



# Informations about dementia

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## What is dementia?

Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease. Dementia affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person's normal social or working life.

## Who gets dementia?

Most people with dementia are older, but it is important to remember that not all older people get dementia. It is not a normal part of ageing. Dementia can happen to anybody, but it is more common after the age of 65 years. People in their 40s and 50s can also have dementia.

## What causes dementia?

There are many different forms of dementia and each has its own causes. The most common types of dementia are; Alzheimer's disease, Vascular dementia, Parkinson's disease, Dementia with Lewy bodies, Fronto Temporal Lobar Degeneration (FTLD), Huntington's disease, Alcohol related dementia (Korsakoff's syndrome) and Creutzfeldt-Jacob disease.

## Alzheimer's disease

### What is Alzheimer's disease?

Alzheimer's disease is the most common form of dementia accounting for between 50% and 70% of all dementias.

Alzheimer's disease is a physical disease which attacks the brain resulting in impaired memory, thinking and behaviour. The disease

is named for the German physician, Alois Alzheimer who, in 1907, first described it.

As brain cells die, the substance of the brain shrinks. Abnormal material builds up as “tangles” in the centre of the brain cells and “plaques” outside the brain cells, disrupting messages within the brain, damaging connections between brain cells. This leads to the eventual death of the brain cells and prevents the recall of information.

Memory of recent events is the first to be affected, but as the disease progresses, longterm memory is also lost. The disease also affects many of the brain's other functions and consequently, many other aspects of behaviour are disturbed.

There are two different types of Alzheimer's disease:

### **Sporadic Alzheimer's disease**

- The disease can affect adults at any age, but usually occurs after age 65
- Sporadic Alzheimer's disease is by far the most common form of Alzheimer's disease
- It affects people who may or may not have a family history of the disease.

### **Familial Alzheimer's disease**

The disease runs in a few families and is very rare

- If a parent has a mutated gene, each child has a 50% chance of inheriting it
- The presence of the gene means that the person will eventually develop Alzheimer's disease, usually in their 40's or 50's
- Familial Alzheimer's disease affects a very small number of people.

## **What are the symptoms?**

In the early stages the symptoms of Alzheimer's disease can be very subtle. However, it often begins with lapses in memory and difficulty in finding the right words for everyday objects.

Other symptoms may include:

- Persistent and frequent memory difficulties, especially of recent events
- Vagueness in everyday conversation
- Apparent loss of enthusiasm for previously enjoyed activities
- Taking longer to do routine tasks
- Forgetting well-known people or places
- Inability to process questions and instructions
- Deterioration of social skills
- Emotional unpredictability.

Symptoms vary and the disease progresses at a different pace according to the individual and the areas of the brain affected. A person's abilities may fluctuate from day to day, or even within the one day, becoming worse in times of stress, fatigue or ill-health.

However, there is always a deterioration over time. It is a progressive and currently irreversible disease.

## **What causes Alzheimer's disease?**

Scientists are rapidly learning more about the chemical changes which damage brain cells in Alzheimer's disease but apart from the few individuals with Familial Alzheimer's disease, it is not known why one individual gets Alzheimer's disease late in life and another does not.

A variety of suspected causes are being investigated including factors in the environment, biochemical disturbances and immune

processes. The cause may vary from person to person and may be due to one factor or a number of factors.

### **Who gets Alzheimer's disease?**

Alzheimer's disease can happen to anybody, but it is much more common after the age of 65. The incidence rate rises with age. For people 85 years and over, 1 in 4 have dementia. It can affect people in their 30's, 40's and 50's.

### **How is Alzheimer's disease diagnosed?**

There is currently no single test to identify Alzheimer's disease. The diagnosis is made only after careful clinical consultation.

The clinical diagnosis might include:

- A detailed medical history
- A thorough physical and neurological examination
- A test of intellectual function
- Psychiatric assessment
- A neuropsychological test
- Blood and urine tests.

These tests will help to eliminate other conditions with similar symptoms such as nutritional deficiencies or depression. After eliminating other causes, a clinical diagnosis of Alzheimer's disease can be made with about 80% to 90% accuracy if the symptoms and signs are appropriate. The diagnosis can only be confirmed after death by examination of the brain tissue.

It is important to have an early and accurate diagnosis to determine whether a treatable condition other than Alzheimer's disease, is causing the symptoms. If Alzheimer's disease is diagnosed medical treatment and other assistance can be discussed.

## **How does Alzheimer's disease progress?**

The rate of progression of the disease varies from person to person.

However, the disease does lead eventually to complete dependence and finally death, usually from another illness such as pneumonia. A person may live from three to twenty years with Alzheimer's disease, with the average being seven to ten years.

## **Is there treatment available?**

At present there is no cure for Alzheimer's disease. However, one group of drugs called cholinergic drugs appears to be providing some improvement in cognitive functioning for some people with mild to moderate Alzheimer's disease.

Drugs can also be prescribed for secondary symptoms such as restlessness or depression or to help the person with dementia sleep better.

