

Topic 1

Understanding dementia

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What is dementia?

Dementia is the term used to describe the symptoms of a large group of illnesses that cause a progressive decline in a person's cognition and ability to function. It is a broad term to describe a loss of memory, intellect, rationality, social skills and what would be considered normal emotional reactions.

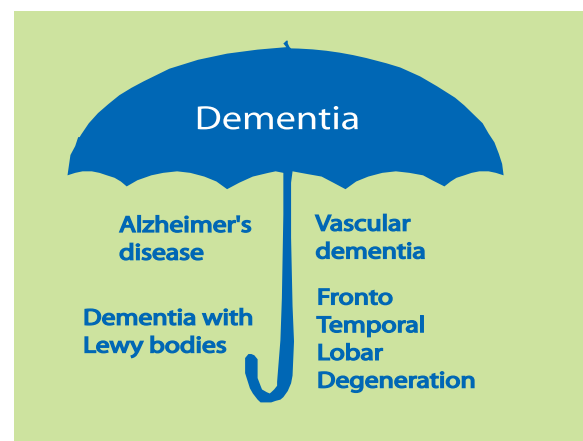
These changes affect the physical, social and emotional life of the person with dementia, and their families, carers and friends.

It is not a normal part of ageing.

There are many different forms of dementia and each has its own causes.

Alzheimer's disease is the most common form of dementia. It accounts for between 50% and 70% of all cases. Vascular dementia is the second most common form.

The diagram below shows the relationship between dementia and its many forms.



The most common forms of dementia

Alzheimer's disease

Alzheimer's disease is a progressive, degenerative illness that attacks the brain. As brain cells shrink or disappear abnormal material builds up as "tangles" in the centre of the brain cells and "plaques" outside the brain cells. These disrupt messages within the brain, damaging connections between brain cells. The brain cells eventually die and this means that information cannot be recalled or assimilated. As Alzheimer's disease affects each area of the brain, certain functions or abilities are lost.

Vascular dementia

Vascular dementia is the broad term for dementia associated with problems of circulation of blood to the brain and is the second most common cause of dementia. There are a number of different types of Vascular dementia. Two of the most common are Multi-infarct dementia and Binswanger's disease. Multi-infarct dementia is caused by a number of small strokes, called mini-strokes or Transient Ischaemic Attacks (TIA) and is probably the most common form of Vascular dementia. Binswanger's disease (also known as Subcortical vascular dementia) is associated with stroke-related changes to the brain. It is caused by high blood

pressure, thickening of the arteries and inadequate blood flow.

Vascular dementia may appear similar to Alzheimer's disease, and a mixture of Alzheimer's disease and Vascular dementia can occur in some people.

Dementia with Lewy bodies

Dementia with Lewy bodies is caused by the degeneration and death of nerve cells in the brain. The name comes from the presence of abnormal structures, called Lewy bodies, which develop inside nerve cells. It is thought that these may contribute to the death of the brain cells. People who have dementia with Lewy bodies tend to see things (visual hallucinations), experience stiffness or shakiness (parkinsonism), and their condition tends to fluctuate quite rapidly, often from hour to hour or day to day. Dementia with Lewy bodies can occur by itself, or together with Alzheimer's or Parkinson's disease.

Fronto Temporal Lobar Degeneration (FTLD)

This is the name given to a group of dementias when there is degeneration in one or both of the frontal or temporal lobes of the brain. It includes Fronto Temporal Dementia, Progressive non-Fluent Aphasia, Semantic Dementia and Pick's disease. About 50% of people with FTLD have a family history of the disease.

Huntington's disease

Huntington's disease is an inherited, degenerative brain disease that affects the mind and body. It usually appears between the ages of 30 and 50 and is characterised by intellectual decline and irregular, involuntary movement of the limbs or facial muscles. There is no treatment available to stop the progression of the disease, but medication can control movement disorders and psychiatric symptoms. Dementia occurs in the majority of cases.

Parkinson's disease

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

Alcohol-related dementia (Korsakoff's syndrome)

Too much alcohol, particularly if associated with a diet deficient in thiamine (Vitamin B1), can lead to irreversible brain damage. If drinking stops there may be some improvement.

