

Understanding dementia



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the dementia care experts

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What is dementia

Dementia is a term used to describe a collection of symptoms which suggest the presence of disease or diseases in the brain. Examples of symptoms may include: memory loss, disorientation, confusion, difficulty concentrating, problems with motor function and the ability to perform daily living activities. Dementia does not just affect the elderly. Younger onset dementia is the term used for people under 65 who are living with dementia.

There is currently no known cure for dementia, however medication is available that may alleviate some symptoms in some types of dementia. Many supports and approaches, which are not related to medication use, are available and these can help to assist with symptoms.

Types of dementia

There are over 300 different types of dementia. Some known types of dementia include Alzheimer's disease, vascular dementia, Lewy body disease, frontotemporal dementia, and alcohol related dementia (Wernicke-Korsakoff syndrome).

Living with dementia

It is important to remember that a diagnosis of dementia is only one part of the whole picture for a person living with the condition. Although people may experience similar symptoms, an individual's experience of life with dementia will be unique and varied.

After a diagnosis of dementia it can become easy to focus attention on the loss of function and ability to carry out daily care tasks, and the individual person can sometimes be overlooked. This can have a negative impact on their wellbeing.

Although the brain is affected by dementia it is still possible to:

- » Learn
- » Contribute to the community
- » Maintain social connections
- » Do things for oneself
- » Live a fulfilling life

Change will occur, however life does not need to stop with a diagnosis of dementia.

Early signs of dementia

It is common to experience difficulties with memory at some point in life, and there can be many reasons why changes in memory might occur. Change in memory does not necessarily mean dementia is the cause. However, in some cases changes may be a sign of early cognitive decline.

The following is a list of potential early signs of cognitive decline. It is common to experience more than one of these symptoms at the same time and there can be other reasons why you may experience some of these symptoms.

If you are experiencing any of these symptoms you should discuss your concerns with your general practitioner or health care professional.

- » **Short term or recent memory loss:** Difficulty recalling things even after a reminder, frequently forgetting names of common objects for long periods, trouble finding words, difficulty remembering upcoming plans or recent events.
- » **Difficulties with performing known tasks:** Experiencing challenges with carrying out a task you used to be able to do easily, for example making a cup of tea.
- » **Disorientation to time and place:** Losing your way in a well-known area or a path that is commonly walked. Having difficulty accurately recalling what month or day it is.
- » **Errors in judgement:** Noticing changes in your judgement, such as being overly generous or taking risks you wouldn't normally.
- » **Difficulties with calculation:** Trouble managing money, calculating the right amount of money when shopping, having difficulty reading a clock.
- » **Losing or misplacing items:** Losing or misplacing items can be a sign of a busy life or stress, however a sign of dementia may be finding an item somewhere it would never normally be put.
- » **Changes in mood:** Experiencing changes in how you are feeling such as apathetic, suspicious or withdrawn despite normally being active, trusting and outgoing. You may experience sudden mood swings, or have started saying or doing things that are not normal for you.



Diagnosing dementia

A diagnosis of dementia does not change who a person is, however some people may be reluctant to seek an official diagnosis when experiencing symptoms that are worrying them, due to fear or stigma.

Timely diagnosis can provide many benefits however the process of diagnosis is one of elimination and can take several months or longer. Receiving a diagnosis is an important step towards being able to access support.

What to expect

The first step is to visit your GP.

Your GP will consider your personal history and may run some initial tests which could include:

- » **Physical assessment:** to rule out other potential conditions
- » **Psychological assessment:** to rule out other disorders which can present like dementia, such as depression
- » **Pathology:** to ensure there is no infection present
- » **Cognitive function / Mini Mental State Exam (MMSE):** assessment of memory, orientation to time and place, problem solving, language, concentration and counting skills.

Other tests may include x-ray, computed tomography (CT) scan, magnetic resonance imaging (MRI) or electrocardiogram (ECG).

Some disorders mimic the symptoms of dementia, and it is important to rule these out as part of the diagnostic process.

These include:

- » Depression
- » Alcoholism
- » Stress
- » Stroke
- » Pain
- » Infection
- » Medication interaction/side effects
- » Vitamin deficiency.

Depending on the results of initial assessments, your GP may refer you to a specialist such as:

- » **Neurologist:** specialising in conditions of the brain
- » **Neuropsychologist:** specialising in function of the brain
- » **Geriatrician:** specialising in older adult health.

After the assessment process you may be given an official diagnosis of a type of dementia. It is very important to understand the information that is given to you at the time of diagnosis. Having someone with you to listen to the information being given and ask questions can be very helpful.