Community support is available for the person with Alzheimer's disease, their families and carers. This support can make a positive difference to managing dementia. Alzheimer's Germany provides support, information and counselling for people affected by dementia. Alzheimer's Germany also aims to provide up-to-date information about drug treatments. For more information contact Dementia Helpline on 01803-17 10 17.

## **Vascular dementia**

Vascular dementia is the second most common cause of dementia after Alzheimer's disease.

## **What is Vascular dementia?**

Vascular dementia is the broad term for dementia associated with problems of circulation of blood to the brain.

## **Are there different types of Vascular 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**

This is probably the most common form of Vascular dementia. Multi-infarct dementia is caused by a number of small strokes, called mini-strokes or Transient Ischaemic Attacks (TIA). The strokes cause damage to the cortex of the brain, the area associated with learning, memory and language. A person with Multiinfarct dementia is likely to have better insight in the early stages than people with Alzheimer's disease, and parts of their personality may remain relatively intact for longer. Symptoms may include severe depression, mood swings and epilepsy.

### **Binswanger's disease (also known as Subcortical vascular dementia)**

This was thought to be rare, but is now being reassessed, and may in fact be relatively common. As with other Vascular dementias, it is associated with stroke-related changes. It is the "white matter" deep within the brain that is affected. It is caused by high blood pressure, thickening of the arteries and inadequate blood flow. Symptoms often include slowness and lethargy, difficulty walking, emotional ups and downs and lack of bladder control early in the course of the disease. Most people with Binswanger's disease have, or have had, high blood pressure.

One single large stroke can sometimes cause Vascular dementia depending on the size and location of the stroke. Risk factors that make strokes more likely to lead to Vascular dementia include:

- Untreated high blood pressure (hypertension)
- Atrial fibrillation
- Other irregular heart rhythms which raise the risk of clots and atherosclerosis (fatty deposits in blood vessels) which causes damage to the arteries of the brain.

### **How is Vascular dementia diagnosed?**

Vascular dementia is usually diagnosed through neurological examination and brain scanning techniques such as computerised tomography (CT) or a magnetic resonance imaging (MRI) test. However, as is the case with Alzheimer's disease, a definite diagnosis of Vascular dementia can only be made by examining the brain after death. Vascular dementia can be very difficult to distinguish from other forms of dementia. Some people have both Alzheimer's disease and Vascular dementia.

### **Who gets Vascular dementia?**

Anyone can be affected by Vascular dementia, but several factors increase the risk. These include:

- High blood pressure
- Smoking
- Diabetes
- High cholesterol
- History of mild warning strokes
- Evidence of disease in arteries elsewhere
- Heart rhythm abnormalities.

Vascular dementia is slightly more common in men than women.

## **How does Vascular dementia progress?**

Vascular dementia usually progresses gradually in a step-wise fashion in which a person's abilities deteriorate after a stroke, and then stabilise until the next stroke. If further strokes do not occur, the abilities of people with Vascular dementia may not continue to decline, or in some cases, may improve. However, these improvements may not last. Sometimes the steps are so small that the decline appears gradual. On average though, people with Vascular dementia decline more rapidly than people with Alzheimer's disease. Often they die from a heart attack or major stroke.

## **Is there treatment available?**

While no treatment can reverse damage that has already been done, treatment to prevent additional strokes is very important. To prevent strokes, medicines to control high blood pressure, high cholesterol, heart disease and diabetes can be prescribed. A healthy diet, exercise and avoidance of smoking and excessive alcohol also lessen the risk of further strokes. Sometimes aspirin or other drugs are prescribed to prevent clots from forming in the small blood vessels.

Drugs can also be prescribed to relieve restlessness or depression or to help the person with dementia to sleep better. In some cases surgery known as carotid endarterectomy may be recommended to remove blockage in the carotid artery, the main blood vessel to the brain. Recent research suggests that cholinesterase inhibitor medications such as Donepezil (Aricept) and Galantamine (Reminyl), which are helpful for some people with Alzheimer's disease, may also be of some benefit to some people with Vascular dementia. However, the evidence is not yet as clear or compelling as that for the use of these medications with Alzheimer's disease.

## Dementia with Lewy Bodies

Dementia with Lewy bodies is a common form of dementia, sharing many similarities with Alzheimer's disease. Lewy bodies, its causes, diagnosis and progression is described here.

### **What is 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 spherical structures, called Lewy bodies, which develop inside nerve cells. It is thought that these may contribute to the death of the brain cells. They are named after the doctor who first wrote about them. It is sometimes referred to as Diffuse Lewy body disease.

### **What is the cause?**

At present there is no known cause of dementia with Lewy bodies, and no known risk factors have been identified. There is no evidence that dementia with Lewy bodies is an inherited disease.

### **How is dementia with Lewy bodies diagnosed?**

This type of dementia is diagnosed by taking a careful history of the pattern of symptoms, and by excluding other possible causes such as Vascular dementia and Alzheimer's disease. A brain scan may reveal brain degeneration, but the Lewy bodies can only be identified by examination of brain tissue after death.

