

# Advancing practice in the care of people with dementia

4th Edition

## Module 1: Overview of dementia



Dementia  
Training  
Australia



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# Module 1: Overview of dementia

## Introduction

This module presents an overview of dementia and will assist you to understand dementia within the context of what is known of population statistics, normal ageing, and illness. It aims to engage you in considering the scope and challenge of this condition through an exploration of dementia from the perspectives of normal age-related brain changes, definition, dementia type, accurate diagnosis and a discussion about how dementia is identified and diagnosed. The module also provides some insight into the impact of dementia on the individual with dementia, their family and carers, and the community as a whole.

## Objectives

On completion of this module you will be able to:

- Differentiate between the effects of normal and pathological ageing on the brain
- Categorise dementia type based on aetiology
- Debate key issues related to diagnosis
- Highlight current controversies and issues relating to dementia

## Module topics

Dementia in Australia

The brain cognition and normal age-related change

Defining dementia

Types of dementia

Impact of dementia

Current controversies and issues

Summary

References and resources

## Suggested reading for this module

Ames, D., O'Brien, J. & Burns, A. (2017). *Dementia*. (5th ed.). London. CRC Press.

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## Dementia in Australia

In 2019, there was an estimated 447,115 Australians living with dementia. Without a medical breakthrough, the number of people with dementia is expected to increase to 589,807 by 2028 and 1,076,129 by 2058 (NATSEM, 2018).

In 2018 dementia was the second leading cause of death in Australia This has changed from 2006 where dementia was the fourth leading cause of death overall in Australia. In 2018 dementia was the leading cause of death for females in Australia, and the third leading cause of death for males. This change may be due to changes in recording of deaths related to dementia. People diagnosed with Vascular dementia were previously coded as a death related to cerebrovascular disease rather than dementia. There have also been other legislative changes enabling a death of a veteran to be classified as dementia related to their area of service. The other factor is that while rates of dementia increase as our population ages, rates of death due to cardiovascular disease and stroke have remained stable. (ABS, 2019).

The average age of death of a person diagnosed with dementia is over 88 years. The Australian Bureau of Statistics estimate the median age at death from dementia occurs at 89.0 years (2019).

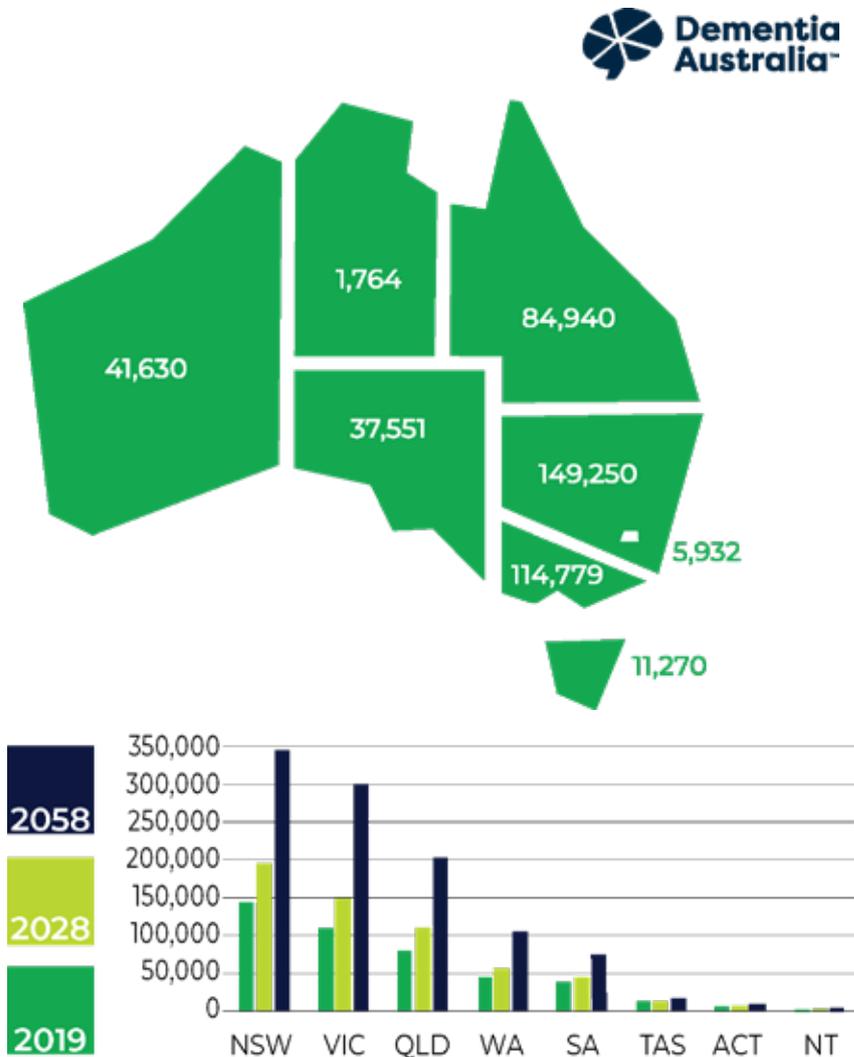
One person in ten over the age of sixty-five years has a diagnosis of dementia, the rate increases to three people in ten over the age of eight-five years. It is currently estimated there are 250 new cases of dementia in Australia each day. This is expected to increase to 318 people per day by 2025 (Brown, Hansnata & La, 2017).

In 2019, it is estimated there are over 27,000 people living with younger onset dementia. This is expected to increase to over 29,000 people by 2028, and to over 41,000 by 2058 (NATSEM, 2018).

There are also significant numbers of Australians involved in providing care for a person living with dementia. In 2019, this is estimated to be almost 1.5 million people (Dementia Australia, 2019b).

Source: Dementia Australia (2019c). *Dementia in Australia: Prevalence Estimates 2019-2058*.

**People living with dementia estimates 2019-2058**



Prevalence data research in Australia is conducted on a regular basis. See the Dementia Australia website for updated information: <https://www.dementia.org.au/information/statistics/prevalence-data>

Dementia impacts on the Australian community in several ways. The economic impact is estimated to cost more than \$15 billion. This is expected to increase to \$18.7 billion in 2025, and to \$36.8 billion in 2056 (Brown et al, 2017). Dementia is noted to be the greatest cause of disability in Australians aged over 65 years and is the third leading cause of disability overall (AIHW, 2012). 52% of people living in residential aged care facilities have a diagnosis of dementia (Brown et al, 2017).

