - Making Dementia a National Health Priority. I should like to thank the Minister for Ageing and the Department for the support they have given to Alzheimer’s Australia in promoting greater awareness of younger onset dementia.

I should also like to acknowledge the unconditional grant received from Novartis to fund the printing and distribution of the publication.

Finally, in acknowledging Professor John Hodges and his team for this publication, I would also like to thank the members of the Alzheimer’s Australia National Consumer Committee, Patty Hodder, and Dr Adrienne Withall who contributed comments.



Marc Budge

President
Alzheimer’s Australia



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Contents

Foreword

About this publication

A. About younger onset dementia **1**

1. What is dementia? 2
2. How common is younger onset dementia? 2
3. Understanding symptoms of dementia 3
4. How is younger onset dementia diagnosed? 4
5. What causes dementia? 5

B. Practical approaches to management of dementia **13**

1. Memory and other cognitive abilities: working with strengths 14
2. Challenging behaviours in dementia: tips on management 17
3. Activities of daily living: practical tips for improving everyday life 18
4. Sexuality and younger onset dementia 20
5. Employment issues 21
6. Driving and the law 21
7. Common drug treatments 22

C. The caring role **25**

1. Changes in relationships 26
2. Caring and personality types 26
3. Coping styles 27
4. Carers' well-being 27
5. Impact on other family members 27

D. Planning for the future **29**

1. Advance care planning 30
2. Legal issues 30
3. Financial issues: where to go for advice and help 32
4. Payments for carers 32
5. Practical assistance in the home 32
6. Residential respite and permanent residential care 33

Research into younger onset dementia: brain donation, the ultimate gift **34**

- Further information 35
- Books 36
- Alzheimer's Australia publications 37
- 



About this publication

In many areas of dementia care, difficult judgements are involved about what might be appropriate or what would not, given the unique characteristics of the person being cared for. This publication contains much information that will assist those with younger onset dementia to better understand, and those providing care to gain some practical insights about possible approaches. *However, professional advice should always be sought if there are doubts about the care provided.*

This booklet is evidence-based and draws on a very extensive research base. The following key documents may be particularly useful to readers wishing to further consider the evidence.

Burns A, O'Brien J and Ames D, *Dementia*, Third Edition 2005 Hodder & Arnold

Hodges, J.R. (Editor) 2001 *Early-onset Dementia: A Multidisciplinary Approach*, Oxford University Press: Oxford

Hodges, J.R. (Editor) 2007 *Frontotemporal dementia syndromes*, Cambridge University Press: Cambridge

Alzheimer's Australia, *Understanding Younger Onset Dementia* Quality Dementia Care Series #4, Alzheimer's Australia 2008

Websites and further reading listed at the rear of the booklet are also sources of practical information and support.



A.

About younger onset dementia



A

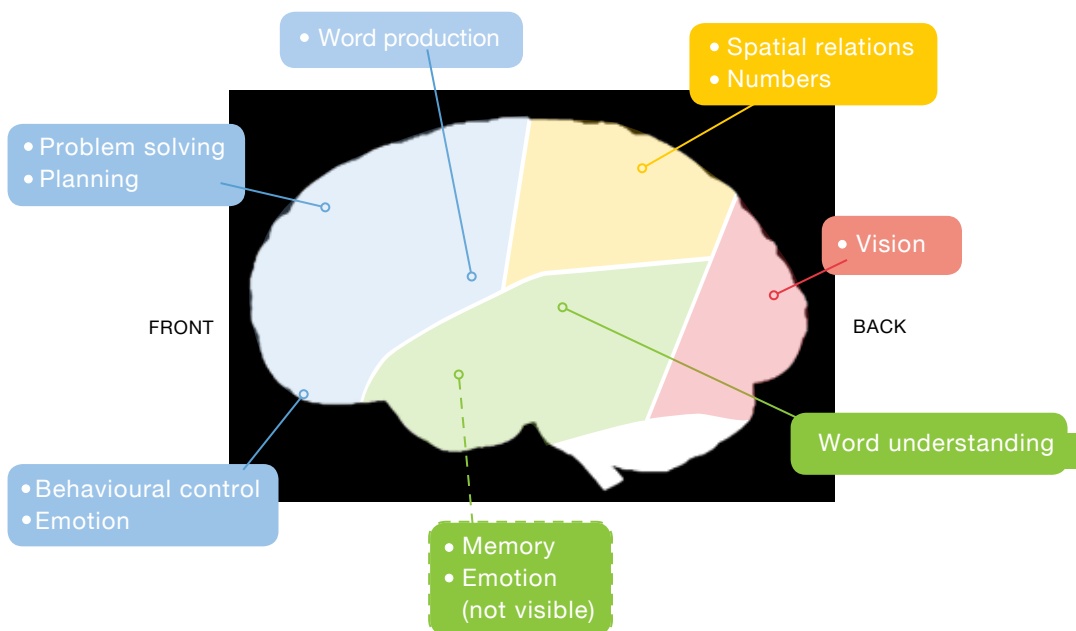
1. What is dementia?

Dementia is not a single disorder. It is the term used to describe the symptoms of a number of disorders that usually cause a progressive decline in a person's intellectual functioning. It is a broad term used to describe a loss of memory, intellect, language skills, planning ability, social skills and what would be considered normal emotional reactions. Not all of these areas need to be affected to make a diagnosis of dementia. Different types, or causes, of dementia present in different ways. For instance, Alzheimer's disease typically causes memory loss while frontotemporal dementia presents with loss of communication abilities or alterations in social behaviour. While most of the diseases that cause dementia are not currently reversible, a few rare conditions which cause younger onset dementia are curable. For this reason, it is important that every person with suspected dementia is thoroughly investigated.

2. How common is younger onset dementia?

Dementia becomes increasingly common with age. It is a medical condition and not simply a normal part of ageing. As such, it is important to remember that not all older adults get dementia. In the population of individuals aged 80 years and over, up to a quarter of people have dementia. By comparison, dementia in younger adults, defined as an onset below the age of 65, is much rarer. Less than one percent of people under 65 years of age have dementia. Access Economics has estimated that in Australia around 10,000 individuals have younger onset dementia¹. These figures are based on surveys undertaken in Europe and may not apply to other populations.

¹ Access Economics, *Dementia Estimates and Projections: Australian States and Territories*. Alzheimer's Australia February 2005.



3. Understanding symptoms of dementia

The brain is made of two halves, called the hemispheres, which are connected by a thick bundle of nerve fibres. The hemispheres can be divided into four main regions or lobes. The diagram opposite shows the left hemisphere with the lobes highlighted in different colours: frontal (blue), temporal (green), parietal (yellow) and occipital (pink). Other important brain structures, such as the hippocampus (memory storage area) and the basal ganglia (voluntary movement area), are located deep within the brain and are not visible in the diagram.

Each lobe is composed of an outer layer (the grey matter) and an inner layer (the white matter). The grey matter is where the nerve cells, or neurons, reside. The neurons are the source of information within the brain. They allow us to think, reason, learn and feel. In contrast, the white matter consists of connecting fibres. These fibres transmit information between neurons within or across different brain regions.

In dementia, such as Alzheimer's disease or frontotemporal dementia, pathological changes take place within the brain. These changes include the loss of neurons, abnormal accumulation of protein in and around the cells, and changes in the white matter. The type and location of these changes within the brain depend on the type of dementia. Progression of the pathology is often slow and insidious and, in many instances, takes years, even decades, before changes in behaviour and cognition become apparent.

The brain is highly organised and each lobe supports one or several thinking abilities, such as memory, language or emotion processing as described in the diagram. For that reason, the brain pathology associated with each dementia type is associated with predictable changes in thinking and behaviour. For example, the pathological changes associated with Alzheimer's disease are most pronounced in the hippocampus, which is located in the temporal lobe. The hippocampus is the brain structure that is crucial to the ability to lay down new memories and keeping track of day-to-day events. Clinically, change in memory

Effect of younger onset dementias on brain function

Brain function	Alzheimer's disease	Behavioural variant FTD	Semantic dementia	Progressive nonfluent aphasia	Vascular dementia	Dementia with Lewy bodies
Word understanding	● to ●●	-	●● to ●●●	-	-	-
Memory (new learning)	●●●	variable	-	-	variable	variable
Emotion	variable	●● to ●●●	●● to ●●●	-	variable	-
Spatial relations	●●	-	-	-	-	● to ●●
Numbers	variable	-	-	-	-	-
Vision	variable	-	-	-	-	● to ●●●
Problem solving	● to ●●	●● to ●●●	-	-	● to ●●●	● to ●●●
Word production	● to ●●●	variable	-	●● to ●●●	-	-
Behaviour control	variable	● to ●●●	variable	-	variable	variable
Emotion	variable	● to ●●●	● to ●●●	-	variable	variable
Movement	-	-	-	-	-	●● to ●●●
Coordination	-	-	-	-	-	●● to ●●●

For each function deficits can be: ● mild ●● moderate ●●● severe - absent

Variable indicates that a deficit is sometimes observed but not always.

Colours refer to the diagram of the brain opposite.

functioning is the most common deficit observed on testing and the most common complaint reported by individuals with Alzheimer's disease and their carers. The table on page 3 outlines the major cognitive and behavioural deficits that are commonly observed in each dementia type. The colours refer to the diagram of the brain and indicate the location of the function within the brain.

4. How is younger onset dementia diagnosed?

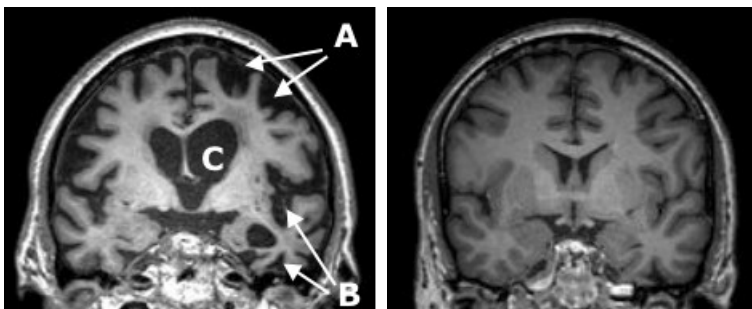
Consulting a doctor to obtain a diagnosis at an early stage is critical. A complete medical and psychological assessment may identify a treatable condition. A number of conditions exist that produce symptoms similar to dementia. These include vitamin and hormone deficiencies, depression, overmedication, infections and brain tumours. If the symptoms are caused by dementia, an early diagnosis will mean early access to support, information, and medication.

It is important that anyone with suspected dementia has a thorough assessment by a neurologist, geriatrician or psychiatrist with a special interest in dementia to establish the diagnosis. Another option is to attend a memory clinic. A referral can be obtained from a general practitioner. A typical work-up is likely to include the following:

- **Detailed medical history.** If possible, this history ought to be provided by the person with the symptoms and a close relative or friend. Medical history helps establish the onset (sudden or insidious) and progression of the symptoms (fast or slow). Often, behavioural changes are more apparent to family and friends than to the person with dementia.
- **Thorough physical and neurological examination.** Usually this examination includes

tests of the senses and movements to rule out other diseases and to identify medical conditions which may worsen confusion associated with dementia.