Dementia with Lewy bodies is similar to Alzheimer's disease in many ways, and in the past it has sometimes been difficult to distinguish the two. It has only recently been accepted as a disease in its own right. Dementia with Lewy bodies can occur by itself or together with Alzheimer's disease and/or Vascular dementia. It may be hard to distinguish Dementia with Lewy bodies from Parkinson's

disease, and some people with Parkinson's disease develop a dementia which is similar to that seen in Dementia with Lewy Bodies.

### **What are the symptoms?**

The symptoms of dementia with Lewy bodies include:

- Difficulty with concentration and attention
- Extreme confusion
- Difficulties judging distances, often resulting in falls.

There are also three cardinal symptoms, two of which must be present in order to make the diagnosis:

- Visual hallucinations
- Parkinsonism (tremors and stiffness similar to that seen in Parkinson's disease)
- Fluctuation in mental state so that the person may be lucid and clear at one time and confused, disoriented and bewildered at other times. Typically this fluctuation occurs over a period of hours or even minutes and is not due to any underlying acute physical illness.

Some people who have dementia with Lewy bodies may also experience delusions and/or depression.

### **Who gets dementia with Lewy bodies?**

Both men and women can develop this disease, although it is more common in men.

### **How does dementia with Lewy bodies progress?**

Dementia with Lewy bodies differs from Alzheimer's disease in that the progression of the disease is usually more rapid. However, like Alzheimer's disease it is a degenerative condition, eventually leading to complete dependence. Death is usually a result of another

illness, such as pneumonia or an infection. The average lifespan after the onset of symptoms is about seven years.

### **Is there treatment available?**

At present there is no cure for dementia with Lewy bodies. Symptoms such as depression and disturbing hallucinations can usually be reduced by medication. However, medications to relieve hallucinations may increase muscle tremors and stiffness. Conversely, anti-Parkinson drugs may make hallucinations worse. Emerging evidence suggests that cholinesterase inhibitor drugs may be quite helpful for some people with this condition. People with this form of dementia are very sensitive to the side effects of neuroleptic drugs such as antipsychotic medications. It is essential all medications are supervised by a specialist to avoid these severe side effects.

## **Fronto Temporal Lobar Degeneration**

This section describes a group of dementias, known as Fronto Temporal Lobar Degeneration including Fronto Temporal Dementia, Progressive non-Fluent Aphasia, Semantic Dementia and Pick's disease. It discusses their causes, diagnoses and symptoms.

### **What is Fronto Temporal Lobar Degeneration?**

This is the name given to dementia when there is degeneration in one or both of the frontal or temporal lobes of the brain.

#### **Frontal Lobes:**

The right and left frontal lobes govern mood, behaviour, judgement and self-control. Damage leads to alterations in personality and behaviour, changes in the way a person feels and expresses emotion and loss of judgement.

## **Temporal Lobes:**

The right and left temporal lobes are involved in the organisation of sensory input such as what you hear or see. Damage may lead to difficulty placing words or pictures into categories. There is considerable difference in FTLD symptoms depending on which parts of the frontal and temporal lobes are affected. The three main subtypes or variants are:

- **Fronto Temporal Dementia (FTD)** is the most common subtype or Frontal Variant. It is mainly a disorder of behaviour. People with FTD may be disinhibited or apathetic
- **Progressive non-Fluent Aphasia (PA)**, which was formerly known as **Primary Progressive Aphasia (PPA)**. People with PA may lose the ability to speak or may begin to speak gibberish
- **Semantic Dementia (SD)** (**Progressive Fluent Aphasia**) is also known as the **Temporal Variant**. People with SD may lose the meaning of words and also may become preoccupied with a single activity. Although people with FTLD may be assessed as one of the three subtypes above, the disease will progress and people with FTLD are likely to develop signs and symptoms that are a mixture of two or three subtypes.

FTLD causes progressive and irreversible decline in a person's abilities over a number of years.

## **What is Pick's disease?**

Pick's disease is a type of **Fronto Temporal Lobar Degeneration**, named after the German neurologist who first described it in 1892. Pick's disease affects the frontal lobes, but in some cases can affect the temporal lobe of the brain. If the temporal lobe is damaged, memory is more likely to be affected.

## **What are the symptoms?**

Early symptoms can affect behaviour, and sometimes language. People may show a change in their character and in their social behaviour. For example, they may show insensitivity when they have previously been very considerate of others. A person with FTLD may become obsessive and repeat the same action over and over again. Language problems often occur early in the disease and may range from limited speech to total loss of speech. Repeating phrases over and over, or echoing what others have said are also common symptoms. Instead of being able to find the right word to describe an object, a person with FTLD may give a description of it instead. For instance, instead of naming a watch, the person may refer to something you tell the time with.

## **Who gets frontal lobe dementia?**

Frontal lobe dementia, including Pick's disease, can affect both men and women. Although it can affect people at any age, it usually begins between 40 to 65 years of age.

## **How is Fronto Temporal Lobar Degeneration diagnosed?**

There are several techniques such as brain scans, an electroencephalogram (EEG) and neuropsychological tests which can be used to make a probable diagnosis. These tests can help to determine whether the dementia is likely to be FTLD, or another disorder, such as Alzheimer's disease. Like Alzheimer's disease however, the diagnosis can only be confirmed after death by examination of the brain tissue.