The level of awareness and understanding of dementia in the community is variable and will probably be influenced by a person's working environment and personal experience. Research indicates ongoing poor knowledge and some entrenched negativity regarding dementia among the community (Olsen et al, 2019; Rosato et al, 2019). Australian researchers have examined dementia knowledge amongst nurses, direct care workers, and family members. Their findings indicate concerns with dementia knowledge in all levels of aged care staff and with family members. Unfortunately, this contributes to a poor understanding of the progression of dementia and appropriate selection of treatments and care options (Robinson et al, 2014).

The 2019 World Report from Alzheimer's Disease International (2019) found ongoing concerns and knowledge gaps in both the general public and health professionals:

- 95% of the public believe they will develop dementia eventually
- Two thirds of respondents believe dementia is a normal part of ageing
- 25% of respondents believe there is nothing that can be done about dementia
- Over 60% of health professionals believe dementia is a normal part of ageing
- Over 85% of respondents living with dementia stated they had not been taken seriously when expressing opinions
- Over 40% of the general public believe doctors and nurses ignore people living with dementia

Respondents described being avoided, ignored and ostracised in their social lives (Alzheimer's Disease International, 2019).

Awareness of dementia is also low in the Australian community. A report by the Australian Government Department of Health (2019) found 63% of people stated they know very little about dementia and 40% felt awkward if they were with a person living with dementia.

Challenging fears and understanding dementia as a process of slowly decreasing ability rather than absolute dependence, will support individuals, health professionals and family carers to feel empowered to plan and contribute positively to health and emotional outcomes.

## Prevalence and Incidence dementia in Australia

Prevalence refers to the number of people living with dementia in the overall population at a specific time point. Incidence refers to the numbers of people being diagnosed with dementia in a specific time period.

Age is strongly related to dementia prevalence, with the greatest number of people with dementia in the 85+ years age bracket increasing to 496,860 in 2056. It is projected that in less than 40 years' time 45% of people living with dementia will be aged 85 years and older. This growth has major implications for health care costs and the carer burden of dementia in Australia (Brown et al, 2017).

**Table 1. Estimated number of Australians with dementia by age - 2036 and 2056**

Age in Years	2036	2056
30-64	32,450	42,252
65-69	59,893	80,152
70-74	75,324	100,902
75-79	136,024	165,934
80-84	160,778	214,790
85+	296,204	496,860
<b>Total</b>	<b>760,672</b>	<b>1,100,890</b>

Source: Brown et al, 2017.

In 2016 dementia was the second leading cause of burden of disease in men aged 85 and over and the leading cause of burden of disease in women aged 85 and over. The years of disability caused by dementia and the years of life lost contribute equally to the burden of disease from dementia (Brown et al, 2017).

These figures highlight the significance of dementia as a major consideration in healthcare planning. Data from the Australian Institute of Health and Welfare indicates people living with dementia rely heavily on health and aged care services. Many people living with dementia have other complex medical conditions, and many people living with dementia need high care (2012).

The diagnosis of dementia is a life event which engenders fear and dread within communities that value independent thought and action. Bryden (2016) describes the fear and denial associated with a diagnosis of dementia. She describes the social isolation that she attributes to community stigma and misunderstandings of the condition. Bryden demonstrates it is possible to live a full positive life following the diagnosis of dementia.

Table 2 shows dementia prevalence estimates from the Australian Bureau of Statistics nationally and by state and territory. The results are broadly representative of the population, with New South Wales projected to have the greatest number of people with dementia followed by Victoria and Queensland. However, the greatest percentage increase is expected to occur in the Northern Territory (Brown et al, 2017).

**Table 2: Estimated number of Australians with dementia by State and Territory: 2036 and 2056.**

State	2036	2056
NSW	240,171	326,108
Vic	190,632	280,241
Qld	154,339	233,298
WA	84,161	143,957
SA	58,559	74,091
Tas	18,232	21,220
ACT	10,849	16,313
NT	3,729	5,662
<b>Australia</b>	<b>760,672</b>	<b>1,100,890</b>

Source: Brown et al, 2017.

It is estimated that approximately 244 people develop dementia each day in Australia, future estimates increase to over 650 people developing dementia each day by 2056 (Brown et al, 2017).

## Aboriginal and Torres Strait Islander Australians

The statistics on prevalence of dementia amongst specific population groups is limited.

Older epidemiological studies on Aboriginal and Torres Strait Islander Australians in remote regions suggested rates of dementia up to five times higher than in non-Indigenous populations and that the onset occurred in younger age groups. A larger proportion of Indigenous Australians diagnosed with dementia were in the 45-69 years age group (Arkles et al, 2010). However, these studies were conducted in small communities and there was uncertainty as to the application of these statistics to all Indigenous Australians, particularly in urban areas.

Further research, the Koori Growing Old Well Study (KGOWS), is being undertaken in a variety of Indigenous Australian communities to ascertain the prevalence rate (Radford et al, 2014). Early results indicate Indigenous Australians are three times more likely to develop dementia as compared to non-Indigenous Australians. The research findings also confirm Indigenous Australians present with higher rates of dementia at a younger age. The most common presentation is Alzheimer's dementia (Radford et al, 2015). A five-year study by Lo Giudice et al (2016) found Indigenous Australians have the highest rates of dementia in the world. This study found an association with age and history of head injury.

The KGOWS is continuing to gather longitudinal data to investigate the causes of high rates of dementia in this population (Dementia Australia, 2016). Further findings from the KGOWS have established a significant association between childhood stress and the later development of dementia in Indigenous Australians (Radford et al, 2017). Broe and Radford (2018) discuss the emerging problem of dementia for Indigenous Australians and postulate the higher rates are likely to be linked to cumulative mental and physical multimorbidity. Broe et al (2018) believe prevention of dementia in Indigenous Australians requires a public health approach incorporating social determinants of health such as trauma and adversity. Module Two will consider risk factors for the development of dementia in more detail. Specific information to support Indigenous Australians living with dementia may be found on the Dementia Australia website (2019f).

## Culturally & Linguistically Diverse (CaLD) people

One third of older Australians come from culturally and linguistically diverse (CaLD) backgrounds (AIHW, 2016). This figure is reflected in data from the residential aged care sector which indicates that approximately 70% of permanent residents living with dementia were born in Australia (AIHW, 2012). One in five people living with dementia are from a CaLD background (Brown et al, 2017).

A report for Alzheimer's Australia (2008) found understanding of dementia varied across different communities. Overall this report found a significant lack of overall understanding

of dementia. Some communities perceived dementia as a normal part of ageing. Social isolation was an issue and seemed to be related to the stigma associated with dementia in some communities. Some terminology used to describe dementia in some languages contributed to negative perceptions.