- **Laboratory tests.** These blood and urine tests are sometimes called a 'dementia screen'. They test for a variety of possible illnesses which could be responsible for the symptoms such as an under-active thyroid gland or vitamin B12 deficiency.
- **Brain imaging.** Imaging of the brain is mandatory in all younger adults with suspected dementia to rule out reversible causes such as a benign brain tumour or hydrocephalus (fluid on the brain) and to look for patterns of brain changes associated with the specific types of younger onset dementia, such as local shrinkage (atrophy) of the frontal lobes in frontotemporal dementia. Computerised Tomography (CT) and Magnetic Resonance Imaging (MRI) are forms of structural imaging methods that are widely available. In some specialist centres, structural imaging may be supplemented by functional imaging (SPECT or PET), which show how the brain is working.
- **Psychiatric assessment.** This investigation helps identify treatable disorders such as depression, which can mimic dementia. It also helps to identify and manage symptoms such as anxiety or delusions which may occur in conjunction with dementia.
- **Neuropsychological assessment.** Tests of cognition are administered to identify retained abilities and specific problems in areas such as memory, comprehension, visual abilities, problem solving and numerical skills. These results can help with determining the diagnosis.

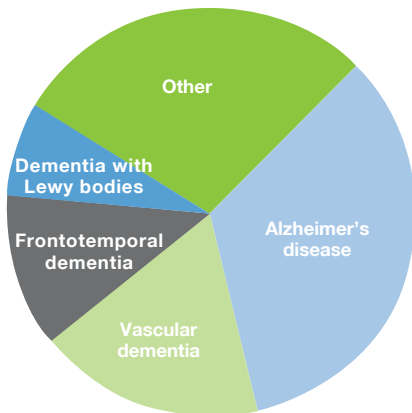


Brain MRI in the vertical plane of a patient with frontotemporal dementia (left) and a healthy subject of similar age (right). Compared to the healthy brain, the brain on the left shows marked tissue loss (atrophy) of the frontal (A) and temporal (B) lobes and enlargement of the spaces in the brain (ventricles)(C)

5. What causes dementia?

Younger onset dementia comes in many forms. Each type of dementia has its own signature of symptoms, signs and findings on investigation, and is caused by a specific type of pathology in the brain.

A breakdown of the main causes of younger onset dementia is shown in the figure below.



Causes of younger onset dementia

Alzheimer's disease

Alzheimer's disease remains the most common form of dementia even in adults under the age of 65 years and accounts for around 30% of all cases of younger onset dementia. First described by Alois Alzheimer in 1906, Alzheimer's disease is a progressive, degenerative illness, the basic cause of which remains unclear (except in the small proportion of individuals with a known genetic mutation). The pathology of Alzheimer's disease involves two proteins that are usually present in normal healthy brain cells. In Alzheimer's disease, these proteins accumulate in a toxic form and cause cell death. The most important protein is amyloid, which forms 'plaques' outside brain cells (neurons) and induces an inflammatory response. The second protein is tau which is the major constituent of 'tangles' found within neurons. Together, plaques and tangles are the hallmark of Alzheimer's disease. Research is currently focusing

on ways of removing the abnormal accumulations or, at least, preventing their further build up.

In the early stages of the disease, the plaques and tangles are confined to the hippocampus which is part of the temporal lobe. Because of the pivotal role of this brain region to memory, the presence of pathology here causes problems with learning and remembering new information and recent events. As the disease progresses, the plaques and tangles spread to other parts of the brain causing more generalised deficits. In addition, the part of the brain that produces a key chemical called acetylcholine, which is involved with memory and attention, is also affected early in Alzheimer's disease. Many of the currently available drugs attempt to enhance levels of acetylcholine in the brain.

Diagnosis in the very early stages can be difficult. If the problems are confined to impaired memory without the other signs of dementia then the label **mild cognitive impairment** is applied. Research has shown that the risk of converting to dementia in individuals diagnosed with mild cognitive impairment is around 10% per year.

As well as difficulty with new learning and recall of recent events, other early symptoms are reduced attention and difficulty with solving problems. Using household appliances may become difficult and tasks previously undertaken with ease (checking the bank balance and completing tax returns) become problematic. Many of these symptoms are often attributed to stress and depression. A common claim is that people with Alzheimer's disease are unaware of their problems but this is incorrect. Early on, awareness can remain intact leading to substantial mood disturbance, such as depression or aggression. As the disease progresses, language breakdown (particularly word finding problems and difficulty understanding word meaning) increases and disorientation in time and place often develops.

Psychiatric symptoms are also frequently observed, notably depression, irritability and anxiety. Apathy (loss of motivation) is common and people with dementia may withdraw from family and friends and lose interest in pastimes. In some cases, delusions (false beliefs) involving theft of possessions, intruders, phantom lodgers or marital infidelity are observed. In contrast, hallucinations (sensing or

experiencing things that do not exist) in the early stages of Alzheimer's disease are uncommon and are much more suggestive of another type of dementia: dementia with Lewy bodies.

No tests exist that can absolutely confirm a diagnosis of Alzheimer's disease in life. Currently, investigations focus on ruling out other potential causes of dementia, as well as looking for the characteristic changes seen on neuropsychological testing and on brain imaging. In the early stages, routine structural brain imaging (CT or MRI) may be normal. Functional imaging (SPECT or PET) will often reveal changes in brain metabolism, but such scans are not available in all centres and are quite costly.

Compared to the situation in older adults, younger onset Alzheimer's disease is more often inherited, especially when the onset is very early (40s or 50s). Up to a half of the people with younger onset Alzheimer's disease have another family member with dementia, typically a single relative with late onset dementia. Familial Alzheimer's disease is defined as younger onset disease if the affected individual has two or more affected relatives with younger-onset dementia in two generations. This is much rarer (accounting for less than a fifth of cases) but such people should be offered genetic screening, after appropriate counselling, to look for the presence of one of the known gene mutations causing the disease. Together these mutations account for about a half of cases with Familial Alzheimer's disease. It is assumed, therefore, that there are important genes yet to be discovered.

Three different genes have been identified in which mutations cause Familial Alzheimer's disease. All three gene mutations are inherited in an autosomal dominant pattern: this mode of transmission means that each child of a person with a known mutation has a 50% risk of developing the disease. This is because we all have two copies of each gene on our chromosomes. We inherit one version of each gene from our mothers and one version of the same gene from our fathers. If a person inherits the mutant gene that causes Familial Alzheimer's disease from one parent and a normal gene from the other parent, the mutant gene will override the normal gene and the person will develop the disease.

The genes are called:

- *Presenilin-1*, located on chromosome 14 and is by far the commonest cause of Familial Alzheimer's disease
- *Presenilin-2*, located on chromosome 1 and is implicated in Familial Alzheimer's disease in a small group of families from an ethnic group known as the Volga Germans, who mostly live in the USA and Canada
- *Amyloid precursor protein (APP)* located on chromosome 21 and implicated in Familial Alzheimer's disease in only 20 or so families in the world.

Younger onset Alzheimer's disease is also seen in a high proportion of people with Down's syndrome. These individuals, who have an extra copy of chromosome 21 and who experience premature ageing, develop the same plaques and tangles in their brains as other individuals with Alzheimer's disease.

Frontotemporal dementia (FTD)

Frontotemporal dementia, sometimes called frontotemporal lobar degeneration, was first described 100 years ago by Arnold Pick and was previously referred to as **Pick's disease**. It is the second most common degenerative disease causing dementia in younger adults. The age of onset is typically in the 50s or 60s but can be as young as 30.

Damage to brain cells is more localised than in Alzheimer's disease, and begins in the frontal and/or temporal lobe. In FTD the clinical presentation varies, depending on whether the frontal or temporal lobe is affected first. When the initial pathology affects the frontal lobes, the main changes are in personality and behaviour. Individuals with predominant temporal lobe involvement present with loss of language skills known as **progressive aphasia** (aphasia is the loss of the ability to produce or understand language).

The pathology of FTD is much more complex and variable than the pathology of Alzheimer's disease. Instead of the 'plaques and tangles' which characterise Alzheimer's disease, the brains of people with FTD brains show a severe loss of brain cells (neurons). In some individuals, the tau protein, which is also involved in Alzheimer's disease, collects in neurons known as 'Pick bodies'. A

small proportion of people with tau accumulations have a mutation of the tau gene on chromosome 17. More commonly, the brains of people with FTD shows an accumulation of another cell protein – ubiquitin. Ubiquitin is involved in clearing waste products from brain cells but for reasons that are currently unknown, this protein builds up in some people with FTD. Very recent research has suggested that the accumulation of ubiquitin is attached to another protein (called TDP-43) which has a fundamental role in cell nuclei. Again, a small proportion of people with ubiquitin accumulation have a genetic mutation, this time of the progranulin gene which is also located on chromosome 17.

In the frontal or **behavioural variant of frontotemporal dementia**, the person's mood and behaviour may become fixed and difficult to change, making individuals appear selfish and unfeeling. A loss of empathy and emotional warmth is very common. In contrast to Alzheimer's disease, recent memory is typically preserved. Apathy or lack of motivation is very common, leading people with FTD to abandon hobbies and avoid social contact. Others lose normal inhibitions and start talking to strangers or exhibiting embarrassing behaviour in public. Difficulty in reasoning, judgement, organisation and planning is frequent, along with a reduction in spontaneous conversation. Changes in eating patterns are very common often with a craving for sweet food, a tendency to overeat and a restriction in food preferences. A decline in self-care and a reduction in the ability to perform activities of daily living is another early feature. As the disease progresses, the person may become 'obsessional', repeating patterns of movement and behaviours like hand-wringing or echoing back whatever is said.

In the **progressive aphasia** version of the disease, the initial symptom is usually a decline in language abilities. This can take two different forms. In the first form, the problem is a loss of memory for words and impaired comprehension of word meaning. The left temporal lobe is critical for the fluent production of words and especially for assigning meaning to words. Because the language disorder reflects a breakdown in the meaning (or semantic) system underlying language, the term **semantic dementia** is used to describe this form of FTD. Reading and spelling are also typically affected, although numerical abilities can

be remarkably well preserved. Everyday memory and skills associated with posterior brain regions such as navigation, route finding and eye-hand coordination are spared, at least until very late in the disease. Subtle personality changes of the type seen in the behavioural form are also common.