## **What causes Fronto Temporal Lobar degeneration?**

About 50% of people with FTLD have a family history of the disease. Those who inherit it seem to have a mutation in the tau protein gene on chromosome 17, leading to abnormal tau protein being produced. Other risk factors are less well known.

## **How does the disease progress?**

The course of FTLD is one of inevitable progressive deterioration. From the onset of the disease, life expectancy is two to fifteen years, with an average of six to twelve years. Death usually comes from another illness such as infection.

## **Is there treatment available?**

Unfortunately, there is not yet a cure for FTLD, nor is there currently any treatment. However secondary symptoms, such as depression, can be helped by medication. Management lies in developing coping strategies. Knowing more about the disease and why the person is behaving as they are can in itself be an effective means of helping people to cope with the disease. Family members and carers can develop their own coping strategies, such as avoiding confrontation and working around obsessions, rather than trying to change the behaviour of those affected.

## **Alcohol related dementia**

What is alcohol related dementia? What is the cause? What are the symptoms? Who gets alcohol related dementia? Is there treatment available? All these questions are answered in this section.

### **What is alcohol related dementia?**

Alcohol related dementia is, as the name suggests, a form of dementia related to the excessive drinking of alcohol. This affects memory, learning and other mental functions. Korsakoff's syndrome and Wernicke/Korsakoff syndrome are particular forms of alcohol related brain injury which may be related to alcohol related dementia.

## **What is the cause?**

It is currently unclear as to whether alcohol has a direct toxic effect on the brain cells, or whether the damage is due to lack of thiamine, vitamin B1. Nutritional problems, which often accompany consistent or episodic heavy use of alcohol, are thought to be contributing factors. Key parts of the brain may suffer damage through vitamin deficiencies, particularly marked levels of thiamine deficiency and the direct effect that alcohol has on the absorption and use of thiamine.

## **What are the symptoms?**

This can vary from person to person, but generally symptoms will include:

- Impaired ability to learn things
- Personality changes
- Problems with memory
- Difficulty with clear and logical thinking on tasks which require planning, organising, common sense judgement and social skills
- Problems with balance
- Decreased initiative and spontaneity.

Generally skills learned earlier in life and old habits such as language and gestures tend to be relatively unaffected.

## **Who gets alcohol related dementia?**

Anyone who drinks excessive amounts of alcohol over a period of years may get alcohol related dementia. Males who drink more than six standard alcoholic drinks a day, and women who drink more than four, seem to be at increased risk of developing alcohol related dementia. The risk clearly increases for people who drink high levels of alcohol on a regular basis. The National Health & Medical Research Council of Australia recommends that for health

reasons related to the prevention of brain and liver damage adult males should drink no more than four standard drinks per day and adult females should drink no more than two standard drinks per day.

Some people who drink at high levels do not develop alcohol related dementia, but it is not currently possible to understand and predict who will and who won't develop alcohol related dementia. Some people who develop alcohol related dementia might also show some degree of recovery over time if they reduce alcohol intake to safe levels or abstain from alcohol and maintain good health. Alcohol related dementia can affect both men and women of any age.

### **Is there treatment available?**

At an early stage of the disease, problems may be reduced or reversed if the person abstains from alcohol, improves their diet and replace vitamins especially thiamine and vitamin B1. Thiamine is important to limit some of the toxic effects of alcohol, and is an important supplement for heavy drinkers.

Community support is available for the person with dementia, their family and carers. This support can make a positive difference to managing dementia.

## **Memory loss**

When we talk about memory loss, we all tend to associate it as a normal part of ageing. This section talks about memory loss associated with dementia and how it is not a part of normal ageing.

## Memory changes

There is a difference between memory loss as a part of normal ageing and as a symptom of dementia. This information describes those differences and provides some tips on keeping your memory sharp.

One of the main symptoms of dementia is memory loss. We all forget things from time to time, but the loss of memory with dementia is very different. It is persistent and progressive, not just occasional. It may affect the ability to continue to work, or carry out familiar tasks. It may mean having difficulty finding the way home. Eventually it may mean forgetting how to dress or how to bathe. An example of normal forgetfulness is walking into the kitchen and forgetting what you went in there for, or misplacing the car keys. A person with dementia however, may lose the car keys and then forget what they are used for.

### Key points about normal forgetfulness

- As we get older, the most common change that we complain about is memory change. Knowledge about how memory changes as we get older is a lot more positive than in the past. Memory change with healthy ageing certainly doesn't interfere with everyday life in a dramatic way.
- Everyone is different, and the effect of getting older on memory is different for each person.
- Recent research describes the effect of getting older on attention processes, on the ability to get new information into storage, on the time it takes to recall things and “on the tip of the tongue” experiences.
- Research also suggests that immediate memory and lifetime memory do not change as we get older.

*Based on Remembering Well, by Delys Sergeant and Anne Unkenstein.*

## Debunking memory myths

### Myth One

*Forgetfulness is a sign that something is wrong with your brain.*

#### Fact

If we didn't possess the capacity to forget we'd all go crazy. The ability to remember what is important and discard the rest is a skill to be treasured.