As a person diagnosed with dementia, you may fear loss of independence. Gaining as much knowledge as possible about living well with dementia is important for you, and for those who care for you. Good information will be underpinned by person-centred principles and acknowledge the lived experience as well as the biological impacts of dementia.

Types of dementia

Alzheimer's disease

Alzheimer's disease is a progressive, degenerative condition of the brain and is the most common form of dementia, accounting for up to 70 per cent of all dementia diagnoses in Australia. It primarily affects those over the age of 65, but can also occur in younger people. Diagnosis can sometimes be difficult and it is important to rule out other causes of cognitive impairment.

Alzheimer's disease is thought to be related to abnormal protein build up, tangles of nerve fibres and inflammation in the brain over a period of up to 20 years before the onset of clinical symptoms.

The two systems necessary for the communication between brain cells are affected; the stimulatory brain messenger acetylcholine is down-regulated, while over-activation of another messenger, glutamate, leads to the death of neurons.

Every person living with Alzheimer's disease experiences the condition differently, depending on what areas of the brain are affected and how the person responds to the changes.

Initially you might notice:

- » Lapses in memory
- » Problems with finding the right words when speaking or repeating what was said only a short time ago
- » Mood changes
- » Difficulty in 'thinking things through'
- » Getting lost when visiting previously familiar places
- » Being unable to identify common items or know where they belong.

Later, communication problems may increase, with a loss of ability to talk, read or write.

A comprehensive information sheet on Alzheimer's disease is available to download from alzheimerswa.org.au

Vascular dementia

Vascular dementia is the second most common type of dementia, and is characterised by abnormal or damaged blood supply to brain tissue.

Vascular dementia is caused by damage, narrowing or blockage of blood vessels, which impedes blood flow and causes neurons to die. This cumulative damage results in loss of brain function over an extended period of time.

Vascular dementia can be caused by a number of different diseases that affect the circulatory system, including type 2 diabetes. This is called subcortical vascular dementia. It can also be caused by multiple small strokes. This is called multi-infarct dementia (MID).

Symptoms vary depending on the degree of vascular damage and the part of the brain affected. They may include memory loss, confusion, disorientation, difficulty organising thoughts, planning and concentrating, difficulties speaking or understanding speech, or vision loss.

A comprehensive information sheet on vascular dementia is available to download from alzheimerswa.org.au

Frontotemporal dementia

Frontotemporal dementia results from progressive, degenerative changes in the frontal and temporal lobes of the brain. It is the third most prevalent form of dementia across all age groups and most commonly affects behaviour, executive function (such as planning, organising and decision making), and language. Short term memory loss may not be one of the early symptoms as seen with Alzheimer's disease.

Subtypes:

- » **Behavioural variant frontotemporal dementia:** a subtype of frontotemporal dementia which affects the frontal lobes of the brain and primarily impacts aspects of personality.
- » **Primary progressive aphasia:** Neurodegenerative syndromes where language is the main area of impairment (includes Logopenic variant PPA, Semantic variant PPA, Nonfluent PPA).

A comprehensive information sheet on frontotemporal dementia is available to download from alzheimerswa.org.au



Dementia with Lewy Bodies

Dementia with Lewy Bodies has some different characteristics to other dementias, and a specific treatment approach and accurate diagnosis is essential.

The brain of a person with Lewy body dementia typically shows less overall shrinkage than the brain of someone with Alzheimer's disease or frontotemporal dementia. Instead, tiny deposits of protein (Lewy bodies) are seen in the cerebral cortex, limbic system and brain stem.

Early damage is seen in the visual pathways and in the frontal lobes. This may explain why problems with vision and attention are common early symptoms of Lewy body dementia.

Lewy bodies in the brain stem have been linked to problems with movement, as seen in Parkinson's disease.

More than 25% of people with Parkinson's disease are expected to develop dementia within 10 years of diagnosis.

Symptoms may include:

- » Fluctuating levels of cognitive ability
- » Changes in attention, alertness, talking and movement
- » Visual hallucinations and sensitivity to medication prescribed for hallucinations
- » Loss of sense of smell
- » Noticeable daytime sleepiness
- » REM sleep behaviour disorder.

A comprehensive information sheet on dementia with Lewy bodies is available to download from alzheimerswa.org.au



Wernicke-Korsakoff syndrome

Wernicke-Korsakoff syndrome is a preventable form of dementia associated with excessive alcohol intake. It is also referred to as alcohol related dementia or alcohol related brain impairment or injury. This type of dementia particularly targets memory, often leaving other thought processes intact.

The term Wernicke-Korsakoff relates to two conditions: Wernicke's encephalopathy and Korsakoff's syndrome. As these two conditions are so closely related the diagnosis is frequently referred to as Wernicke-Korsakoff syndrome.