People from CaLD backgrounds are likely to face barriers when accessing services related to dementia. They may experience difficulties with language and a lack of knowledge of the service systems. There may be a lack of culturally and linguistically appropriate services and culturally appropriate assessment, depending on the actual background of the person. This can be a major impediment to the accurate diagnosis and treatment for dementia (Dementia Australia, 2019). Brain changes associated with dementia will be discussed later in this module. However, these changes may present unique challenges to people from non-English speaking backgrounds. It is not uncommon for people to revert to their primary language and past experiences. These changes may have a significant impact on family relationships and create difficulties for provision of suitable services (Tipping & Whiteside, 2015). Another issue may be a lack of understanding of dementia by people in some CaLD communities (Dementia Australia, 2019a).

Numerous resources for people CaLD backgrounds living with dementia are available from Dementia Australia (2019a). These include many help sheets that have been translated into over 40 different languages.

## People identifying as LGBTIQ

Lesbian, gay, bisexual, trans, intersex, queer and questioning (LGBTIQ) (Victorian Government, 2020) people are commonly collectively grouped as a single community and have historically been subject to persecution and discrimination (Hogan, 2017). However, people who are LGBTIQ are just as diverse as others in the general community, including interests and preferences.

Dementia Australia (2014) estimate approximately 100,000 LGBTIQ people will be living with dementia by 2050. This does not include the numbers of LGBTIQ people who will be caring for people living with dementia.

Common issues with LGBTIQ people living with dementia relate to stigma, discrimination and invisibility (Barrett & Cramer, 2015; Barrett, Cramer, Lambourne & Latham, 2015; Cramer, Barrett, Firth & Latham, 2015; Petrie & Cook, 2019).

Resources to support LGBTIQ people are available from Dementia Australia (2019d).

## The brain, cognition and normal age-related change

Ageing is the biggest risk factor for developing dementia. However, dementia is not a normal part of growing old. Any cognitive impairment that interferes with normal life and function is not normal ageing, it should be regarded as abnormal and investigated (Wicking, 2015).

Dementia results from pathological changes in the brain, it is not due to normal age-related

changes. As people age there are many age-related changes in body systems and organs. These changes are considered normal and need to be differentiated from pathological changes that cause disease and disability, such as dementia.

## ACTIVITY

### ***Consider what these normal age-related changes might be.***

These normal age-related changes to the brain include:

Reduced brain weight (Lindenberger, 2014; Miller & Hunter, 2016; Sayers & Cotton, 2017; Wicking, 2015; Wyss-Coray, 2016).

- It is estimated that approximately 0.5% of total brain volume is lost each year in older adults (Ritchie et al, 2017). One study found brains of people aged 90 years or older had brain weight differences of 11% less when compared to the brains of people in their sixth decade (Wyss-Coray, 2016).
- Specific losses are noted in the cortical areas, especially in the frontal lobes (Miller & Hunter, 2016; McKetton et al, 2018).

Some neuronal cell death (Lindenberger, 2014; Miller & Hunter, 2016; Sayers & Cotton, 2017; Wyss-Coray, 2016)

Deterioration and loss of myelin sheath (Lindenberger, 2014).

- This decreases impulse transmissions and nerve conduction rates. This leads to decreases in reaction time (Zator Estes, Calleja, Theobald & Harvey, 2016).
- There are also changes in white and grey matter in the brain tissue (Lindenberger, 2014; Shafto & Tyler, 2014). Losses of both grey and white matter are noted. The white matter contains nerve fibres and myelin, while grey matter contains nerve cells (Miller & Hunter, 2016).

Decreased cerebral blood flow (Gutchess, 2014; Sayers & Cotton, 2017; McKetton et al, 2018; Miller & Hunter, 2016; Wicking, 2015).

- There is also a decline in the ability of the ageing brain to effectively regulate blood flow (McKetton et al, 2018).

Reduction of neurotransmitter levels, or of their binding sites (Miller & Hunter, 2016).

- These changes are known to impact sleep, temperature control, and mood (Zator Estes et al, 2016).

It must be noted that none of these changes impact significantly on cognitive ability. Despite changes in the older person's brain they remain responsive and capable of flexible interactions (Shafto & Tyler, 2014). Age related changes in the brain do not determine cognitive abilities (Miller & Hunter, 2016).

## What is cognition?

Cognition has been defined as:

*The processes of thinking, learning and remembering (Miller & Hunter, 2016, p 199)*

Although there is no evidence to substantiate normal age-related deterioration in cognitive function, a general perception exists that declining cognition is inevitable as we age (Miller & Hunter, 2016; Ritchie & Artero, 2017). Indeed, commonly used terminology refers to episodes of forgetfulness as 'senior moments'; or people refer to the adage 'You can't teach an old dog new tricks'. Normal age-related changes to cognition do not significantly impact on social or occupational functioning.

There are four types of altered cognition that may be experienced by older adults:

1. Mild cognitive impairment
2. Dementia
3. Delirium
4. Depression

Each of these conditions has specific features and different treatment strategies. These do not necessarily occur independently of each other; an older person may develop a combination of these types of altered cognition. This indicates the complexity of recognising and diagnosing cognitive impairment in the older person (Miller & Hunter, 2016).

It is important to remember that changes such as increasing confusion in the older person should not be attributed to 'normal ageing'. Further investigation needs to be initiated (Sayers & Cotton, 2017).

Normal age-related changes to cognition include:

- A generalised decline in speed of processing of information but accuracy of response is not affected
- A decline in mental flexibility and abstract thinking
- A decline in visual-spatial ability
- Slower and more cue-dependent memory performance – a need to make lists
- A decrease in learning speed and recall, but if given extra time to complete the task, intellectual functioning is adequate (Zator Estes et al, 2016).

However, there is no:

- Alteration to insight or attention
- Change in language skills
- Impairment to learning capacity; contrary to popular belief you can teach an old dog new tricks.

Changes in affect, mood, and orientation need to be further investigated as they may be indicative of pathology and may be treatable (Zator Estes et al, 2016).

## Dementia explained

### Defining Dementia

In 2013 the American Psychiatric Association (APA) released the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) in which the term 'dementia' has been replaced with major neurocognitive disorder and minor neurocognitive disorder (APA, 2013). It is said this is an attempt to reduce the stigma associated with the word 'dementia', which has its roots in the Latin words for mad or insane. Despite this new terminology it is accepted that the word 'dementia' will remain in common use except perhaps by specialist health professionals (Kane & Thomas, 2017).