### Myth Two

*You lose 10,000 brain cells a day, and one day you just run out.*

#### Fact

This is an an exaggerated fear. Some parts of the brain do lose nerve cells, but not where the process of thinking takes place. You lose some nerve connections, but it's possible to grow new ones, or maintain the connections you have, by exercising your mind.

### Myth Three

*Compare yourself to others to tell if your memory is normal.*

#### Fact

A huge range of ability exists across the general population. Even a single individual experiences variations in memory over the course of a lifetime. Just as certain people have a talent for music and others do not, some of us are naturally gifted at various types of remembering.

*From Memory: Remembering and forgetting in everyday life, by Dr Barry Gordon.*

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## **Tips for keeping your memory sharp**

As yet, there is no prevention or cure for dementia. However, here are a few tips for keeping your brain fit and memory sharp:

- Avoid harmful substances. Excessive drinking and drug abuse damages brain cells
- Challenge yourself. Reading widely, keeping mentally active and learning new skills strengthens brain connections and promotes new ones
- Trust yourself more. If people feel they have control over their lives, their brain chemistry actually improves
- Relax. Tension may prolong a memory loss
- Make sure you get regular and adequate sleep
- Eat a well balanced diet
- Pay attention. Concentrate on what you want to remember
- Minimise and resist distractions
- Use a notepad and carry a calendar. This may not keep your memory sharp, but does compensate for any memory lapses
- Take your time
- Organize belongings. Use a special place for unforgettables such as car keys and glasses
- Repeat names of new acquaintances in conversation.

## Distinguishing points between normal memory loss and that of a person with dementia

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

## Mild Cognitive Impairment (MCI)

Memory loss has long been accepted as a normal part of ageing. Recently there has been increasing recognition that some people experience a level of memory loss greater than that usually experienced with ageing, but without other signs of dementia. This has been termed Mild Cognitive Impairment (MCI). As MCI has only recently been defined, there is limited research on it and there is much that we do not yet understand.

## What is MCI?

MCI is generally defined as significant memory loss without the loss of other cognitive functions. People with MCI have more memory problems than would be expected from someone at a similar age. People with MCI are able to function independently and do not show other signs of dementia, such as impaired reasoning or judgment.

Typical complaints from people with MCI include having trouble remembering names of people they met recently, remembering the flow of a conversation and a greater tendency to misplace things.

People with MCI can usually accomplish all of their daily tasks, but often compensate for their memory problems by relying on memory prompts such as reminder notes or calendars.

In 2001, the American Academy of Neurology (AAN) set the following criteria for use by medical practitioners in determining if a person has MCI:

- report of memory problems, preferably confirmed by another person
- measurable, greater-than normal memory impairment detected with standard memory assessment tests
- normal general thinking and reasoning skills
- ability to perform normal daily activities.

A recent update of these criteria does allow the person to be unaware of the memory problems, and also allows more complex activities, such as managing finances, to be affected.

Determining if a person has MCI can be problematic because it is difficult to define how much memory impairment is considered 'more than normal'. Currently, a great deal of research is being conducted into MCI.

## **How is MCI detected?**

MCI is usually detected by using similar testing methods to those used for dementia. This begins with the doctor talking to both the person and, if possible, a friend or family member, to get a thorough understanding of the person's medical history, the medication they are taking, the memory problems they are experiencing and any other relevant information.

A physical examination and blood tests may be done in order to rule out other causes of memory loss such as depression, stress, medication problems or a nutritional deficiency.

People suspected of having MCI will also be tested with general tests for cognition and memory function such as those used in diagnosing dementia.

## **Does MCI lead to dementia?**

Recent studies indicate that people with MCI are more likely to develop dementia, especially Alzheimer's disease. It is currently estimated that people with MCI have a 3 to 5 times increased risk of developing dementia than others their age.

A large treatment trial with selected people with more severe diagnosis of MCI found that about 15% of subjects progressed to dementia each year.

However, MCI does not always lead to dementia and can take many years to do so. In tests conducted regularly over a number of years, a substantial proportion of people with MCI have remained stable or even improved. Various studies show differing results in their estimates of how many people with MCI will progress to dementia.

## **Can MCI be treated?**

Currently, there is no specific treatment for MCI. A number of studies are investigating different treatments, such as the cholinesterase inhibitors used to treat Alzheimer's disease, Ebixa, nonsteroidal anti-inflammatory drugs (NSAIDs), Vitamin E and statins (for controlling cholesterol). At this stage no drug therapy for MCI has proven effective, but work continues. As new medical treatments for Alzheimer's disease arise, it is likely that they will also be tested in people with MCI. Studies involving drug trials have shown preliminary evidence that drug treatments can effectively delay the progression to dementia.

Cognitive training (exercising the mind and memory) has been suggested as useful for MCI and it is important to maintain a healthy diet, have regular physical exercise and maintain good general health – particularly controlling blood pressure, lowering cholesterol levels and stopping smoking.

In most cases a person diagnosed with MCI will not undergo any medical treatment as such, but will be regularly monitored for changes in their memory. Counselling may assist people with MCI to find ways to adjust to the changes they are experiencing and to learn about ways to compensate for their memory difficulties.