In the other form of progressive aphasia, known as **progressive nonfluent aphasia**, the main symptom is a difficulty communicating due to slow and laboured production of words often with distortion of speech and a tendency to produce the wrong words and make grammatical errors. Using the telephone and communicating with groups of people is particularly difficult. Changes in behaviour are uncommon in the early stages but do occur later. Some people develop clumsiness of hand-use, known as apraxia. In later stages, the disease spreads to the frontal lobes, so that many of the features described above, especially the changes in organisational abilities, emotional responses and empathy occur. There is considerable overlap between progressive nonfluent aphasia and corticobasal degeneration.

As with Alzheimer's disease the diagnosis depends on careful clinical evaluation supplemented by neuropsychological testing and brain imaging to look for the characteristic pattern of atrophy (shrinkage).

Most cases of FTD are not inherited but there are a number of families, perhaps accounting for 20% to 30% of cases, where the disease is passed on in the genes. In these cases there is a strong family history of a dementia (or sometimes of Motor Neurone Disease) usually with an early onset of the disease. Abnormal (mutated) genes that are found on chromosome 17 and are related to tau protein and progranulin (which is normally involved in growth and repair) have been found in families around the world. It is possible to screen for these mutations but screening is usually only offered only to people with a clear family history of younger onset dementia.

[More detailed information on frontotemporal dementia can be found on the website of FRONTIER, the Frontotemporal Dementia Research Group \(www.ftdrg.org\)](http://www.ftdrg.org)

Motor Neurone Disease with dementia

Motor Neurone Disease (MND) - also referred to as Amyotrophic Lateral Sclerosis (ALS) – was thought to spare mental abilities and that FTD, in turn, did not cause significant muscle problems. This has been found to be incorrect. In fact, a proportion of people with frontotemporal dementia do develop features of MND, typically slurring of speech, problems swallowing or weakness and wasting of the muscles of the limbs. Conversely, a proportion of people with MND go on to develop behavioural and/or language problems. The degree of overlap between MND and FTD is not yet known. A proportion of people with the FTD-MND overlap condition have delusions (abnormal and sometimes bizarre beliefs that are not true) or hallucinations (seeing or hearing things that are not there) that are otherwise rare in FTD.

Parkinsonian disorders associated with dementia

Parkinson's disease

Parkinson's disease is a degenerative disorder characterised by impairments in motor skills, speech, and in some cases, cognitive functions. The condition is named after the English physician James Parkinson, who made a detailed description of the disease in his historic publication: *An Essay on the Shaking Palsy* (1817). Most cases have an onset in later life but one in 20 cases are reported to occur in people under the age of 40 years and one in five under 65.

The typical features of Parkinson's disease are muscle rigidity, tremor and a slowing of physical movement (bradykinesia). The primary symptoms are caused by a deficiency of dopamine, which is produced in the dopaminergic neurons of the substantia nigra, a structure located deep within the brain. Dopaminergic neurons are the main source of dopamine, a neurotransmitter that has many roles and is involved in behaviour, cognition, movement, mood, sleep and attention. Except in a very small proportion of inherited cases, the cause of Parkinson's disease remains unknown.

Not everyone with parkinsonism, a term which refers to the syndrome of tremor, rigidity and bradykinesia, has Parkinson's disease. Other causes of parkinsonism are drug side effects (most notably the drugs used to treat psychosis)

and the so-called Parkinson-plus diseases: progressive supranuclear palsy (PSP), corticobasal degeneration (CBD) and dementia with Lewy bodies (DLB). The Parkinson-plus diseases are important because they progress more quickly than the more common idiopathic Parkinson's disease and are typically associated with more marked cognitive dysfunction and respond less well to the dopaminergic drugs used to treat Parkinson's disease. Dopaminergic drugs affect the levels of dopamine in the brain.

The pathological hallmark of Parkinson's disease is the presence of Lewy bodies (clumps of the protein alpha-synuclein) found in the dying dopamine-producing nerve cells within the substantia nigra region of the brain stem.

In the early stages of Parkinson's disease, cognitive changes are mild and variable. The most common symptoms are mental slowness (bradyphrenia), problems with executive functions such as mental flexibility, prioritising and goal setting; and the correct interpretation of social cues. Dementia is a late development occurring in approximately 20% to 40% of people, typically starting with slowing of thought and progressing to difficulties with abstract thought, memory, and behavioural regulation accompanied by visual hallucinations.

Psychiatric symptoms are common in Parkinson's disease. Estimates of the prevalence of depression range from as low as 20% to as high as 80%. A proportion of people develop 'punding', a behaviour in which there is an intense fascination with repetitive handling and examining of mechanical objects, such as taking apart watches and radios or arranging common objects (lining up pebbles, rocks, or other small objects). Punding is thought to be related to dopaminergic stimulation secondary to the commonly prescribed medications, which help relieve physical symptoms. Behaviours associated with impulse control - including compulsive shopping, hypersexuality, binge eating and pathological gambling have also been associated with the dopamine agonist medications used to treat Parkinson's disease.

Sleep disturbance is also common in Parkinson's disease particularly Rapid Eye Movement (REM) sleep behaviour disorder that causes abnormal motor activity during the REM sleep phase

characterised by rapid eye movements. There is a loss of the muscle paralysis that is normally present during intact REM sleep when most dreaming occurs. People with Parkinson's disease may simply have limb twitches or appear to be unconsciously acting out their dreams causing violent movements which can result in injury to either the person or his or her partner.

Dementia with Lewy bodies

Dementia with Lewy bodies is associated with the build-up of a protein called alpha-synuclein inside dying nerve cells that are distributed throughout the cerebral cortex (the layer of grey matter covering the brain). This build-up takes the form of abnormal spherical structures that are called Lewy bodies. Often, this pathology is combined with the plaques and tangles in the brain that are also seen in Alzheimer's disease.

In many ways, dementia with Lewy bodies represents a cross between Parkinson's disease and Alzheimer's disease. People with this disorder show the cognitive features of Alzheimer's disease combined with the movement disorder of Parkinson's disease. In dementia with Lewy bodies, people tend to have particularly real or vivid visual hallucinations, such as seeing animals or faces, experience stiffness or shakiness of their limbs (parkinsonism), and are prone to falls. A particular feature of dementia with Lewy bodies is the tendency for the condition to fluctuate quite rapidly, often from hour to hour, or day to day, with periods of confusion and hallucinations alternating with periods of clear thinking. People are often described as having distinctive good and bad days. The degree of memory impairment is generally less severe than in Alzheimer's disease but people have difficulty with attention. They also typically perform very poorly on tests involving the copying of shapes or understanding visual material, and this is due to changes in their visual area of the brain.

People with Lewy body dementia are also very susceptible to the side effects of antipsychotic (neuroleptic) drugs which should be avoided as they tend to aggravate difficulties with movement. Furthermore, the dopamine replacement therapies used to treat Parkinson's disease typically do not help and usually worsen hallucinations and confusion. There may be a good response to the

cholinergic-based drugs which are used to treat Alzheimer's disease.

As with Parkinson's disease, sleep disturbance is common with many people experiencing rapid eye movement sleep behaviour disorder.

The distinction between dementia with Lewy bodies and Parkinson's disease can be difficult to make. Some individuals who have Parkinson's disease do indeed develop a dementia similar to that seen in dementia with Lewy bodies but this typically occurs after a period of several years during which time they have shown response to dopaminergic treatment.

Progressive supranuclear palsy


Progressive supranuclear palsy (PSP) is a rare, but increasingly recognised, disorder that was first described by Steele, Richardson and Olzsewski in 1964. It is sometimes named after them. The pathological features resemble those found in Alzheimer's disease (presence of tangles) but the distribution of pathology in the brain is different and involves structures deep in the brain and brainstem. The main neurotransmitter deficit is dopamine.

Clinically, PSP is similar to Parkinson's disease, except that the motor deficits are symmetrical in onset, and severe rigidity is more prominent in the neck and body rather than the limbs. Tremor is rare. Another early feature is a marked tendency to falls. The characteristic feature, which gives it the name progressive supranuclear palsy, is an inability to voluntarily move the eyes in an up-and-down direction. This causes difficulty reading and walking downstairs. Eventually, eye movements are affected in all directions.

Problems with speech and swallowing are common. People with this disorder typically converse much less than normal and may have slurring of speech. Cognitive impairment is present in the majority and reflects dysfunction of the frontal areas of the brain. Apathy is a frequent feature.

Corticobasal degeneration (CBD)

Corticobasal degeneration is a progressive neurodegenerative disease related to frontotemporal dementia. It is associated with atrophy (shrinkage) of the frontal lobes, the parietal lobes and the basal ganglia.



The disease usually begins with motor symptoms, such as parkinsonism (rigidity, slow movements and postural instability) or apraxia. **Apraxia** is an inability to perform complex purposeful motor tasks even though there is no weakness or sensory loss. This is because the brain cannot send the correct messages to the limb. In some people, the hand may behave as if it has a will of its own (so called 'alien limb syndrome'). Typically one side of the body is affected more than the other. The affected side may become increasingly stiff and useless and may even develop involuntary jerks in response to a variety of stimuli, such as noise and surprise.

As the disease progresses many people develop features of the behavioural variant of frontotemporal dementia such as apathy, loss of empathy, disinhibition and poor decision-making. Others with CBD may develop features of progressive nonfluent aphasia.

The majority of people with CBD present with motor problems. But, existing research indicates that cognitive, emotional or language problems may be the first signs, followed by (sometimes several years later) the onset of parkinsonism or apraxia.

CBD progresses slowly over a number of years. Unfortunately, no treatment currently exists for this disease. Management requires the expertise of speech and language and occupational therapists.

Vascular dementia

Vascular dementia is the broad term for dementia associated with problems of circulation of blood to the brain and is a relatively common form of dementia even in younger adults. Two of the most common forms of vascular dementia are **Multi-infarct dementia** and **Binswanger's disease**.

Multi-infarct dementia is caused by an accumulation of damage from small strokes, called mini-strokes or transient ischaemic attacks (TIA), in the grey and white matter of the brain. Binswanger's disease (also known as subcortical vascular dementia) is associated with changes to the deep white matter of the brain due to blockage of very small blood vessels in the brain but without discrete stroke-like events. Both of these diseases reflect underlying disease of the blood vessels and usually occur in association with cardiovascular risk factors such as smoking, hypertension, high cholesterol or diabetes.

In younger adults, the presence of vascular dementia may be due to a genetic disorder. Cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy, usually called **CADASIL**, is an inherited condition that causes stroke and dementia. The underlying abnormality involves the muscle cells surrounding these blood vessels (vascular smooth muscle cells). The resulting blood vessel damage can cause migraines and, later in life, recurrent strokes that progressively damage the brain, causing dementia. Mutations in the NOTCH3 gene on chromosome 19 cause CADASIL. The NOTCH3 gene provides instructions for producing a receptor protein, which is important for the normal function of vascular smooth muscle cells.

A range of unusual inflammatory and autoimmune disorders (such as the lupus anticoagulant syndrome) can also affect the blood vessels in the brain, or clotting function, and lead to mini-strokes. Autoimmune disorders are ones in which a person's body tissues are attacked by that person's own immune system. Some of these disorders are treatable. For this reason, any younger adult showing signs of vascular dementia should be investigated to exclude these rare causes of stroke.