*"The neurocognitive disorder category encompasses the group of disorders in which the primary clinical deficit is in cognitive function, and that are acquired rather than developmental. ... and thus represent a decline from a previously attained level of functioning" (APA, 2013, Ch 22).*

See Module 3: *Diagnosing Dementia* for more information regarding diagnostic criteria.

### Types of Dementia

Dementia is an umbrella term used to label cognitive impairment. There are many sub-types of dementia, each with its own aetiology and risk factors. There are around 100 different conditions or diseases that cause dementia, of which Alzheimer's is just one.

The major sub-types of dementia include:

1. Alzheimer's Disease (AD), which accounts for about 50-70% of all types of dementias.
2. Vascular Dementia (VaD), which accounts for 15-20% of all types of dementias. 20% of which are 'pure' vascular dementia. It is estimated approximately 50% of cases of people living with Vascular Dementia are caused by high blood pressure.
3. Frontotemporal dementia, accounts for approximately 5-10% of cases of people living with dementia. More common in males and may present as a younger onset.
4. Dementia with Lewy Bodies (DLB), accounts for approximately 5% of cases of people living with dementia. This type is associated with the presence of abnormal cells, called Lewy bodies, in the brain.
5. Mixed Dementia – most often the co-existence of AD and VaD, or AD and DLB.

*(AIHW, 2012; Dementia Australia, 2019h)*

There are also many rarer types of dementia. These account for approximately 5% of all cases of people living with dementia.

Posterior cortical atrophy

- Parkinson's disease
- Corticobasal degeneration
- Creutzfeldt-Jakob disease
- HIV-related cognitive impairment

- Huntington's disease
- Alcohol-related brain damage and Korsakoff's syndrome
- Multiple sclerosis
- Niemann-Pick disease Type C
- Normal pressure hydrocephalus
- Progressive Supranuclear Palsy
- Chronic Traumatic Encephalopathy (repeated head injuries)
- Down syndrome

*(Dementia Australia, 2018h).*

These different types make up a small but important proportion of dementia. It is essential that these specific diagnoses are made, as treatment options vary according to the type of dementia and because significant harm may occur if people with these sub-types are treated in the same way as those with Alzheimer's disease.

Differential diagnosis of the type of dementia is important so as to:

- Explain to the person with dementia and their family
- Understand the biological basis of the disease in relationship to behavioural change
- Appreciate the range of therapeutic interventions possible
- Formulate a differential diagnosis
- Understand settings where diagnosis can be made
- Contribute to demographic and research data.

## Alzheimer's Disease

Alzheimer's disease was first described in 1907 by Dr Aloysius (also known as Alois) Alzheimer and is the most common form of dementia. Alzheimer described significant behavioural issues with 51-year-old Augusta Deiter who had been admitted to an asylum in Frankfurt, Germany. Augusta was described as psychotic and delusional with significant short-term memory loss. Following her death, Alzheimer had permission to examine Augusta's brain. Several changes were noted at the post-mortem:

- A profound decrease in the size and mass of the brain (atrophy)
- Abnormal deposits within and around the brain cells.

Further research following Alzheimer's death in 1915 revealed these abnormal deposits to be:

- Extracellular neuritic plaques
- Intracellular neurofibrillary tangles

*(Sayouni, Verna & Chen, 2017).*

Developments in medical science over the last 30 years have improved the understanding of the pathogenesis of Alzheimer's disease. There are several macroscopic pathological changes. These include amyloid plaques, neurofibrillary tangles, granulovacuolar degeneration, Hirano bodies, neuronal loss, abnormalities of neuronal processes and synapses, glial changes, vascular abnormalities, and changes in the white matter (Masters, 2017). Microscopic changes occur throughout the cerebral cortex, however, early sites for

changes occur in the hippocampus, the entorhinal cortex, and associated areas of the cerebral cortex (Splittgerber, 2019).

Diagnostic features of probable Alzheimer's disease include:

- History
- Insidious onset with progressive memory decline, initially impaired new learning and short-term memory
- Gradual progression involving long-term memory and other functions, such as language, praxis, perception and executive function
- Cognitive loss documented by neuropsychological tests (rapid forgetting)
- No physical signs/laboratory evidence of other causes of dementia
- Reduced functioning on activities of daily living (ADLs).

*(Corey-Bloom & Rafii, 2017)*

## Alzheimer's Disease Pathology



Normal Brain



Alzheimer's Disease

Alzheimer's disease is categorised into three relatively distinct stages, ranging from mild through to severe dementia.

### Mild or early

Deficits are evident in a number of areas (such as memory and personal care) but the person can still function with minimal assistance.

Symptoms include: moderate memory loss especially for recent events, some disorientation in time, moderate difficulties with problem solving, reduced interest in hobbies, and the need for prompting regarding personal care tasks.

### Moderate or middle

Deficits become more obvious and severe, and increasing levels of assistance are required to help the person maintain their functioning in the home and community.

Symptoms include: severe memory loss, considerable difficulty orienting to time and place, obvious difficulties in finding words, severe impairment of judgement and problem solving, need for assistance with personal care tasks, and emergence of behavioural difficulties (for example, wandering, aggression, sleep disturbance and disinhibited behaviour).

## Severe or late

Characterised by almost total dependence on the care and supervision by others.

Symptoms include: very severe memory loss, very limited language skills, unable to make judgements or solve problems, regularly not recognising familiar people, frequent incontinence, requires substantial assistance with personal care, and increased behavioural difficulties.

By this stage most people living with dementia are in residential care.

*(Dementia Australia, 2019g)*

The information in the above table should be regarded as a general guide only as the course of the condition may vary in individual people. A three-stage model of Alzheimer's disease is often used because it is generally easier to understand. Some authors refer to a seven-stage model which breaks the three stages into more detailed increments (Queensland Brain Institute, 2019).

Another approach developed by Tolman (Unpublished) describes the stages in terms of: the following three stages

### Stage 1: Still at home

- Short-term memory loss with repetitive questions
- Loss of interest in hobbies and previously enjoyable activities
- Impaired instrumental functions

### Stage 2: Escalating care needs, transitioning to 24 hour care

- Progression of cognitive deficits
- Declining function
- Behaviour changes

### Stage 3: Diminishing quality of life

- Increasing loss of independence: dressing, feeding, bathing
- Responsive behaviours
- Physical decline

*(Based on unpublished work by Dr Jane Toleman)*

Again, these stages are not distinct and should be used as a guide.