Creutzfeldt-Jacob disease

Creutzfeldt-Jacob disease is an extremely rare, fatal brain disorder caused by a protein particle called a prion. It occurs in one in every million

people per year. Early symptoms include failing memory, changes of behaviour and lack of coordination. As the disease progresses, usually rapidly, mental deterioration becomes pronounced, involuntary movements appear, and the person may become blind, develop weakness in the arms or legs and finally, lapse into a coma.

Other conditions that may produce or be associated with dementia are:

- HIV/AIDS
- multiple sclerosis
- certain types of head injuries
- brain tumours and brain haemorrhages
- infections of the brain
- exposure to certain toxins
- substance abuse.

Can dementia be inherited?

Having a close relative with dementia is not evidence of a genetic link, depending on the cause of the dementia. Dementia can happen to anybody but is more common after the age of 65. About one-third of the people with dementia have a close relative who has, or has had, dementia. Alzheimer's disease occurs relatively frequently in the elderly. For people over 80 years, about 1 in 4 have the condition regardless of family history.

If you are concerned about the risk of inheriting dementia, Alzheimer's



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Australia provides professional staff for counselling and support. Ring the **National Dementia Helpline** on **1800 100 500** to arrange an appointment with a counsellor.

What are the early signs of dementia?

The symptoms of dementia can vary widely with different diseases and different people, even in those with the same condition such as Alzheimer's disease. The early signs can be very subtle and vague, and may not be immediately obvious. Usually though, people seem to notice a problem remembering recent events.

Common symptoms may include:

Changes in memory

- Repeating the same questions and stories
- Being absent-minded or forgetful
- Losing valuables, keys, wallet
- Getting lost in once-familiar environments

Changes in orientation

- Difficulty remembering the year, date, month, day
- Difficulty remembering the names of friends, family, home address

Changes in behaviour

- Impaired judgement
- Poor planning and organising ability
- Deterioration in appearance and hygiene
- Behaving in ways that are not normally the way the person would behave, such as swearing more, or becoming more withdrawn

Changes in emotions

- Easily aroused, readily changing moods
- Unable to handle stress or noise, perhaps becoming agitated
- Withdrawing socially
- Losing drive and interest in things that used to provide interest and motivation, such as fishing, bowls or clubs

Changes in thinking

- Less flexible, more rigid
- Difficulty mastering new tasks
- Difficulty finding the right word, reduced language fluency
- Difficulty starting new topics, thinking beyond the present

“My father, Zvonko migrated from the island of Korcula, Croatia in the early 1950s. Twelve months later my mother Maria and the rest of my family joined him. Like many others, they came to Australia in search of a better life. Dad loved Australia, and he worked hard and provided well for his family.

“In 1988 Dad made a return visit to Croatia and realised his decision to migrate had been the right one for himself and his family. However, shortly after his trip, Dad’s life began to change. Just as he was looking forward to retirement and an easier life, Alzheimer’s disease began to sneak up on him.

“At first it was unclear to anyone in the family exactly what was happening. Dad had always been a quiet man and relished his moments of relaxation. When he retired the family simply thought Dad had just ‘switched off’ and was overdosing on relaxation. However, as his disease progressed and when Mum retired and was spending all day with Dad, it became apparent that something was wrong.

“When Dad was given his diagnosis of Alzheimer’s disease, my first thought was ‘No. Not my Dad. He has never had a day sick in his life. How can this be?’ And so for my family, and me the role of caring and support began.

“With the benefit of hindsight, we could look back and piece together

the bits of the puzzle. Mum recalled when they were in Croatia on holiday and an old friend had asked Dad what he did in Australia. Dad turned to Mum and asked ‘What do I do in Australia?’ At the time she thought nothing of it, but looking back she realised this must have been the beginning of Dad’s disease.”

The brain and behaviour

When a person has dementia:

- One or more areas of the brain are damaged.
- These areas of damage can differ between people.
- The person cannot help his or her behaviour resulting from this brain damage.
- Dementia develops at different rates; there is no normal progression and the rate of the progression can depend on the cause of the dementia.
- In most cases of dementia progressive deterioration occurs over time; however temporary conditions such as stress, illness, medication and time of day can make symptoms appear worse.
- People with dementia are all different individuals both in the way they are affected (their behaviour) and the nature and extent of the underlying brain damage.