In vascular dementia, memory is usually less affected than in Alzheimer's disease. Problems with organisation, motivation (apathy) and planning are common in the early stages. Language and communication difficulties are also frequent as are motor problems such as difficulty walking and controlling the bladder. Behavioural problems can also occur, particularly if the strokes occur in the frontal areas of the brain. Vascular dementia typically progresses in a stepwise fashion; deterioration in memory and reasoning abilities are followed by periods of stability, only to give way to further decline. Because the site of damage in vascular dementia varies from person to person the symptoms and signs of the dementia are also variable.

The management of vascular dementia depends upon the underlying cause and may involve control of vascular risk factors such as high blood pressure, diabetes and raised cholesterol.

Huntington's disease

Huntington's disease is an inherited brain disease.

The disorder is named after George Huntington, the American physician who first described it in 1872. It is caused by a mutation in a specific gene, the Huntingtin gene, located on chromosome 4. The diagnosis of Huntington's disease is established by testing for the gene abnormality. It is inherited as an autosomal dominant disorder which means that each child of a person with Huntington's disease has a 50% chance of inheriting the disease.

Physical symptoms are usually the first to be noticed and typically appear between the ages of 30 and 50. The most characteristic are jerky, random, and uncontrollable movements called chorea. People with Huntington's disease also show a general lack of coordination causing an unsteady gait and slurring of speech. Eating difficulties commonly cause weight loss and may lead to malnutrition in the late stages of the disease.

The cognitive features of Huntington's disease reflect involvement of the frontal lobes of the brain, giving rise to problems with planning, motivation, flexibility and abstract thinking. As the disease progresses, memory problems tend to appear.

Psychiatric symptoms are also common but vary far more across individuals than the cognitive and physical symptoms. These symptoms may include anxiety, depression, reduced display of emotions (blunted affect), irritability and aggression, as well as compulsive behaviour, which can cause, or worsen addictions, including alcoholism and gambling.

No treatment currently exists to stop the progression of Huntington's disease, but medications are available that can control movement disorders and psychiatric symptoms.

Alcohol related dementia and Korsakoff's syndrome

Too much alcohol, particularly if associated with a diet deficient in thiamine (Vitamin B1) can lead to irreversible brain damage. Prisoners of war who have a very poor and restricted diet, have been observed to have similar brain damage to people who chronically abuse alcohol.

The National Health & Medical Research Council of Australia recommends that men 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.

Korsakoff's syndrome is characterised by an abrupt onset of severe loss of recent memory (amnesia) accompanied by confusion and apathy, as well as physical problems such as loss of balance, painful or weak limbs, and disordered eye movements. If not treated urgently, this can be fatal or leave the person with permanent and severe memory loss.

Whether chronic high alcohol intake can produce a gradual and progressive dementia remains controversial. Accumulating evidence indicates that high alcohol consumption (over six standard drinks per day) can cause shrinkage of the frontal lobes producing poor initiation, planning, organisation, motivation and problem solving. People with alcohol-related brain damage also have a memory disorder called 'confabulation' (false memories). These people can seem very convincing when reciting personal anecdotes and recent events. Such people are not deliberately making things up but rather subconsciously filling in gaps in their memory. These changes may be partially reversible if the person stops drinking and, as such, alcohol-related dementia is often described as static.

*For more information on the different types of dementia, see the Alzheimer's Australia website at alzheimers.org.au, then select *About Dementia & Memory Loss > Types of dementia**




B.

Practical approaches to management of dementia



B



The following sections cover aspects of the management of dementia emphasising aspects that are particularly relevant to younger people. The literature on this topic is quite extensive and the following is meant to be an outline only with key points and signposts to further reading. In particular the Alzheimer's Australia website has many excellent help sheets (see www.alzheimers.org.au/helpsheets) or you can call the National Dementia Helpline on 1800 100 500.

In the first section common cognitive problems are identified and some suggestions made on the way to help individuals overcome them. This is followed by sections on challenging behaviours, activities of daily living, and sexuality. The final section raises a number of employment issues.

1. Memory and other cognitive abilities: working with strengths

As part of the diagnostic process, many people with younger onset dementia have been asked by their medical specialist to have an assessment by a neuropsychologist. The assessment looks at a person's cognitive abilities (e.g. attention, memory, thinking, problem solving), particularly their strengths and weaknesses. This information is important for both carers and the medical team as it can be used to develop strategies to assist with cognitive and behavioural interventions which will vary from individual to individual. It is, therefore, important to have information about what the person can still do well, and in what areas they may need extra assistance. Once you know the person's strengths, you can use these to try to overcome some of their weaknesses.

At the current time there is no way of restoring lost memory and thinking capabilities. The most effective way to manage cognitive difficulties is by making changes to the way information is presented to the person with younger onset dementia and by adapting the surroundings. By adapting the surroundings the individual may have less need to rely on memory and thinking skills.

Attention and concentration

Attention refers to the ability to focus and to sustain concentration over prolonged periods of time. Dual-tracking, another component of attention, is the ability to attend to more than one thing at once. Impairments in these areas cause the following problems:

Common problems:

- Easily distracted
- Difficulty paying attention
- Inability to 'follow through' with a task or instruction.
- Inability to do more than one thing at a time (multi-task)

Strategies:

- Remove distractions whenever possible (turn off the TV and radio during conversations)
- Talk one-on-one rather than in a large group

- Concentrate on relevant material
- Simplify information and written instructions
- Reduce the amount of information that is presented
- Present information in small chunks in both a verbal and written format
- Get the person to repeat back information to ensure he or she has understood
- Get the person to focus on one task at a time, one step at a time
- Keep the person focused by breaking down tasks into manageable parts
- Allow enough time – it will take longer to process information

Memory

Problems with what is called 'episodic memory' (the ability to recall personally experienced events from the recent or more distant past) are very common in all the dementias but are the hallmark of Alzheimer's disease. Impairments in this domain cause the following:

Common Problems:

- Forgetting phone messages/conversations
- Misplacing commonly used items
- Repeating stories
- Poor recall of events
- Forgetting appointments/meetings/medications

Strategies:

- Keep a notepad by the phone for messages
- Use an answering machine for phone messages
- Decide on a consistent place to keep handbags, keys and wallets
- Attach important items so they cannot be mislaid (using a neck cord for glasses, tying keys to a belt)
- Label desk drawers and cupboards
- Avoid reminding the person that he or she has asked the question already
- Use distraction by introducing other enjoyable

activities or conversations if the person continues to repeat him or herself

- Try giving a different response or turning the questions into a discussion
- When a person is trying to recall an event, assist them by providing a meaningful context (who was there, what the event was for, how long ago it occurred); providing cues and prompts can aid recall
- Try to understand why the person is repeating the question – is it due to increasing anxiety about an upcoming event/issue?
- Write down all appointments in a clear and simple diary or wall-calendar. Make sure the person checks the diary or calendar at the same time each day (e.g. after breakfast and after dinner)
- Only use one diary or wall-calendar; use it consistently and encourage the person to refer to it every day
- Set an alarm to remind the individual of things that he or she needs to complete - if the person is used to using a mobile phone or electronic daily planner these are ideal tools to assist with remembering
- Ask your local pharmacist about having tablets placed in a Webster-pak which can help in remembering to take tablets
- Make sure the person has his or her name, address and contact in his or her wallet/purse and consider an identity bracelet if disorientation is becoming a problem.

Speech and Language

Language is a complex human ability which depends upon a network of structures in the dominant (usually left) hemisphere of the brain.

Common Problems:

- Difficulty finding words or constructing sentences
- Difficulty expressing oneself and in being understood
- Difficulty understanding others
- Difficulty understanding the meaning of words
- Frustration because of difficulties communicating

- Reduced ability to express needs and therefore needs not met

Strategies:

- Allow more time to communicate
- If the person is struggling to find a word in conversation, offer assistance after allowing a reasonable amount of time (do not jump in too soon)
- Stand in front of the person and minimise distractions
- Place yourself at eye level
- Avoid talking over the person with dementia
- Speak gently and clearly – do not shout
- Use statements rather than questions
- Wait for a response from the person with dementia before continuing
- Smile and use humour

If the ability to communicate through spoken word or written language is lost, then other forms of communication can be used. Non-verbal communication refers to all other forms of communication and includes:

- Facial expressions (such as smiling and frowning)
- Gestures (such as pointing, touching or waving)
- Eye contact (such as looking at or away from others)
- Behaviour (such as walking away or crying)
- Volume (such as speaking loudly or softly)
- Tone of voice (such as high or low pitch)

An assessment by a speech pathologist can be very helpful in devising strategies to enable more effective communication for the person with dementia. Talk to your doctor about organising an assessment.

Executive functioning

The term 'executive functioning' refers to higher-level thinking abilities that enable a person to successfully engage in independent goal-directed behaviour. These abilities are most commonly linked to the frontal cortex and they guide complex

behaviour over time through planning, decision-making and self-monitoring of judgments and impulses.

The term 'executive functioning' originated in the business world, where the executive monitors all the departments so that the company runs efficiently and is well-organised. Impairments in this domain may cause the following:

Common Problems:

- Difficulties with planning and organisation
- Difficulty making decisions
- Poor judgment
- Impulsive behaviour (e.g. spending recklessly, dangerous driving)
- Disinhibition (e.g. talking inappropriately to a work colleague)
- Rigid or concrete thinking
- Inability to stop or start an action
- Inability to monitor behaviour or pick up on others responses
- Frequent changes in mood (emotional rollercoaster)
- Lack of remorse toward people
- Reduced drive or motivation
- Unawareness or denial that the behaviour is a problem

Strategies:

Executive difficulties are the hardest of all cognitive problems to manage. You may need to try a number of approaches and review these regularly.

- Establish a consistent daily routine
- Use a diary, mobile phone and/or electronic daily planner
- Break down tasks into manageable components
- Minimise external distractions and stressful situations
- Allow time for decision making and ensure that the person has access to the relevant information and support
- If initiation is a problem, start the activity with the

person and show him or her what to do

- Guide the person through the steps of making a decision
- If the person is still working, make sure that there are checks in place to monitor work performance; supervision is crucial, especially if the person is making important decisions that have ramifications for others
- Socially inappropriate behaviour can be challenging and needs expert assistance. Ask your doctor to assist you in finding help. A good place to start is the Dementia Behaviour Management Advisory Service (DBMAS)* or the National Dementia Helpline 1800 100 500.
- Ask for a driving assessment for the person with dementia to ensure that he or she is safe on the road.

Cognitive problems can have a significant impact on the well-being of affected individuals and their families. Try to remember that it is the disease that is causing these changes in thinking, personality and behaviour. The person with dementia is not intentionally trying to be difficult. It is very important that both you and the person with younger onset dementia continue to enjoy pleasurable and relaxing activities and to maintain social contacts. It might be helpful to take up a pursuit together or to involve friends and family members.