## **Implications of MCI**

The implications of detecting MCI can be viewed as mostly positive. Many people with MCI are very aware of their memory problems and are often concerned that they have dementia. Knowing that they have MCI confirms to them that their memory concerns are valid and they can feel reassured to know that having MCI does not necessarily mean they will develop dementia.

Knowing that they are at a higher risk of developing dementia also allows people with MCI to plan for the possibility that they may deteriorate in the future, to evaluate their support systems and to make important legal, financial and personal decisions such as

powers of attorney. They can also take steps to establish and maintain a healthy lifestyle.

Regular monitoring is critical since the borderline between normal age related memory difficulties and dementia will vary for each individual. Detection and monitoring of MCI allows dementia to be identified at an early stage. Given that most of the drugs currently used to treat Alzheimer's disease are at their most effective in the early stages of the condition, early identification of dementia means the person can make their choices about taking this medication at the most optimum time. People can then also be assisted with information and support services.

As new treatments for dementia become available, it is likely that detection of MCI will become even more important. In addition, approaches to prevent dementia can be expected to be potentially helpful to those with MCI.

*Thanks to Associate Professor Michael Woodward for reviewing this material.*

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## Behavior

This section talks about how dementia affects a person's behavior and how as a caregiver or a family member we can cope with managing this behavioral change.

### **Behavior changes**

Common behavior changes that may occur when a person has dementia, why do these changes occur? Answers to this and some general guidelines for coping with them.

Changes in the behavior of a person with dementia are very common. This may place enormous stress on families and caregivers. It can be particularly upsetting when someone previously gentle and loving behaves in a strange or aggressive way.

### **Why does behavior change?**

There are many reasons why a person's behavior may be changing. Dementia is a result of changes that take place in the brain and affects the person's memory, mood and behavior. Sometimes the behavior may be related to these changes taking place in the brain. In other instances, there may be changes occurring in the person's environment, their health or medication that trigger the behavior. Perhaps an activity, such as taking a bath, is too difficult. Or the person may not be feeling physically well. Dementia affects people in different ways. Understanding why someone is behaving in a particular way may help you with some ideas about how to cope.

### **Where to begin**

Always discuss concerns about behavior changes with the doctor, who will be able to check whether there is a physical illness or discomfort present and provide some advice. The doctor will be able to advise if there is an underlying psychiatric illness.

## **Coping**

Coping with changed behaviors can be very difficult, and is often a matter of trial and error. Always remember that the behavior is not deliberate. Anger and aggression are often directed against family members and carers because they are closest. The behaviour is out of the person's control and they may be quite frightened by it. They need reassurance, even though it may not appear that way.

## **What to try**

- A calm, unstressed environment in which the person with dementia follows a familiar routine can help to avoid some difficult behaviors
- Try to keep the environment familiar. People with dementia can become upset if they find themselves in a strange situation or among a group of unfamiliar people where they feel confused and unable to cope.
- The frustration caused by being unable to meet other people's expectations may be enough to trigger a change in behavior.
- If behavior becomes difficult, it is best not to attempt any form of physical contact such as restraining, leading them away or approaching from behind. It may be better to leave them alone until they have recovered, or call a friend or neighbour for support
- Try not to take it personally
- Try not to use a raised voice
- Avoid punishment. The person may not remember the event and is therefore not able to learn from it
- Speak slowly, in a calm and reassuring voice
- Try not to become provoked or drawn into an argument.

## **Aggression**

This can be physical, such as hitting out, or verbal such as using abusive language. Aggressive behavior is usually an expression of anger, fear or frustration.

## What to try

- The aggression may be due to frustration. Locking the door may prevent wandering, but may result in increased frustration
- Activity and exercise may help prevent some outbursts
- Approaching the person slowly and in full view may help. Explain what is going to happen in short, clear statements such as “I’m going to help you take your coat off”. This may avoid the feeling of being attacked and becoming aggressive as a self-defense response
- Check whether the aggressive behavior is about getting what the person wants. If so, trying to anticipate needs may help.

## Catastrophic reactions

Some people with dementia over-react to a trivial setback or a minor criticism. This might involve them screaming, shouting, making unreasonable accusations, becoming very agitated or stubborn, or crying or laughing uncontrollably and inappropriately. This tendency to over-react is part of the disease and is called a catastrophic reaction. Sometimes a catastrophic reaction is the first indication of the dementia. It may be a passing phase, disappearing as the condition progresses, or it may go on for some time.

### **Catastrophic behaviour may be a result of:**

- Stress caused by excessive demands of a situation
- Frustration caused by misinterpreted messages
- Another underlying illness

This behavior can appear very quickly and can make family and carers feel frightened. However, trying to figure out what triggers catastrophic behavior can sometimes mean that it can be avoided.

Keeping a diary may help to identify the circumstances under which they occur. If this isn't possible, you can find ways of dealing with the behavior quickly and effectively using some of the guidelines listed earlier.

## **Hoarding**

People with dementia may often appear driven to search for something that they believe is missing, and to hoard things for safekeeping.