Imagine the brain as a factory

It can help to understand how the brain works if you think of the brain as a factory. The factory runs at peak efficiency when all parts are working properly.

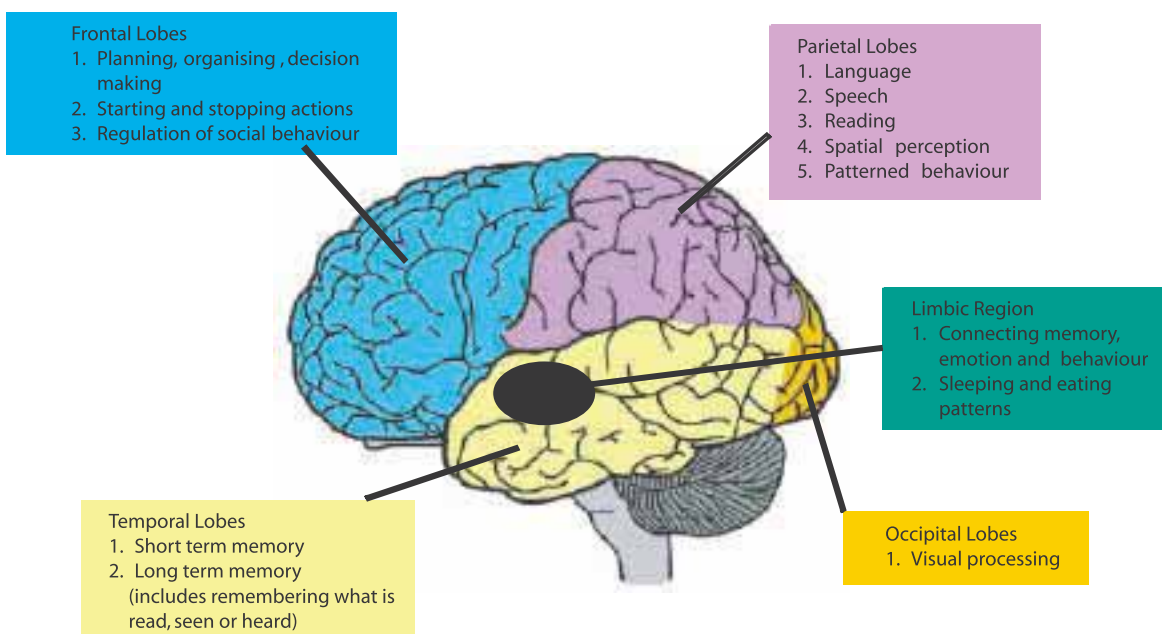
The directors

Up at the front of the factory (frontal lobes) are the directors. They make plans for the factory and decide who's going to do what and when. As things get under way, they get information as to how well things are going, and they judge it – what is good or not so good? Then they make further decisions – change that, keep this – and show appreciation and annoyance.

So up at the front you have planning, organising, decision making, judging and appreciating.

The managers

In the middle (parietal lobes) are the managers. Each manager runs a department. On the left side of the brain is a speech department (moves the throat, tongue and lip muscles); a language department (finds the words you want, knows what the words mean); a motor department (moves the right arm and leg); and a spatial knowledge department (finds your way around the building, knows where you are when driving a car). There is also a music department and



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a few incidental departments. The right side is the picture side and the left side is the talking side.

The plan

The managers know what the plan is from the directors and they make sure it is carried out.

To do this they send messages back and forth.

At the bottom (limbic region) are the workers. They don't know what the plan is from the directors but they know their job and they do the same job day in, day out. They take care of things like appetite control, need for water, staying alert and awake or going to sleep and basic emotions.

When the brain is damaged, someone can't do their job. Depending on the damage, it can be a director, manager or worker. You can also have someone go on a leave of absence. That occurs when there is a temporary swelling or loss of blood supply that is returned in a short time. The result of the injury is to reduce the efficiency of the factory. Messages are sent but aren't picked up. Directors get annoyed, the managers get tired and the emotional workers get overwrought. Confusion reigns.

Understanding who can no longer do the job and who is still on the job can help in understanding behaviour.