Wernicke's encephalopathy is caused by lack of thiamine and symptoms can include confusion, jerky eye movements, double vision and inability to coordinate voluntary movement.

Korsakoff's syndrome can develop when Wernicke's encephalopathy is left untreated or treated later in the illness. Symptoms include short and long term memory loss, inability to form new memories or learn new information, and making up information to fill in memory gaps (known as confabulation).

A comprehensive information sheet on Wernicke-Korsakoff syndrome is available to download from alzheimerswa.org.au

Younger onset dementia

Younger onset dementia is a term used to describe any type of dementia in a person under the age of 65.

Younger onset dementia impacts the lives of individuals and families differently to those of older people. At the time of diagnosis, the person may still be working and supporting a family which can create unique challenges.

Dealing with the stigma associated with dementia may be more complex for someone diagnosed with younger onset dementia. Negotiating everyday life can present challenges, as the dementia is not outwardly apparent and not expected in a younger person.

This can make younger onset dementia more difficult to diagnose.

Progression of the condition differs for each person depending on their unique circumstances and type of dementia.

Symptoms vary depending on the area of the brain affected. These may include:

- » Short term memory loss
- » Challenges in planning or problem solving
- » Difficulty in completing tasks at home, work or in the community
- » Difficulty communicating with others

A comprehensive information sheet on younger onset dementia is available to download from alzheimerswa.org.au

Research

Alzheimer's WA works with local, national and international researchers and universities to further our knowledge and develop evidence for best practice, treatment and service outcomes in relation to the care and support of people living with dementia.

Latest research

Current worldwide research into dementia focuses specifically on:

- » Ability to diagnose dementia earlier and more accurately
- » Finding new treatments to reduce or halt symptoms in different types of dementia

For more information on the latest research into dementia, visit alzheimerswa.org.au/research

Medical treatments

Currently there is no cure for dementia however there are a number of therapies which may reduce the symptoms or slow the progression of the condition.

Disease modifying drug treatments, such as cholinesterase inhibitors (known as rivastigmine or donepezil) and glutamatergic agents (known as memantine) have been found to be helpful for some people with some types of dementia. They do not reverse or halt the condition, but may assist with symptoms for a time.

Symptom management is complex however antidepressants, sedatives and anti-anxiety medications have been used to manage some of the symptoms, as well as some of the personal impacts people experience with dementia.

Occasionally medications may interact, resulting in unintended effects, however a specialist doctor can assist you to find the right balance.



Next steps

If you have a diagnosis of dementia there are some important next steps to consider:

- » Accessing support
- » Deciding who to tell
- » Living well with dementia

Accessing support

Support is available for you and your family. Often referred to as 'early intervention', accessing support as early as possible after a diagnosis can be very beneficial.

Dementia Advisory Service

Our Dementia Advisory Service can help you to navigate the support available to you. We can meet with you in your home or at our office to discuss your dementia diagnosis and answer any questions you have around living with dementia in the early stages.

Adjusting to Change program

Our Adjusting to Change program provides relevant information, emotional support and practical assistance for people in the early stage of dementia and their support person, usually a family member or friend.

To find out more about the Dementia Advisory Service or the Adjusting to Change program, call 1300 66 77 88 or email support@alzheimerswa.org.au

Deciding who to tell

Telling people about your diagnosis is a very personal decision.

It is common for a person with a diagnosis of dementia to want to hide their diagnosis from family and friends, and to worry about how people will react.

Some people decide to share their diagnosis with everyone in their life. Others share it only with close family and friends. There is no right or wrong way to share your diagnosis, and it is possible that some family members or friends may not know how to react, however many will want to know how they can help you.

Our *Communication and engagement* booklet is a useful resource for family and friends.

Living well with dementia

Life doesn't stop with a diagnosis of dementia. It is possible to continue to live a meaningful and engaged life.

Our *Living with dementia, Caring for a person living with dementia: The lived experience* and *Caring for a person living with dementia: Every day living* booklets covers topics such as:

- » Understanding wellbeing
- » Importance of staying connected and how to retain connections
- » How the physical impacts of dementia affect the human experience
- » Accepting support and types of support
- » Safety, risk and independence
- » Future planning for over 65s and under 65s.



Our Vision

A world where people living with dementia and their families are supported and valued on their dementia journey.

Our Philosophy

Dementia is a lived human experience rather than just a biological condition. We therefore embrace and support a holistic, person-centred approach that respects the individuality and the experience of those living with dementia.

Our Purpose

To improve the lived experience of those on the dementia journey through our advocacy, leadership, innovation, education, partnerships and holistic, person-centred care and support, and to support the pursuit of risk reduction, treatment and a cure for dementia.

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