For more information on changes in memory see the Alzheimer's Australia website at alzheimers.org.au, then select *About Dementia & Memory Loss*>*Memory Loss*

* The Dementia Behaviour Advisory Service is available to care-workers, services and carers providing care to people with dementia who are seeking or accessing Australian Government aged care services, where the behaviour of the person is impacting on their care, including staff and volunteers of Australian Government funded aged care services, other clinicians (eg GPs, staff of mental health services for older people), and family carers.

2. Challenging behaviours in dementia : tips on management

People with dementia may develop behavioural symptoms that may be a consequence of the person no longer being able to meet his or her own needs, or be a direct symptom of changed brain function. Behavioural symptoms vary between individuals and change over time as the illness progresses.

If behaviour is having an impact on the person with dementia or those around them, consider the following:

Know what functions of the brain have been affected:

To manage behavioural symptoms the family carer needs information.

This includes finding out from the medical specialist or GP what functions of the brain have been affected by the illness. If the person with dementia has seen a neuropsychologist he or she will also be able to give this information.

Know the person:

It is important to know the person well. This includes his or her personality, past experiences, likes and dislikes, and the things which are important to him or her. The family carer is best placed to know this information and use this knowledge when developing behavioural management plans.

Ensure the person with dementia is as physically well as possible:

When people with dementia are unwell they will be less able to use the skills they still have. Having check ups with the GP, providing good nutrition, encouraging exercise and managing medications will assist with this. Check for visual and hearing problems and make sure the person has glasses or hearing aids if needed. If behaviour deteriorates rapidly see your GP as there may be a medical cause for this (such as urinary tract infection).

Manage/examine your own behaviour:

Behavioural symptoms in people with dementia are made worse when their family carers are stressed. A high proportion of carers develop significant depression which further lowers the ability to deal with the person with dementia.

Modify the environment:

The environment has an impact on the ability of the person with dementia to use his or her skills. An environment which has cues for people with memory loss and disorientation will assist in meeting their needs more effectively and can reduce frustration or fear. A noisy and over-stimulating environment may interfere with concentration and comprehension leading to more agitation.

Reflect on incidents:

Reflecting on what is happening can be a useful learning tool. Think about possible triggers that have promoted the well-being of the person and triggers that contribute to the person's behavioural symptoms.

Be aware of your own limitations:

Acknowledge when you respond appropriately and when you need assistance from others. We all have our strengths and weaknesses and you may be able to manage some behaviours better than others.

If you are having difficulty coping with behavioural symptoms, especially those relating to safety, you may find contacting a health professional useful. Alzheimer's Australia's Help Sheets provide general information on various behaviours. They can be found on the website alzheimers.org.au

For more information on changed behaviours and dementia see the Alzheimer's Australia website Help Sheets section at alzheimers.org.au, then select *Publications & Resources > Help Sheets & Update Sheets > Changed behaviours and dementia*.

For 24 hour assistance contact the Dementia Behaviour Management Advisory Service (DBMAS) 1800 699 799

3. Activities of daily living: Practical tips for improving everyday life

People with dementia typically encounter difficulties performing activities that were once very easy. These difficulties can be caused by lack of motivation, planning difficulties, memory decline, or because of language problems. It is possible, however, to help the person to continue performing their everyday activities. Independent of the reasons for the decline in activity, there are three important points to remember when trying to keep the person active:

- Keep the person with dementia and the carers safe. This is crucial.
- Focus on strengths
- Avoid conflict between you and the person with dementia

Try to keep the individual involved in everyday activities as much as possible, but if this creates too much distress or conflict consider taking a break, ask other family members to participate, or as a last resort, to take over the activity.

The importance of early assessment by the local Age Care Assessment Team (ACAT) cannot be overemphasised; this is typically the key to accessing local services, including occupational therapy.

Using telephones and mobile phones

There are usually three distinct problems with using the telephone: memory problems, language difficulties, and problems caused by behavioural change.

If there are memory problems:

- The individual does not pass on messages ask your friends to contact you on your mobile, or to call again later. Answering machines can also be an alternative. Some carer partners prefer to turn the volume down so that the calls reach the answering machine directly.
- The person with dementia forgets how to use the telephone: help by taking the individual through each step of the task.
- Write important phone numbers on a large sign placed next to the phone or store them as quick-dial numbers.

If there are language difficulties:

- Motivate or help the person with dementia to prepare a script to be used when making a call.
- If the person has some computer skills, using email is usually better because it can be re-read a few times. There is also more time to reply and deal with any issues.

If the problems are caused by behavioural changes:

- The telephone is constantly used for unnecessary calls: contact your telephone provider to set up a control system for outgoing calls e.g. using a pin number before mobile calls, or interstate calls, etc.
- Too many mobile calls are being made: change to a pre-paid mobile
- The person with dementia buys too many products over the phone: contact your telephone provider to block marketing calls.

Managing finances

Breakdown in the ability to manage personal and family finances may be due to a lack of motivation and interest, memory loss, language difficulties, or planning and organisation problems.

If there is lack of interest:

The person with dementia may lose interest in the management of finances. If you feel too overwhelmed, consider involving your bank manager, a family member or trusted friend. Asking for help might be difficult, but it generally prevents unwanted financial problems and reduces stress.

If there are memory problems:

- The person with dementia may forget to pay bills. You may prefer to remind the person or to arrange for bills to be paid automatically. Check if you can use Bpay, direct debit, credit card, etc.
- Pin numbers can be forgotten. We tend to have several cards nowadays, so it is a good idea to keep one pin number only for all. Alternatively, you can contact the bank and request a card that requires signatures only.

If there are language difficulties:

Sometimes the person only needs support to continue managing finances. If you can offer some support without taking over the activity, this is usually very rewarding for all concerned.

If there are behaviour changes:

A common problem is overspending, so limiting access to a single card/bank account might be a good idea.

If there are planning and organisation problems:

Deal with bills and financial issues one at a time, one step at a time.

Shopping

For a variety of reasons, many people with dementia have difficulty shopping. It may be helpful to talk to local shopkeepers and explain the nature of the problem.

If there are memory problems:

- Forgetting what to buy. The most efficient way is making a shopping list
- Getting confused in the supermarket. Some families help the person by making a list which is divided by groups of goods/aisles, for instance, all cleaning products written together, then all dairy products, then all greens, and so on.

If there are language difficulties:

If the person has difficulties understanding the names of the products, fruits or vegetables, he or she might avoid shopping altogether due to embarrassment. The use of pictures or labels from cans and packets can help, and may motivate the person to do a familiar activity.

If there are behaviour changes:

Some people with dementia have difficulties in controlling their shopping habits, for instance they may want to buy things they do not need, spending more money than necessary. Strategies to control impulsive shopping are closely related to strategies to control finances. Limiting the amount of money easily accessible may be a good solution to avoid overspending.

Household chores

If there are memory problems:

Use a white board, or any similar device. You can write the tasks for the day together; the person should be reminded to look at the board, and to tick off each completed task. This board can be especially useful if the person keeps repeating questions as you can refer back to the board so that you do not need to answer the same question over and over again.

If there are planning difficulties:

Planning difficulties usually occur because the person with dementia cannot cope with all the steps in a complex task. But if the task is broken down into small steps, the person can usually perform them without a problem. For instance, meal preparation with several dishes may pose a big challenge, but doing one dish at a time may be easier. Also, breaking down the preparation of one dish into smaller steps, e.g. fetching potatoes, peeling, boiling, draining, seasoning, etc, makes the task easier and boosts confidence.

If the problem is lack of motivation:

The person with dementia might start an activity and then leave it. It may be better to involve the person for a short period rather than not involving him or her at all. It is important to remember that the less the person is asked to do, the less he or she will do, and the likelihood of losing that ability is greater. Lack of participation in activities may also create a sense of helplessness for the individual.

Correspondence

If there are language difficulties:

The person with dementia may feel less confident writing letters or managing correspondence because of he or she has problems, for instance not remembering how to spell. Support from a family member, e.g. by proof reading, can allow the person to continue doing this activity with confidence.

If there are behavioural changes:

Problems receiving important correspondence because it is intercepted by the person with dementia may cause difficulties. Consider organising a post office box or redirecting mail to a family member living nearby.

Taking medications

If there are memory problems:

- Use alarm clocks/mobile phones to remind the person with dementia of the time of each dose. Link a regular event to taking medication, for example having the medication at breakfast time, or before going to bed.
- Organise a medibox: Preparing the dosages in advance once a week can prevent people from taking the same medication more often than prescribed.

If there are behavioural changes:

Sometimes the person with dementia may refuse to take their medications, in which case you may want to speak to your pharmacist about alternative forms of the same medication, e.g. powder, or liquid forms. It is important not to try changing it yourself (e.g. crushing a tablet) because this may cause significant alterations to the medication.

4. Sexuality and younger onset dementia

Dementia affects the sexual life of both the person with dementia and his or her partner. Anxiety and stress may have an impact on the physical expression of affection, love and sexual desire. The illness may cause apathy resulting in disinterest. It may also cause the person to be less caring and affectionate which reduces the partner's willingness to be sexually expressive. If the person with dementia needs assistance with personal care this too may affect sexual desire. As the illness progresses, the partner can be confronted with feelings of loss relating to this area of their lives together. The partner may also feel that he or she is taking advantage of the person with dementia by desiring intimacy. Finding ways which suit you and your partner to express affection and intimacy will assist in adjusting to these changes gradually. Counselling may also assist in these adjustments.

For more information on Intimacy and sexuality see the Alzheimer's Australia website at alzheimers.org.au, then select *Family & Carers>Personal Care>Intimacy & Sexual Issues*.

5. Employment issues

Dementia causes various impairments, which may affect a person's ability to carry out his or her job. A neuropsychologist can provide detailed testing which will indicate the areas of ability that have been affected. Neuropsychologists can also provide strategies which may assist in overcoming these problems. They may be able to liaise with the employer to assist in planning changes. Occupational therapists may also be able to assist in developing strategies that build on the person's remaining skills. Occupational therapists work within hospitals and also in private practice.

Commonwealth Rehabilitation Services may be able to assist the person with dementia to continue employment in the early stages of the illness. Phone 1800 277 277 or mail crs@australia.gov.au

For more information about employment and decision making see the Alzheimer's Australia website at alzheimers.org.au, then select *I Have Dementia>Early Planning>Making Employment Decisions or I Have Dementia>Younger Onset Dementia>Employment and Younger Onset Dementia*.

6. Driving and the law

The prospect of having one's driving licence cancelled can be extremely upsetting. Driving is usually strongly associated with independence and autonomy. When a person loses his or her licence important changes to his or her routine follow. This can also mean changes to family members' routines and roles.