Source: Verna Arnell PhD, Psychologist, G F Strong Rehabilitation Centre, Vancouver

Why is correct diagnosis important?

A medical diagnosis is critical at an early stage when symptoms first appear because there are a number of potentially reversible causes and other less serious

conditions that resemble the symptoms of dementia.

These conditions include:

- some vitamin and hormone deficiencies
- medication clashes or over medication
- depression.

If the symptoms are caused by dementia, an early diagnosis will mean early access to support, information and medication, should it be available.

“I was worried about how the assessment would go but the staff provided an interpreter and treated my mother with dignity, so despite the fact that she was diagnosed with dementia the experience was not so horrible.”



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Who gets dementia?

Most older people do not get dementia. It is not a normal part of ageing.

Approximately 200,000 people in Australia are currently living with dementia. The numbers are increasing due to Australia's ageing population. By the year 2050, it is estimated that there will be more than 730,000 people with dementia.

How the prevalence of dementia increases with age

- Under 64 years, less than 1% may have dementia.
- From 65 to 74 years, 1.5% may have dementia.
- From 75 to 84 years, 6.3% may have dementia.
- Over 85 years, over 30% may have dementia.

Source: Access Economics P/L, Dementia Estimates and Projections: Australian States and Territories, February, 2005

Younger onset dementia

Dementia has been diagnosed in people in their 50s, 40s and even in their 30s, although this is much less common than dementia occurring after the age of 65. Younger onset dementia can be difficult to diagnose and its incidence in the community is still not clear.

Consulting a doctor to obtain a diagnosis is critical at an early stage. A complete medical and psychological assessment may identify a treatable condition, or it may confirm the presence of dementia.

A person with younger onset dementia will need extra consideration because the condition appears at an earlier stage of their life when they are likely to be more physically and socially active. They may be in full-time employment, raising young children, managing financial responsibilities and be physically strong and healthy

Changed behaviours associated with dementia may be more difficult to accept and manage in a younger person. Families may have to face many very personal and difficult emotional issues.

“Getting the diagnosis is so important and that doctors understand ... When David was diagnosed by the specialists, our GP said ‘I can’t understand it, he’s too young’.

“You expect this sort of thing only happens to older people. I can’t take it in – you can’t visualise what’s going to happen. That’s why I think counselling is vitally important. You’re trying to cope with loss of income, possible loss of your partner and, as well, loss of freedom.

“I used to associate dementia with old age. I had never known anyone young with dementia before David.”

Treatment for dementia

A number of drugs are currently available in Australia for use by people with dementia. These include drugs that may have a temporary effect of improving mental functioning in some people.

Dementia can cause a number of behavioural and psychological symptoms that can be very distressing. Sometimes they may require medication for relief. All medications should be discussed with your GP or specialist.

Some effects of dementia

Behaviour and personality changes

As we can't see what is happening to the brain, we can only observe the changes in the person. Have you observed any changes in behaviour, personality, emotions and attitudes?

Some examples of possible changes are:

- strange or uncharacteristic behaviours: easily upset or unusually aggressive
- unduly suspicious: blaming others for lost items, accusing others of stealing
- memory loss: increasing forgetfulness, poor or confused recall of events, distorted recall of past events
- changes in the ability to do everyday tasks: dressing, eating, driving.

If any of these changes worry you, discuss them with the doctor.

Communication changes

How the person with dementia lets you know what they need, or how they generally get a message across, will change.

Verbal communication refers to the words used by the person when speaking. While these words might be expressed clearly in the early stages of dementia, they may become jumbled and confused later.

The ability to communicate through spoken or written language may deteriorate or may be lost. The person then has to use other forms of communication to express a need.

Non-verbal communication refers to all other forms of communication and includes:

- facial expressions (such as smiling or frowning)
- gestures (such as pointing, touching or arm 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).

Being aware of non-verbal communication can help you and the person with dementia when verbal communication becomes difficult.

“Tone of voice is important when the person can’t understand what you are saying. My father got to the stage where he couldn’t understand English but would respond to the tone of my voice.”

“People with dementia may enjoy being touched by some people but not others. Use touch carefully and don’t continue if it is not appreciated.”