### **Hoarding behaviors may be caused by:**

- Isolation - When a person with dementia is left alone or feels neglected, they may focus completely on themselves. The need to hoard is a common response
- Memories of the past - Events in the present can trigger memories of the past, such as living with brothers and sisters who took their things, or living through the depression or a war with a young family to feed
- Loss - People with dementia continually lose parts of their lives. Losing friends, family, a meaningful role in life, an income, and a reliable memory can increase a person's need to hoard
- Fear - A fear of being robbed is another common experience. The person may hide something precious, forget where it has been hidden, and then blame someone for stealing it.

### **What to try**

- Learn the person's usual hiding places and check there first for missing items
- Provide a drawer full of odds and ends for the person to sort out as this can satisfy the need to be busy
- Make sure the person can find their way about, as an inability to recognize the environment may be adding to the problem of hoarding.

## **Repetitive behavior**

People with dementia may say or ask things over and over. They may also become very clinging and shadow you, even following you to the toilet. These behaviors can be very upsetting and irritating.

### **What to try**

- If an explanation doesn't help, distraction sometimes works. A walk, food or favourite activity might help
- It may help to acknowledge the feeling expressed. For example "What am I doing today?" may mean that the person is feeling lost and uncertain. A response to this feeling might help
- Do not remind the person that they have already asked the question
- Repetitive movements may be reduced by giving the person something else to do with their hands, such as a soft ball to squeeze or clothes to fold.

*Based on Understanding and dealing with challenging behavior, Alzheimer Scotland – Action on Dementia.*

Dementia affects people in different ways. Common behavior changes that may occur when a person has dementia, and why these changes occur are explained under the behavior changes section.

Understanding why someone is behaving in a particular way may help you with some ideas about how to cope.

## Am I at risk?

Information about the early signs and symptoms of dementia, the role of heredity in dementia, managing the risk factors and advice on reducing the risk of developing dementia.

### **What are the early signs of dementia?**

The early signs of dementia are very subtle and vague and may not be immediately obvious. Early symptoms also vary a great deal. Usually though, people first seem to notice that there is a problem with memory, particularly in remembering recent events.

Other common symptoms include:

- Confusion
- Personality change
- Apathy and withdrawal
- Loss of ability to do everyday tasks

Sometimes people fail to recognise that these symptoms indicate that something is wrong. They may mistakenly assume that such behaviour is a normal part of the ageing process. Or symptoms may develop gradually and go unnoticed for a long time. Sometimes, people may refuse to act even when they know something is wrong.

### **Ten warning signs**

This is a checklist of common symptoms of dementia. Go through the list of the symptoms, if there are several that you say 'yes' to, a doctor should be consulted for a complete examination of the person with the symptoms.

*Recent memory loss that affects job skills*

- It is normal to forget meetings, colleagues' names, or a business associate's telephone number occasionally, but then remember them later.
- A person with dementia may forget things more often, and not remember them later.

#### *Difficulty performing familiar tasks*

- Busy people can be so distracted from time to time that they may leave the carrots on the stove and only remember to serve them when the meal has finished.
- A person with dementia might prepare a meal and not only forget to serve it, but also forget they made it.

#### *Problems with language*

- Everyone has trouble finding the right word sometimes.
- A person with dementia may forget simple words or substitute inappropriate words.

#### *Disorientation of time and place*

- It is normal to forget the day of the week or your destination for a moment.
- People with dementia can become lost on their own street, not know where they are, how they got there or how to get back home.

#### *Poor or decreased judgement*

- Dementia affects a person's memory and concentration and this in turn affects their judgement. Many activities, such as driving, require good judgement and when this ability is affected, the person will be a risk, not only to themselves, but to others on the road.

### *Problems with abstract thinking*

- Balancing a chequebook may be difficult for many of us.
- Someone with dementia could forget completely what the numbers are and what needs to be done with them.

### *Misplacing things*

- Anyone can temporarily misplace a wallet or keys.
- A person with dementia may repeatedly put things in inappropriate places.

### *Changes in mood or behaviour*

- Everyone becomes sad or moody from time to time.
- Someone with dementia can have rapid mood swings from calm to tears to anger, for no apparent reason.

### *Changes in personality*

- People's personalities can change a little with age.
- A person with dementia can become suspicious or fearful, or just apathetic and uncommunicative. They may also become dis-inhibited, over-familiar or more outgoing than previously.

### *Loss of initiative*

- It is normal to tire of housework, business activities or social obligations.
- The person with dementia may become very passive and require cues prompting them to become involved.

Based on *Is it Alzheimer's? Ten Warning Signs You Should Know*, [Alzheimer's Association, USA](#).

Information about the early signs of dementia, the importance of early and correct diagnosis and the ways in which it is diagnosed.

## Dementia and heredity

People affected by dementia are often concerned about whether the condition can be passed along in families. Here we discuss the role of heredity in Alzheimer's disease and other forms of dementia.

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

Alzheimer's disease is the most common form of dementia, accounting for 50% to 70% of all cases of dementia. It occurs relatively frequently in older people, regardless of family history. For females aged 65 to 69 years dementia affects 1 person in 80 compared to 1 person in 60 for males. For both males and females aged 85 and over the rate is approximately 1 person in 4.