In general, family members are the first to notice changes in the driving skills of the person with dementia, but may find it very difficult to address such a delicate issue. Often the person is unaware of problems but even those who do realise that their driving is deteriorating may be reluctant to report this in fear of losing their driving licence.

Whatever the starting point, driving is an issue that has to be addressed, and the earlier the better, to avoid greater distress later. The risks involved are too great to be postponed.

Reporting to the Driver Licensing Authority

By law, it is the person with dementia or the family's responsibility to report to the Driving Licensing Authority any permanent or long-term illness that is likely to affect the ability to drive safely. Your doctor can advise on whether the diagnosis is one that should be reported. If necessary, the doctor will refer the person for a driving assessment. If a driving assessment is to be undertaken there may be costs involved that vary depending on the centre. There are three possible outcomes from a driving assessment

- Conditional licence issued: the person with dementia may drive without restrictions but requires regular review at a specified time interval
- Conditional licence issued: the person is able to drive but only with modifications to the vehicle or with certain restrictions
- Licence cancelled: the person is deemed unfit to drive and the licence cancelled (the person can appeal and request reassessment)

However daunting the prospect of the assessment and its outcome, it is very important that the person with dementia and their family receive clear advice. It is important to remember that should the person be involved in an accident and it is determined that the accident was caused the health condition, the person may be prosecuted and the insurance may not be valid.

Due to confidentiality, the doctor will not normally notify the Driving Licensing Authority of the person's condition. But if the person poses a significant threat to public safety and continues to drive, despite being advised not to, the doctor may notify the Driving Licensing Authority.

Alternative transport options

If there is a need to consider alternative transport options, think of your social network and the public transport around you. Can you involve friends or family members to drive the person, or you, around? Perhaps you can share petrol costs with them? Community transport is available in many areas and may be able to assist in transport to appointments. Contact Carelink on 1800 052 222.

Changes to the routine can be overwhelming at times, but some creative ideas can bring you

closer to friends or family members, and may even have surprising benefits.

Language difficulties and driving

Sometimes there are no changes in driving abilities, but the individual may feel concerned about his or her ability to speak if an accident were to occur. Language difficulties are generally worsened by stress. If this is the case, it might be helpful for the person with dementia to carry a letter from the doctor explaining the nature of the language difficulties. This would be helpful for others to understand the situation and can also help the person to be more confident. The person might wear a necklace or bracelet that lists the person's address and emergency numbers.

For more information about driving an dementia see the Alzheimer's Australia website at alzheimers.org.au, then select *I Have Dementia>Driving & Dementia>Driving and Dementia*.

7. Common drug treatments

There are no curative treatments for any of the common disorders that cause young onset dementia, although there are ongoing and interesting developments in many areas.

But there are treatments available for Alzheimer's disease that try to slow progression of the disorder, i.e. disease modifying agents. In addition there are pharmacological strategies for the treatment of behavioural and psychological symptoms of dementia or BPSD, as they are known. These symptoms include depression, anxiety, agitation, delusions and hallucinations and occasionally aggression. These may arise in the course of younger onset dementia of any pathology.

It is important to note that people with dementia may be particularly vulnerable to adverse reactions to drugs. Any such reaction should be reported to the Adverse Medicine Events Line 1300 134 237. All prescribing and monitoring should be in accordance with the National Prescribing Service guidelines (visit www.nps.org.au).

Treatments for Alzheimer's disease

Acetylcholinesterase inhibitors target the main neurochemical abnormality in Alzheimer's

disease that is the reduction in acetylcholine neurotransmission. They are also useful in dementia with Lewy bodies which shares this deficit.

Three drugs are currently available. They are Galantamine (Reminyl), Donepezil (Aricept) and Rivastigmine (Exelon), licensed for mild to moderate Alzheimer's disease. All three drugs primarily work by reducing the breakdown of naturally occurring acetylcholine in the brain. They do this by inhibiting the enzyme that is responsible for its breakdown and recycling.

Studies have shown that while these treatments do not work for everyone, a significant proportion of people experience an improvement in various aspects of cognition, for a period of time, perhaps in the order of a year. For some individuals there may be striking improvements and so a trial of treatment with at least one of these agents is worthwhile.

As with all medications an individual may experience adverse effects and there are relative contraindications, that is, reasons for not prescribing the medication. Common adverse effects include, gastrointestinal upset, with nausea or loose stools, dizziness and sleep disturbance. But these are often mild and settle quickly or can be managed by increasing doses more slowly or by adding treatment to counteract the adverse effects. Significant cardiac or respiratory problems may be a relative contraindication to trying the acetylcholinesterase inhibitors.

Memantine: In addition to drugs which act on the acetylcholine system, Memantine (Ebixa) acts on an important receptor in the brain, the NMDA receptor, and is thought to have a neuroprotective effect. Again studies have shown improvements in areas of cognition and function. This agent is licensed for moderate to severe Alzheimer's disease. Common adverse effects are visual problems, gastrointestinal disturbance and agitation. Sometimes an acetylcholinesterase inhibitor is combined with Memantine with good clinical effect.

Other non-prescribed agents that are used include Gingko Biloba, Vitamin E and Folic acid, but the clinical evidence from trials of medication to support their use is weak.

Pharmacological treatment of behavioural and psychological symptoms of dementia (BPSD)

Behavioural and psychological symptoms of dementia may occur at any point during the course of dementia. These symptoms include depression, anxiety, irritability, agitation, aggression or psychotic symptoms such as hallucinations or delusion (abnormal beliefs). They may be relatively short-lived or mild but may, on occasion be severe and/or persistent and cause distress to the individual or their carer.

Before any pharmacological treatment is considered it is important to make a thorough assessment of the concerning symptom or behaviour. This assessment should consist of a physical review to exclude new medical problems as a potential cause of the symptoms. For example constipation or pain may cause irritability or aggression, and an unidentified infection e.g. a urinary tract infection can be a cause of a superimposed delirium or confusional state resulting in delusions (abnormal beliefs) or visual hallucinations. A repeat brain scan may be indicated, if there is a sudden deterioration in cognition. If there is no apparent physical cause for the change in mental state or behaviour then environmental triggers need to be considered. Tensions in the relationship between the carer and the person with dementia, or changes to the care staff if the patient is in a nursing home, may trigger anxiety or depressive symptoms. In the early stages of dementia, soon after diagnosis, an individual may experience considerable emotional distress that, if sufficiently severe, may need to be considered for pharmacological therapy if general support, education or counselling are insufficient.

Antidepressants

At any stage of the dementia antidepressant medication may be considered for an individual who has depression or anxiety. They may also be considered if the individual has become irritable or aggressive as this can sometimes be due to underlying depression or anxiety. There are a number of antidepressants that may be tried and the choice of agent used is often dominated by the possible side effect profile of the medication. There is little evidence to suggest that any particular drug is more effective than any another.

Antipsychotic medication

Antipsychotics (also known as neuroleptics) are occasionally used when an individual has developed psychotic symptoms, for example hallucinations or delusions (abnormal beliefs) or severe agitation. Examples of such agents include risperidone, olanzepine and quetiapine. There is concern about the use of these agents for a number of reasons. The use of antipsychotics is particularly problematic in people with dementia with Lewy bodies and other parkinsonian dementias as they can cause significant, and sometimes irreversible, deterioration. In other dementias there is concern that they may hasten deterioration. Despite these concerns if the behavioural symptoms are severe and causing the individual distress or preventing his or her from receiving the necessary care, then it may be appropriate to undertake a cautious trial. The risk/benefits should be discussed with the patient (when possible) and the carer or guardian. Arrangements for review of their effectiveness should be made.

Other medications

Other medications may be used in severe cases. These include anticonvulsants (sodium valproate and carbamazepine), and benzodiazepines (diazepam and lorazepam), amongst others.

Again, risk and benefits should be discussed with a clear plan of what symptoms the drugs are being used to control, and how any effect, good or bad, will be monitored.

*For more information on treating dementia see the Alzheimer's Australia website at alzheimers.org.au, then select *About Dementia & Memory Loss*>*Treating Dementia*.*




C.

The caring role and the family



C



Caring for someone with a younger onset dementia can be very challenging. Many people never imagine being a carer for a partner, relative or friend in early or mid-life. It is often the case that the diagnosis of younger onset dementia is delayed and this delay and associated uncertainty of diagnosis can cause considerable stress to all involved.

A diagnosis of dementia can come as a shock, even after years of doctors' visits and medical investigations. In the initial stages shock, sadness, anger and disbelief are common reactions to the diagnosis. These feelings are normal.

When a person is younger, a diagnosis of dementia raises many challenges for the rest of the family. People with younger onset dementia are generally active, mobile and physically capable. As a consequence caring for a younger person is more demanding than caring for an older person. The person may have been in full-time employment, actively raising a family and be financially responsible for the family. A carer may have to juggle caring for the person with dementia with employment, childcare, and even care of an older frail parent.

Everyone feels differently about becoming a carer. People react in different ways. "Why me?", "Why our family?", "What did we do to deserve this?", "What caused the disease?" These are very common questions often with no definitive answers. This uncertainty can lead to feelings of anger and frustration. By obtaining an accurate diagnosis you can begin to learn about the type of dementia, the causes and symptoms, and what to expect in the future. Your feelings and experiences are individual and may differ from those of other carers. You will feel many different emotions along the journey.

1. Changes in relationships

The act of caring for someone with younger onset dementia can lead to a change in relationships. Younger onset dementia is a disease that affects the whole family and social network. The carer and the person with younger onset dementia have to adjust to major shifts in their roles in the relationship. Carers may feel a sense of resentment that comes with the responsibility of looking after someone. Many people have to alter their hopes, dreams and expectations regarding their future together.

Carers often find the change of roles difficult to adjust to. For some families the person they are caring for is 'not the same person' anymore. Feelings of resentment, anger, guilt, frustration, love, hate, loss, and grief are normal. Sometimes you will feel all of these emotions in the same day. There may come a time when the person with younger onset dementia becomes unable to care for or provide for the family. This can lead to financial difficulties within the family and may place the carer under financial strain. It is important to obtain sensible financial advice early on so you can make decisions together and plan for the future.

2. Caring and personality types

Some people are 'born carers'. Some people are not suited to the caring role. You need to think carefully and honestly about yourself and your own strengths and limitations. Why are you the carer? Is it because you love the person you are caring for? Do you feel a sense of duty or obligation to take on the caring role? Is there an expectation from either the person with dementia or extended family or friends? Are there financial reasons why you are the carer? Or is it because there is no one else available? It is important to understand the reasons behind your decision to become the carer.

Caring can be a rewarding and positive experience for some individuals. They surprise themselves by finding inner strength, resilience, and an ability to tolerate adversity, and they find a sense of humility and purpose. But for some people the responsibility and work involved is overwhelming and mentally and physically exhausting. Every carer needs regular breaks to avoid burn out. You will need to continually assess how you are managing

the multiple demands. Some people will not be able to continue as a carer for their own health and well-being.