Research into dementia is continuing and aetiology is still being elucidated. There may be a genetic predisposition and research is ongoing into several abnormal genes (Splittgerber, 2019). Improvements in understanding can be expected as knowledge increases. See up to date information on dementia staging at the Dementia Australia website: <https://www.dementia.org.au/about-dementia/what-is-dementia/progression-of-dementia>

## Alzheimer's Disease: General Presentation

The common features of Alzheimer's disease are:

### Memory

- Progressive decline
- Inability to recall recently presented material or events, appointments etc.
- Misplace objects, forget to do things
- Repetitious, need constant reminding
- Recent and remote memory loss becomes more pervasive as disease progresses

### Language

- Word finding and naming difficulties initially
- Receptive problems may also occur, usually later
- Language disorders may dominate clinical picture

### Spatial problems and dyspraxia

- Become lost in familiar surroundings, including own home
- Unable to carry out well-learned tasks initially complex (driving) then progressively more basic (dressing)
- Reduced ability to attend to aspects of self-care as the disease progresses
- Executive functioning is increasingly impaired and evidenced by deficits in:
  - Goal-directed, motivating behaviours
  - Difficulty planning and organising tasks
  - Altered judgement
  - Verbal reasoning affected by involvement of pre-frontal structures
  - Reduction in performance of tasks requiring higher cognitive abilities; for example, numeracy and literacy skills, managing finances or declining work performance in younger onset AD

### Responsive behaviours

- Lack of initiative or impulsivity (abulia) also common
- Behaviour changes may be more evident in the evening, this is sometimes called "sun downing" with disorientation and agitation
- May become resistive to care, aggressive, wandering – purposefully or aimlessly, become intrusive, or disinhibited
- Sleep-wake cycle disturbance (not easily treated)

### Other behaviours

- Depression: up to 40% of people with Alzheimer's disease develop symptoms of depression that can be difficult to distinguish from frontal behaviours
- Psychotic features, delusions: belief that objects are stolen (up to 50%), hallucinations – usually visual (up to 25%)

### Personality

- Profound changes – exaggeration or general decay

*(Corey-Bloom & Rafii, 2017)*

## Vascular Dementia

Vascular dementia (VaD) is caused by any damage or disease process that involves the cerebral vasculature. Understanding of this type of dementia has led to a relatively new term: Vascular Cognitive Impairment (VCI). VCI is now regarded as an umbrella term encompassing all causes of cerebrovascular disease leading to dementia (Kalaria, 2018).

VCI occurs across a broad spectrum of cerebrovascular disorders, from major strokes to microvascular disease (APA, 2013). The DSM-5 classifies VCI as cognitive impairment falling short of dementia. VaD represents greater severity and is a major neurocognitive disorder.

Vascular dementia has the following sub-types:

- Cortical dementia
- Sub-cortical ischaemic vascular dementia
  - Binswanger disease
  - CADASIL (genetic variant)
  - Cerebral amyloid angiopathy (rare) (Roman, 2017).
- Post-stroke dementia – this is relatively common and may be apparent after three months, or at 12 months following a period of some stabilisation.
- Mixed dementia – this can be further subdivided according to the neurodegenerative pathology

*(Kalaria, 2018)*

Dementia may often consist of elements of both vascular sub-types and Alzheimer's disease (Smith, 2017).

The traditional view that diagnosis of vascular dementia results only from step-wise progression or a distinct vascular event has been broadened. It is now recognized that the steps may be so small it may appear as a gradual decline instead. The absence of step-wise decline does not exclude a diagnosis of VaD (Dementia Australia, 2019i).

### Importance of diagnosis of VCI or VaD

Vascular disease is a common cause of morbidity and mortality in Australia. It is the main cause of death for Australian men and the second cause of death for Australian women (after dementia) (AIHW, 2012). Early treatment of vascular disease and the associated conditions that lead to vascular disease such as diabetes and hypertension will reduce the risk of organ damage, which includes the brain, and thus dementia or VaD. Any risk factor for stroke is also a risk factor for VCI or VaD.

Risk factors for VaD include:

- Increasing age
- Hypertension
- Diabetes mellitus

*(Smith, 2017).*

Additional risk factors relate to lifestyle. These include smoking, excessive alcohol use, obesity and a sedentary lifestyle. Thus, primary health strategies at a population level may assist with preventing VCI or VaD. It is also important to manage secondary health strategies such as treating existing conditions like hypertension or diabetes mellitus in order to prevent or slow progression towards VaD (Nicholls & Surawski, 2017).

## VaD clinical features

- Early deficits involve attention and executive function. There may be difficulty in completing tasks and poor problem solving.
- Memory is often only mildly affected.
- Often early disturbance of gait, falls are common.
- Apathy is a common neuropsychiatric symptom.
- Depression and mood swings may also be evident.

*(Nicholls & Surawski, 2017; O'Brien & Thomas, 2015; Santos, Bezerra, Correia & Bruscky, 2018; Smith, 2017)*

## VaD diagnosis

Standard screening tests such as the mini-mental state examination are less sensitive. Accurate diagnosis requires evidence of sufficient cerebrovascular disease on brain imaging to account for the clinical presentation. This may be by computerised tomography (CT) although magnetic resonance imaging (MRI) is preferable (O'Brien & Thomas, 2015). MRI was found to be accurate in identifying preclinical vascular dementia in an English study (Lambert et al, 2017).

The DSM-5 requires both the establishment of a neurocognitive disorder and the finding that cerebrovascular disease is the dominant pathology that accounts for the deficits. This relies on establishing evidence of vascular aetiology that may range from a major stroke through to microvascular changes. Diagnosis requires a combination of obtaining the history of the person, along with a physical examination and neuroimaging (APA, 2013).

It is important to establish the presenting disorder cannot be explained by another disorder. The clinician needs to consider other pathologies such as Alzheimer's disease, Parkinson's disease, depression, or other medical conditions (APA, 2013).

## VaD prevention

Prevention of vascular dementia involves recognising the risk factors and using the same preventative measures as for the avoidance of heart attacks and strokes.

Modify cardiovascular risk factors:

- Stop smoking
- Healthy diet - reduce body weight to recommended levels
- Physical activity
- Cognitive activity
- Correct hypertension
- Optimise management of diabetes mellitus
- Treat depression

*(Roman, 2017)*

## VaD treatment

Effective treatments for VaD remain elusive. Cholinesterase inhibitors and Memantine were previously thought to provide small benefits in cognition of uncertain clinical significance in patients with mild to moderate VaD. More recent studies do not support use of these drugs in VaD (O'Brien & Thomas, 2015). Treatment decisions for vascular contributing factors need to be made individually (Roman, 2017).