3. Coping styles

There are lots of different ways of coping when you are caring for someone with younger onset dementia. Carers who use an active 'problem-focused' approach tend to cope better over time. This means they experience greater levels of well-being and lower levels of depression and burnout.

Examples of a problem-focused approach include:

- Making a plan of action and following it
- Brainstorming different solutions to a problem
- Expressing emotions in an appropriate forum (support groups/counselling)
- Seeking social support

'Emotional' coping styles tend to be less productive.

Examples of emotional coping styles are:

- Avoidance and/or denial
- Hoping for a miracle
- Wishful thinking
- Blaming yourself or others for the situation
- Keeping feelings bottled up inside

If you are having difficulties coping and adjusting to your role as a carer it is important to seek assistance. Often the act of talking to someone can help you to understand that you are not alone and that there are potential solutions to common problems. It is very hard to make sensible decisions and to solve problems when you are under considerable stress. There are many places to seek help (see Further Information list). Many carers benefit from seeking professional counselling to assist in the adjustment process.

4. Carers' well-being

The importance of looking after yourself can't be overemphasised. Remember that if you are not physically and emotionally healthy you will not be able to continue in the role of carer.


Looking after yourself includes ensuring that you have pleasurable activities for yourself and that you continue to keep in contact with people who are supportive and positive in your life. Consider ways to manage stress. This may be through activities such as yoga, pilates or tai chi. Many carers find regular exercise either alone or with their partner a great way of reducing stress. You may find local classes on relaxation or meditation beneficial or you may use CD's and books on these techniques. These resources can be bought or borrowed from the local library. Some people find support groups beneficial. These provide a network of people who are caring for people with similar problems. People support each other and share useful tips on how to manage. Contact Alzheimer's Australia for information on 'Younger Onset Dementia Support Groups' and the 'Living with Memory Loss' groups. Contact the National Dementia Helpline 1800 100 500 or visit alzheimers.org.au for contact numbers in your State or Territory.

*For more information on caring for someone with dementia see the Alzheimer's Australia website at alzheimers.org.au, then select *Family & Carers>Caring For Someone With Dementia*.*

5. Impact on other family members

Dementia not only affects the people who have the illness but everyone around them. It may have taken some time to get a diagnosis and this can cause considerable frustration and even changes to the way people think of the person with dementia. Providing information to family and friends will help them to understand the disease and assist the person with dementia. Other people's reactions to the changes they see will vary and their ability to support and help will vary. Remember that we are all individuals with different coping mechanisms. Denial of the illness is common, especially in the early stages.

Many people with younger onset dementia will have dependent children who may still be at



school. Children are very vulnerable and are likely to have difficulty understanding the illness in their parent and the inevitable change in roles within the family. They may not understand the changes in behaviour that happen in dementia and may think that they are causing the behavioural problems. They may benefit from counselling to assist with many conflicting emotions, including fear, grief, frustration, and loss of the person or parent they knew. There are books explaining dementia that have been written especially for children and these may be helpful. It may also be beneficial to advise the child's school teacher or counsellor about the situation. Information for children is available on the Alzheimer's Australia website alzheimers.org.au

Information for children can be found on the Alzheimer's Australia website at alzheimers.org.au, then select *Family & Carers>Young People & Dementia*.



D.

Planning for the future



D

1. Advance care planning

Advance care planning relates to discussion between the person with dementia and his or her family/carers about preferred health care choices for the future. A discussion may be informal and include the decisions the person with dementia would like made if he or she is unable to do so, including future care. This discussion should include the family doctor who can explain potential medical treatments/decisions. An Advance Care Plan may be documented, recording instructions for the use of health professionals in the future.

Resources which may assist you include www.bensoc.org.au (then go to Ageing, then Future Planning), www.respectingchoices.org.au or www.alzheimers.org.au/legal

2. Legal Issues

Part of the following information is extracted from "Legal Planning and Dementia" Alzheimer's Australia Position Paper 5, April 2005. For a full copy of this paper contact the National Dementia Helpline on 1800 100 500 or visit the website www.alzheimers.org.au/legal.

Some of major issues you need to think about are:

- Money management
- Business affairs
- Medical treatment
- Buying and selling item
- Making a contract with someone
- Making a will

A diagnosis of younger onset dementia does not necessarily mean that the person is unable to make decisions. But it is likely that there will come a time when the person will be unable to make decisions due to difficulties with memory, language, thinking, and judgment. This combination of deficits often affects a person's ability to make sound judgments, reason through a problem, and plan for the future.

Some people with younger onset dementia may make risky or ill-informed decisions which can have serious financial, medical, and lifestyle implications for themselves, their families, and their employers. Therefore early planning is essential.

If you are concerned about any of the following, you should contact the Guardianship authority in your State or Territory.

- The person with dementia might not be able to make decisions competently
- The person with dementia is making/acting on decisions to the detriment of other family members/employer
- The person's guardian, or other substitute-decision maker, is not acting in the person's best interests
- The person with dementia is being (or is at risk of being) abused, neglected or mistreated
- If you are a substitute decision-maker for a person with dementia and you want help or advice about your responsibilities.

Alzheimer's Australia has further information on its website at www.alzheimers.org.au/legal or you can call the National Dementia Helpline on 1800 100 500.

Enduring Power of Attorney (EPA)

An Enduring Power of Attorney allows an individual (the donor) to appoint another individual (the attorney) to take control of financial affairs or property when the donor has lost the capacity to manage their affairs.

Enduring Power of Attorney is a formal document which appoints a person to be an individual's substitute decision-maker. It is called an Enduring Power of Attorney because it endures even after the individual loses legal capacity to make decisions. People with dementia can use an Enduring Power of Attorney to appoint a person to make decisions on their behalf after they lose the legal capacity to make decisions. The person appointed can make decisions about financial affairs and, in some States, decisions about the medical treatments.

Why make an EPA?

Making an EPA lets you choose a person whom you trust to manage your financial affairs should you later lose the capacity to make these decisions for yourself. By planning ahead, you can make sure that the person you select understands your priorities and how you want your financial affairs to be managed.

How can I make an EPA?

An EPA has to meet certain requirements for it to be valid. Usually, you will have to use a particular form and get a particular type of person to witness you signing it. You might also need to register an EPA. These requirements are different in each State and Territory. The Alzheimer's Australia website at www.alzheimers.org.au/legal can point you to specific information on how to make an EPA in your State or Territory.

Can I change an EPA?

You can revoke or change an EPA so long as you have the legal capacity to do so. In other words, as long as you have the capacity to make an EPA you have the capacity to change it. If you no longer have legal capacity, you won't be able to change or revoke an EPA. If it becomes necessary, the relevant court or tribunal in your State or Territory may change an EPA or appoint a different person if they think it is in your best interests to do so.

What powers do I give to the person I appoint?

The maximum power the person you appoint can have is the power to make all financial decisions on your behalf. This includes accessing your bank account to pay your bills, selling your house and, in some States, the person you appoint can make decisions about what medical treatment you receive.

Alternatively, you can put restrictions on the power of the person you appoint. For example, you can say that you don't want the person to have the authority to decide where you will live. But remember, someone needs to be able to make these decisions for you if you become legally incapable of making them.

If you do not make legal arrangements to appoint an appropriate person to make these decisions for you, then the relevant government body in your State or Territory may need to appoint a family member, friend, or official body to make such decisions for you.

What are the responsibilities of the person you appoint?

The person you appoint is generally responsible for managing your financial records and accounts, including lodging your tax return. This is an important responsibility. In some States, the person

may be fined if he or she doesn't keep proper records or look after your financial responsibilities carefully. In all States and Territories, the person appointed has a responsibility to make decisions based on what they think is in *your* best interests.

Wills

A Will controls what happens to a person's property after they die.

Why make a Will?

Making a Will lets you choose what happens to your belongings and property when you die. It may also let you make arrangements for the care of dependent children or your pets. Making a Will makes life less complicated for your family or friends, who will have to look after your estate. Everyone should make a Will. It is especially important for a person with dementia to make a Will because to make a valid Will, you need to have legal capacity. At some point the symptoms of the illness may take away the legal capacity to make a Will.

Ways to make a Will

If you have been diagnosed with dementia you should seek the assistance of a lawyer (or the Public Trustee in your State/Territory) when you draft a Will, especially if you have noticed your dementia affecting your decisions in other areas of your life. To make a valid Will, you have to be able to understand and appreciate the decisions that you are making about your assets and the effects of your decisions. If you make your own Will using a kit, your family may later question whether you were mentally capable of making the Will or the Will may not be granted probate after your death.

When you tell a lawyer that you have been diagnosed with dementia, he or she can provide advice about whether you have the legal competence to make a Will. If the lawyer is not sure that you are legally capable of making a Will, he or she might ask a doctor to check your decision-making ability. In this way you can reduce the chance of family and friends arguing about the validity of your Will after you have died.

Decisions about medical treatments

At some stage, dementia might prevent a person from being able to consent to medical treatment by affecting the ability to understand the nature of the medical procedure or the risks that may be involved. Your doctor may ask for an assessment of competency if he or she is unsure about a person's ability to make decisions about treatments or medical tests.

Two things to keep in mind:

- If you lose the legal capacity to make decisions about your medical treatment then someone else needs to make those decisions for you. In all States except Western Australia you can appoint someone you trust to make these decisions. If you have not planned ahead, the law in every State and Territory allows a particular court to appoint someone to make decisions for you.
- You can write down your wishes about what medical treatment you do and don't want. This way you can have your say even if someone else is ultimately responsible for making the decisions on your behalf.

Who can make decisions about your medical treatment if you have lost legal capacity?

If you no longer have legal capacity, there are three alternative types of substitute decision-makers who can manage your health affairs for you.

Family members: In some States and Territories family members have the legal power to consent to medical treatment that will promote your health and well-being. In other States and Territories relatives do not have this legal power.

Doctors: Your treating doctors can manage your health care. Doctors have the legal power to treat people in emergencies. In some States and Territories, doctors can also decide what treatment to give you if you have not appointed a substitute decision-maker.

Tribunal: The third alternative is that a tribunal or court will appoint someone to manage your health care. Each State and Territory has different regulations concerning guardianship, but they all provide for the appointment of *guardians*, (sometimes called *managers* or *administrators*), who can then manage your health care. These

tribunals and courts can also review and regulate the conduct of guardians and can manage a person's health care directly. You can find out more about the laws in your State or Territory at www.alzheimers.org.au/legal

Decisions about medical treatment

There are two types of tools available:

An Enduring Power of Attorney covering health matters: This allows you to appoint a person to be your substitute-decision maker for medical and lifestyle decisions. Some States and Territories, such as South Australia and New South Wales, call these *Enduring Guardianship Orders*.

An Advance Directive: A written document expressing your wishes about medical treatment. (see *Advance Directive* section of this booklet)

3. Financial issues: where to go for advice and help

A dementia diagnosis during active working years may impact greatly on financial plans. Seek advice if the person with dementia has left or is planning to leave employment. This may be obtained from the medical specialist, legal and financial advisors, trade union, and superannuation companies. Alzheimer's Australia has information available at www.alzheimers.org.au/legal.

4. Payments for carers

A fulltime carer may be eligible for the Carer's Payment. Carers may also be eligible for a Carer's Allowance. Contact Centrelink in your local area or through the website www.centrelink.gov.au.

5. Practical assistance in the home

A variety of assistance is available. This may include shopping, cleaning, outings, home respite or accompanying people to appointments. Commonwealth Carelink Centres are resource centres which are able to provide contacts for local services you may require. The phone number is 1800 052 222. If an individual needs assistance in a number of areas, or is unsure about what help is needed, contact the Aged Care Assessment Team

for assessment and advice regarding packages of care that can be provided in the home. It is important that the carer and the person with dementia identify the support that will enable them to maintain quality of life at home for as long as possible. There is a waiting list for most services so it is advisable to seek help before the need is great.

6. Respite and residential care

Respite

To enable a carer to have a break and to give the person with dementia a stimulating environment appropriate to his or her age and interests, it is important to consider respite.

The Government funds many types of respite (home respite, day centre respite, overnight community-based respite, emergency respite, and residential aged care). If you want to know more about the options available to you call a Commonwealth Respite and Carelink Centre on 1800 052 222 or the National Dementia Helpline on 1800 100 500.


It is important that you discuss your preferences/needs with someone who is prepared to listen and respond with creative and flexible options beyond aged care facilities.

Residential care

It is a difficult decision to consider permanent care for the person with dementia. Placement in permanent care typically occurs when there are substantial problems with self-care and mobility or challenging behaviours which can no longer be managed in the person's home. The carer may want to discuss this with family and health professionals, such as the general practitioner and Aged Care Assessment Team (ACAT), or with some professional who has worked closely with them. The decision about when it is appropriate to place the person with dementia in permanent care is a personal one. It depends on many factors, such as the carer's health, employment, impact on family members, available support network, behavioural issues and functional abilities of the person with dementia. Low-care and high-care facilities are available.

To organise for residence in a care facility it is necessary to obtain an assessment from the Aged Care Assessment Team (ACAT) and to complete a form (called the 3020), which begins the process. This form is current for 12 months (as long as the person's condition has not changed much in that time). The ACAT member will be able to give advice as to the most appropriate facilities. You do not have to take a place when one becomes available if you feel you are not ready to do so. Aged Care Facilities primarily cater for older people. People with younger onset dementia have different needs and it is widely accepted that such facilities are often inappropriate for younger people with dementia.

For more information on respite and residential care see the Alzheimer's Australia website at alzheimers.org.au, then select *Family & Carers>Residential care*.



Research into younger onset dementia: brain donation, the ultimate gift

Many of the diseases that cause younger-onset dementia, such as Alzheimer's disease, vascular dementia and dementia with Lewy bodies, are also common causes of dementia in the elderly and are the topic of intense research around the world. Others, notably the rare familial forms of Alzheimer's and frontotemporal dementia, are largely confined to people under the age of 65. In all instances much of the increase in knowledge, including the development of novel drug therapies, has come from the study of post-mortem brain tissue donated either by people with dementia or their families. Advances in knowledge have been slower than scientists would like; unlike the situation with disorders affecting other organs of the body (kidney, liver, gut etc), brain biopsy in life is rarely undertaken because of the risk of serious complications. Continued access to brain tissue, particularly in the case of the less common dementias that affect younger people is vital for combating these devastating diseases.

One of the most valuable contributions to medical science that can be made by a person with dementia, or his or her family, is to volunteer for a brain donor program.

If you are interested in this aspect of research you can talk to your medical specialist. Information can also be found on the website of the Australian Brain Bank Network at www.nnf.com.au. The ABBN is a collaboration of brain banks across Australia; this optimises collection, handling, and use of human brain tissue. Human brains are collected in New South Wales, Queensland, South Australia, Victoria, and Western Australia from people with dementia as well as from people with a wide range of other neurological disorders.

The Prince of Wales Medical Research Institute in Sydney is one of the largest centres of research on the brain and nervous system in Australia. It also has an active brain donor program. Information can be obtained on its website www.powmri.edu.au

Further information

Dementia Associations

- Alzheimer's Australia
www.alzheimers.org.au
- Alzheimer's Society UK
www.alzheimers.org.uk
- Health Services – New South Wales Government
www.health.nsw.gov.au/health_services/index.asp
- Pick's Disease Support Group (UK)
www.pdsg.org.uk
- Association for Frontotemporal Dementias (US)
www.ftd-picks.org

Carers' Associations

- Carers' Australia
www.carersaustralia.com.au
- Frontotemporal Dementia Caregiver Support (US)
www.ftdsupport.com
- Caring for someone - Australian Government
www.health.gov.au/internet/main/publishing.nsf/Content/ageing-carers-index.htm
- Commonwealth Carelink Centres
www9.health.gov.au/ccsd

Websites run by carers

- FTD support forum (worldwide FTD carer forum)
ftdsupportforum.com
- Early Onset Dementia
early-onset-dementia.blogspot.com

Practical Information

- Carers' Allowance - Centrelink
www.centrelink.gov.au/internet/internet.nsf/individuals/carer_index.htm
- Medication - National Prescribing Service Ltd
www.nps.org.au
- Driving
www.austroads.com.au
Australian Capital Territory:
www.tams.act.gov.au

New South Wales: www.rta.nsw.gov.au
Northern Territory: www.nt.gov.au/transport
Queensland: www.transport.qld.gov.au
South Australia: www.transport.sa.gov.au
Tasmania: www.transport.tas.gov.au
Victoria: www.vicroads.vic.gov.au
Western Australia: www.dpi.wa.gov.au

Legal Issues

For further information on legal issues visit the Alzheimer's Australia website:
www.alzheimers.org.au/legal

For further information regarding Guardianship and Administration in each State or Territory:

New South Wales: www.gt.nsw.gov.au
Northern Territory: www.nt.gov.au/justice
Queensland: www.gaat.qld.gov.au
South Australia: www.guardianshipboard.sa.gov.au
Tasmania: www.guardianship.tas.gov.au
Victoria: www.publicadvocate.vic.gov.au and
www.vcat.vic.gov.au
Western Australia: www.sat.justice.wa.gov.au
Australian Capital Territory: www.courts.act.gov.au/magistrates/index.html

Advance Care Planning

www.bensoc.org.au
www.respectingpatientchoices.org.au
www.crsaustralia.gov.au

Information on Communication

- Speakability - Aphasia Charity (UK)
www.speakability.org.uk
- Australian Aphasia Association
www.aphasia.org.au

Research

- Dementia Collaborative Research Centres
www.dementia.unsw.edu.au
- Australian Brain Bank Network
www.nnf.com.au
- Frontier:
Frontotemporal Research Group, Sydney
www.ftdrg.org
- Prince of Wales Medical Research Institute
www.powmri.edu.au

Books

Alzheimer's Disease

Caregiving skills

Coping with Memory Problems: A Practical Guide for People with Memory Impairments, their relatives, friends and carers.

Linda Clare & Barbara Wilson
Thames Valley Test Company, England 1997

36 Hour Day: Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses and Memory Loss in Late Life

Paul R. McHugh (Foreward), Nancy L. Mace, Peter V. Rabins

Paperback: 352 pages
The Johns Hopkins University Press 1999

The Selfish Pig's Guide to Caring

Hugh Marriott, David Lock (Illustrator)
Paperback: 350 pages
Polperro Heritage Press 2003

The Validation Breakthrough: Simple Techniques for Communicating with People with Alzheimer's Type Dementia

Naomi Feil
Paperback: 392 pages
Health Professions Press 2002

Professional and caregiver information

Dementia: Alzheimer's and Other Dementias at Your Fingertips

Harry Cayton, Nori Graham, James Warner
Paperback: 234 pages
Class Publishing 2001

Personal experience

Dancing with Dementia: My Story of Living Positively with Dementia

Christine Bryden
Paperback: 200 pages
Jessica Kingsley Publishers 2005

Caring for Maria: An Experience of Successfully Coping With Alzheimer's Disease

Bernard Heywood
Paperback: 240 pages
Element Books Ltd 1994

Living in the Labyrinth: A personal Journey through the Maze of Alzheimer's

Diana McGowin
Paperback: 176 pages
Delta 1994

Frontotemporal Dementia

Professional and caregiver information

What If it's Not Alzheimer's? A Caregivers Guide to Dementia

Lisa Radin, Gary Radin
Paperback: 300 pages
Prometheus Books 2003

Further resources are available at
alzheimers.org.au/youngeronssetdementia

Alzheimer's Australia Publications

Quality Dementia Care Series

1. Practice in Residential Aged Care Facilities, for all Staff
2. Practice for Managers in Residential Aged Care Facilities
3. Nurturing the Heart: creativity, art therapy and dementia
4. Understanding Younger Onset Dementia
5. Younger Onset Dementia: a practical guide

Papers

1. Dementia: A Major Health Problem For Australia. September 2001
2. Quality Dementia Care. February 2003
3. Dementia Care and the Built Environment. June 2004
4. Dementia Terminology Framework. December 2004
5. Legal Planning and Dementia. April 2005
6. Dementia: Can It Be Prevented? August 2005 (*superceded by Paper 13*)
7. Palliative Care and Dementia. February 2006
8. Decision Making In Advance: Reducing Barriers and Improving Access to Advanced Directives for People With Dementia. May 2006
9. 100 Years of Alzheimer's: Towards a World without Dementia. August 2006
10. Early Diagnosis of Dementia. March 2007
11. Consumer-Directed Care – A Way to Empower Consumers? May 2007
12. Dementia: A Major Health Problem for Indigenous People. August 2007
13. Dementia Risk Reduction: The Evidence. September 2007
14. Dementia Risk Reduction: What do Australians know? September 2008
15. Dementia, Lesbians and Gay Men (*in production*)
16. Australian Dementia Research: current status, future directions? June 2008

Reports commissioned from Access Economics

- The Dementia Epidemic: Economic Impact and Positive Solutions for Australia, March 2003
- Delaying the Onset of Alzheimer's Disease: Projections and Issues, August 2004
- Dementia Estimates and Projections: Australian States and Territories, February 2005
- Dementia in the Asia Pacific Region: The Epidemic is Here, September 2006
- Dementia Prevalence and Incidence Among Australian's Who Do Not Speak English at Home, November 2006

Other Papers

- Dementia Research: A Vision for Australia. September 2004
- National Consumer Summit on Dementia Communiqué. October 2005
- Beginning the Conversation: Addressing Dementia in Aboriginal and Torres Strait Islander Communities. November 2006
- National Dementia Manifesto 2007-2010

These documents and others available on www.alzheimers.org.au