## Frontotemporal Dementia

Frontotemporal dementia is an umbrella term for a diverse group of dementias characterized by progressive deficits in behaviour, executive function, or language.

The group includes three variants. These variants initially present in different ways. However, as the disease progresses the differing symptoms of the three variants converge as the degeneration becomes more diffuse and affects more of the frontal and temporal lobes of the brain. Over time people living with frontotemporal dementia develop global cognitive impairment and motor deficits. In some people this may include parkinsonism or motor neuron disease (MND) (Bang, Spina & Miller, 2015).

The three variants are:

### Behavioural

- Personality changes – the person may demonstrate a loss of empathy to others
- Disinhibition – this may lead to poor financial decision making. It may present as inappropriate sexual comments, but is usually accompanied with a loss of libido
- Apathy – this can be mistaken for depression
- Compulsive or perseverative behaviours
- Hyperorality – this may present as binge eating

### Semantic-variant primary progressive aphasia

- Anomia – for people, places and objects. More pronounced with nouns
- Word finding difficulties
- Impaired word comprehension

### Non-fluent variant primary progressive aphasia

- Slow laboured and halting speech production
- Omission or misuse of grammar
- Difficulty understanding complex sentences
- Anomia is more pronounced for verbs

## Importance of diagnosis

The age of onset is typically between the late 40's and the early 60's. It is the second most common type of dementia in people aged less than 65 years. Survival from diagnosis is approximately ten years. Men and women are equally affected (Nestor, 2017).

This type of dementia does seem to have a genetic component. Studies vary with people reporting a positive family history in up to 40% of cases (Bang et al, 2015; Mann, 2017). To date, several gene mutations have been identified and research continues (Mann, 2017).

There is some association with MND, about 12% of people living with frontotemporal dementia will develop MND. Early signs of parkinsonism are present in up to 20% of people living with frontotemporal dementia (Bang et al, 2015).

In the behavioural variant of frontotemporal dementia, people often present earlier with psychiatric symptoms such as an atypical depression and behavioural changes (Pijnenburg & Dols, 2018). It can be difficult to differentiate between frontotemporal dementia, other neurodegenerative disorders, and psychiatric disorders. One distinguishing factor is that the frontal behavioural symptoms are likely to become worse over time, as opposed to remaining stable or even improving in other disorders (Reus et al, 2018).

Another reason for accurate diagnosis in this group of people is the very high risk of suicide. People living with dementia generally have a lower than average risk of suicide or history of attempts. However, in people living with frontotemporal dementia, the rate of suicidal ideation is 40% and the rate of suicide attempts is 10%. This is much higher than the general population (Zucca et al, 2019).

## **Dementia with Lewy bodies (DLB)**

Dementia with Lewy bodies is characterised by the presence of eosinophilic neuronal spherical or elongated inclusions called Lewy bodies (McKeith, 2017). It is a primary degenerative form of dementia that shares some features with both Parkinson's disease (PD) and Alzheimer's disease (AD) (Halliday, Lewis & Ince, 2017). It is the second most common cause of neurodegenerative dementia in older people and is commonly misdiagnosed. Prognosis and survival rates for people living with DLB is poorer than for people living with AD (Abey Suriya & Walker, 2015).

In DLB there is overall cortical atrophy. Neuronal loss in the amygdala is severe. However, neuronal loss in the temporoparietal regions is milder than seen in AD (Halliday et al, 2017).

There is overlap between DLB and PD. Currently there is a 'one-year rule' used to differentiate between DLB and PD with dementia (PDD). For a person to be diagnosed with PDD they need to have already had Parkinsonism for at least the preceding 12 months. Conversely, the presence of dementia for at least 12 months before the onset of Parkinsonism is indicative of DLB (Abey Suriya & Walker, 2015).

### **Importance of diagnosis of DLB**

It is critical to know this dementia exists because specific treatment options are available. People living with DLB may benefit from a course of cholinesterase inhibitors. This is because there is more profound cholinergic loss in DLB. Any medications with anticholinergic effects should be avoided in people living with DLB (Taylor, 2017).

People living with DLB are extremely sensitive to antipsychotics. These are likely to cause severe neuroleptic reactions associated with increased morbidity and mortality. These should be avoided (Taylor, 2017).

## Dementia with Lewy bodies (DLB) – diagnostic criteria

- Progressive cognitive impairment
- Impaired memory – not necessarily obvious in early stages but becomes more apparent as the disease progresses
- Deficits in attention, executive function, visuospatial ability
- Core features:
  - Fluctuating cognition, attention, alertness
  - Recurrent visual hallucinations
  - Spontaneous motor parkinsonism
- Suggestive features:
  - Rapid eye movement (REM) sleep behaviour disorder
  - Severe neuroleptic sensitivity
  - Low dopamine transporter uptake in basal ganglia – evidenced by single photon emission computerized tomography (SPECT) or positron emission tomography (PET).
- Supportive features:
  - Recurrent falls
  - Syncope
  - Transient loss of consciousness
  - Severe autonomic dysfunction
  - Systematised delusions
  - Other types of hallucinations

(Halliday et al, 2017)

### ACTIVITY

*List six key points from the sections “What is dementia” and “Types of dementia”*

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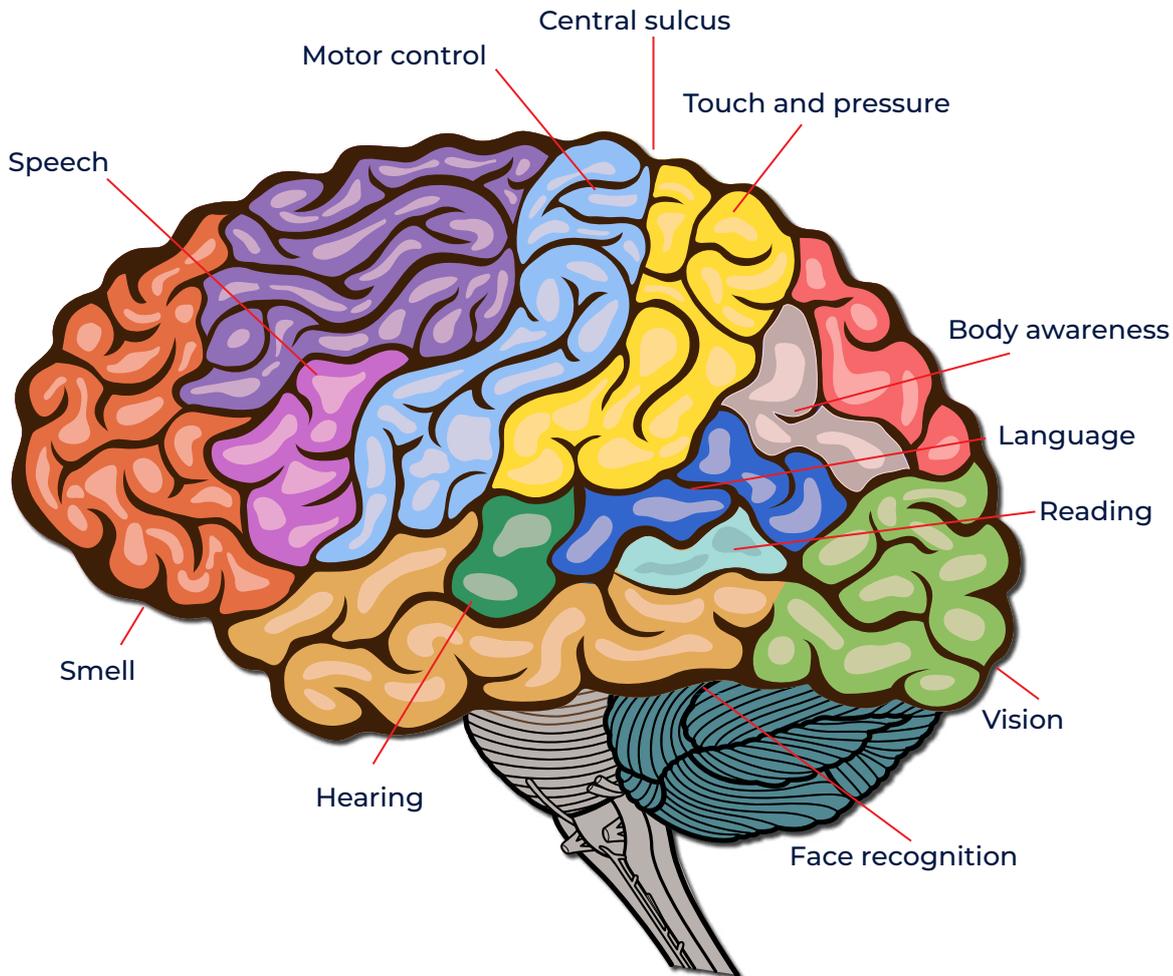
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## Manifestation of dementia

### Functional areas of the brain

The diagram below shows the areas within the brain which control functional activities



### Brief neuroanatomy revision

The bulk of the brain is the cerebrum. This is the area for intellectual thought and function. The cerebrum is divided into two hemispheres – the left and right. Most right-handed people are left hemisphere dominant. This means the language centre is in the left hemisphere. Approximately 70-75% of left-handed people also have a dominant left hemisphere. Each hemisphere is further divided into four lobes. These are described in anatomical terms as the frontal, temporal, parietal, and occipital lobes (Lambiase, DiBella & Thompson, 2018; Sekhon & Griesdale, 2015).

## Frontal Lobe

This is the site of:

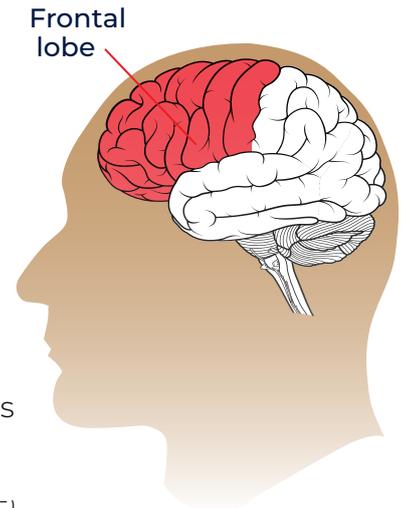
- abstract reasoning
- judgement
- behaviour
- creativity
- initiative
- concentration

Broca's area is in the dominant frontal lobe. This area is responsible for expressive and fluent speech.

*(Jarvis, 2016; Lambiase et al, 2018; Sekhon & Griesdale, 2015)*

Damage to the frontal lobe causes:

- Impaired planning and problem-solving
- Distractibility with inability to task focus
- Behaviour disorders
- Difficulty in learning new information
- Lack of inhibition
- Contralateral hemiplegia, hemiparesis
- Expressive difficulties/motor aphasia



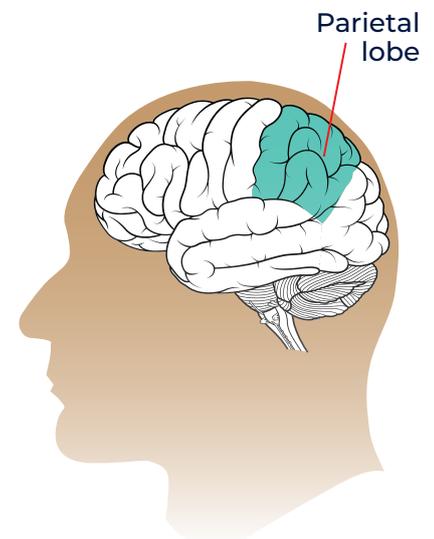
## Parietal Lobe

The parietal lobe is the site of:

- Language
- Maintaining attention
- Memory
- Spatial awareness
- Integration of sensory information, including tactile, visual and auditory

Damage to the parietal lobe causes:

- Difficulties with writing, reading and naming objects
- Inability to discriminate between sensory stimuli
- Inability to locate and recognise parts of the body (neglect)
- Reduced awareness of environment space



## Occipital Lobe

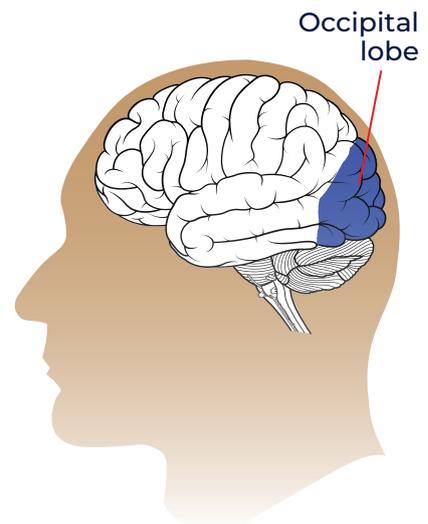
The occipital lobe contains the primary visual cortex and is the site for:

- Sight
- Interpretation of visual stimuli

*(Jarvis, 2016; Lambiase et al, 2018).*

Damage to the occipital lobe causes:

- Visual defects – reduction in opposite visual field
- Loss of ability to recognise objects in opposite field



## Temporal Lobe

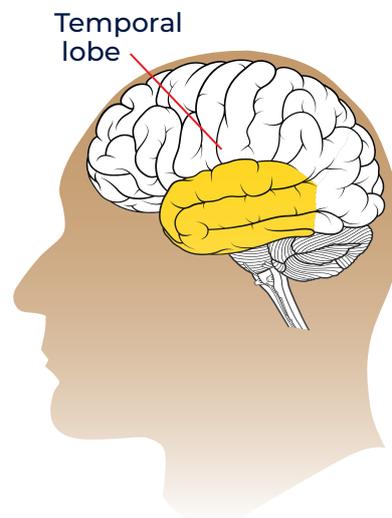
The temporal lobe is the site for:

- Primary organisation of sensory input (auditory perception).
- Wernicke's area is in the dominant hemisphere of this lobe. It is responsible for receptive speech functions and comprehension
- Learning
- Memory

*(Jarvis, 2016; Lambiase et al, 2018, Sekhon & Griesdale, 2015).*

Damage to the temporal lobe causes:

- Memory – difficulties in retrieval of information
- Receptive/sensory aphasia (also known as Wernicke's aphasia)
- Impaired concentration



## Limbic system and hippocampus

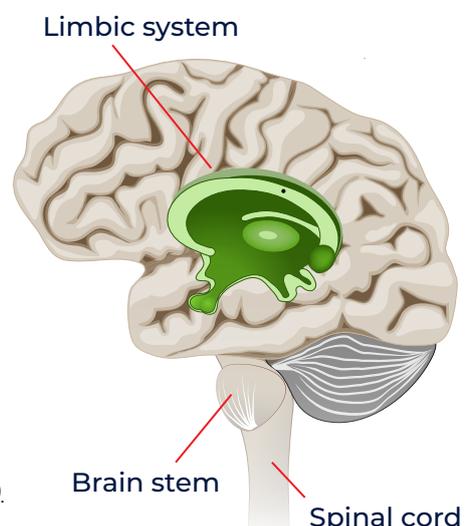
### Limbic system

- Above the brainstem and within the cerebrum
- Describes a group of structures lying in the border zone between the cerebral cortex and the hypothalamus
- Connects areas responsible for high and low functions
- Group of structures controlling
  - Emotions
  - Memories
  - Arousal (stimulation)

### Hippocampus

- Part of the limbic system
- Storage and retrieval of memories

*(Splittgerber, 2019).*



Damage to the limbic system causes:

- Memory impairment
- Emotional disturbances
- Behavioural disturbances

## Impact of dementia

### Impact of dementia on the person living with dementia

The impact of dementia on the person concerned involves gradually progressing changes in:

- Memory – memory loss; short then long term
- Emotions – emotional disturbance
- Language – difficulty finding words
- Insight and motivation – gradual deterioration
- Planning – impact on abstract thought and judgement
- Orientation – confusion of time, place, person
- Function – impact on washing, dressing, planning and recognition
- Behaviour – aggression, withdrawal, wandering, sleep disturbance

Leading to:

- Incontinence – loss of bladder and bowel control
- Malnutrition – through poor oral intake
- Immobility and loss of function
- Death

### Impact on family/informal carers of people living with dementia

Alzheimer's Disease International (2019) found that over 50% of family/informal carers of people living with dementia were positive about their role. However, a similar percentage stated that their own health had suffered and over 60% had a diminished social life because of their caring responsibilities. Stigma was also a concern, over a third of responding carers stated they had hidden the dementia diagnosis from others (Alzheimer's Disease International, 2019).

Although it is important to note that carers find the experience rewarding in many ways, carers of people living with dementia often shoulder a physical, social, emotional, psychological and financial burden of caring (Carers Victoria, 2019). The impact of caring for a person with dementia is discussed further in Module 9: Carer health.

### Impact on the community

A report on the economic cost of dementia in Australia (Brown et al, 2017) made the following findings:

- Most people living with dementia live in the community. About 83% of males and 71% of females living with dementia are in the community

- A little over 50% of residents in aged care facilities are people living with dementia
- The current workforce of paid carers looking after people living with dementia in residential aged care facilities is around 92,000
- Almost 200,000 people are providing care in the community. Most of these people are unpaid family members providing informal care
- By 2056, paid carers for people with dementia in aged care facilities will need to increase to 250,400. It is estimated 525,540 will be required in the community
- Most carers in the community are the person's spouse or partner (35%), child (41%), or other family members (15%)
- It has been projected that the total direct costs of dementia at a national level would grow by 29% every ten years
- Annual costs are anticipated increase from \$8.8 billion in 2016, to \$12.2 billion in 2026, and \$24.1 billion in 2056
- Indirect costs such as loss of income for people living with dementia and their carers was estimated to be \$5.6 billion for 2017. These indirect costs are projected to increase to \$9.1 billion by 2036, and to \$12.8 billion by 2056
- Dementia is a significant burden of disease for both the person and their carer. This is related to premature mortality and prolonged periods of disability

*(Brown et al, 2017).*

There is also considerable impact in the acute hospital sector. In 2016-2017 almost 95,000 people admitted to hospital had at least one diagnosis of dementia. 43% of these admissions were in people aged over 85 years. Most admissions were of people living in major cities. The average length of stay for a person with dementia was 13 days. Approximately half of the people living with dementia admitted to hospital were discharged home. One in five people became a new admission to residential aged care and 6% died while still in hospital. On average, people living with dementia admitted to hospital had another eight health conditions. The most common co-morbidity was Type 2 diabetes mellitus. Almost all the people living with dementia admitted to hospital in this time frame were rated as being the highest or second highest clinical complexity. 71% were rated at the highest level as compared to 16% of people without a diagnosis of dementia (AIHW, 2019).

The impact on the community is extensive in terms of financial burden and social costs.

## Summary

Dementia is an increasingly common cause of disability in our ageing population.

This module has provided an overview of dementia and has identified several important facts in relation to dementia. These include:

- Dementia is a progressive clinical syndrome of which there are many sub-types; the most common being Alzheimer's disease
- Accurate diagnosis is vital
- Early diagnosis is possible and controversial
- Dementia must be differentiated from Mild Cognitive Impairment, delirium and depression
- Diagnosis is a complex and multifaceted process

- Dementia impacts on social and occupational functioning
- Dementia impacts on the individual and their family and carers.

Evidence supports the fact that early diagnosis with appropriate person-specific management and support has potential to reduce the disability and burden to both the person and their carer.

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