### Understanding genes

The genetic material that we each inherit from our parents is packaged into structures called chromosomes. We have 22 pairs of chromosomes plus two X chromosomes (women) or an X and Y chromosome (men). Each chromosome contains thousands of genes like beads on a thread. Genes contain information - they are the blueprints for making a person. Each gene has the instructions for making one tiny aspect of a person. They are the basic units of heredity that allow specific characteristics (e.g. hair colour, height, the tendency to develop diabetes in late life) to be passed from one generation to the next. A mutation is a change in a gene. Some mutations are beneficial but many are potentially harmful.

With regard to diseases, some genes are causative e.g. if a person inherits a gene for a certain form of muscular dystrophy, they will certainly develop that illness in life. Other genes are so called risk factor genes - they may not irrevocably lead to a person developing a certain illness such as diabetes, high blood pressure or Alzheimer's disease but some genes can make this more or less likely.

### **Genes which may influence Alzheimer's disease**

Having a close relative with the Alzheimer's disease is not evidence of a genetic link. People who are influenced by risk factor genes are only at a slightly increased risk in developing the disease than the average population.

The most important gene discovered to date is the Apolipoprotein E gene, which is found in chromosome 19. This gene occurs in three forms in humans: types 2, 3 and 4. Every person in the world carries two Apolipoprotein genes: they can be the same type (2,2; 3,3 or 4,4), or a mixture of two types (2,3; 2,4; 3,4). What has been found is that people with at least one type 4 and especially those with two, such as 4,4, are at an increased risk of developing Alzheimer's disease earlier in life than those with the other types of Apolipoprotein E. Nevertheless half of the people aged 85 who have 2 copies of apolipoprotein E 4 do not have symptoms of Alzheimer's disease at that age.

People with type 2, especially 2,2, appear to be protected against developing Alzheimer's disease, until much later in life. Researchers do not understand why this is so, and there is much research underway to find out why.

The type of Apolipoprotein does not mean definitely that Alzheimer's disease will or will not occur. Indeed it is known that some people can reach 90 with type 4 and not develop dementia, whereas others with type 2 can develop dementia much earlier in life. What this means is that the type of Apolipoprotein a person has, is not enough on its own to cause Alzheimer's disease.

## **Genetic causes of dementia**

One rare form of Alzheimer's disease is passed from generation to generation. This is called Familial Alzheimer's disease (FAD). If a parent has a mutated gene that causes FAD, each child has a 50% chance of inheriting it. The presence of the gene means that the person will eventually develop Alzheimer's disease, usually in their 40s or 50s. This form of Alzheimer's disease affects an extremely small number of people – probably no more than 100 at any given time among the whole population of Australia.

Three genes have been identified which, if mutated in certain ways, will cause FAD. These are called presenilin 1 (chromosome 14), presenilin 2 (chromosome 1) and the amyloid precursor protein gene (APP) on chromosome 21.

### **If Familial Alzheimer's disease (FAD) is suspected**

Genetic testing can identify specific changes in a person's genes. This test can tell if a person has FAD and if a child has inherited the changed gene from a parent and will develop the disease in the future. It cannot determine when the symptoms will begin.

It is essential to ensure that suspected cases in the family have, or have had, Alzheimer's disease and not some other form of dementia. This can only be done through a medical examination, or a careful analysis of past medical records if the person is no longer alive.

### **Testing for Familial Alzheimer's disease (FAD)**

The decision to undergo testing for FAD is very complex and the advantages and disadvantages must be carefully considered. The test does not produce a relative risk of acquiring the dementia, but is a definitive prediction of whether a person will get a profound and progressive illness in one's middle years. The test can only be completed with the informed consent of the person being tested. No one should ever be pressured to have such a test.

Knowing that you are carrying the gene may help some people plan for the future. It enables them to consider future lifestyle choices and to let their wishes be known to someone they trust. However, given that no cure is available an individual has to consider whether they want to know that they will develop dementia at some time in the future.

To help people consider these issues specialised genetic counselling is essential. The doctor can provide details of this service. In the future, when preventive treatments for Alzheimer's disease become available, there may be increased reasons to seek testing.

### **Other rare forms of inherited dementia**

Some other rare forms of dementia can also be inherited. These include Huntington's disease and some forms of Fronto Temporal Lobar Degeneration, where behaviour changes before any change in memory. All these inherited conditions are very uncommon in the general population.

People affected by dementia are often concerned about whether the condition can be passed along in families. This page discusses the role of heredity in Alzheimer's disease and other forms of dementia.

## **Risk factors**

Some of the risk factors associated with dementia can be managed through lifestyle changes or appropriate medical treatments.

### **Cardiovascular risk factors**

Brain infarcts, heart disease and mid-life hypertension increase the risk of Alzheimer's disease and Vascular dementia. Smoking has also been identified as a risk factor.

## **Diabetes**

A recent study found that having diabetes increases the risk of developing Alzheimer's disease by 65%. This risk can be reduced by careful management of diabetes with medications that maintain blood glucose levels within a healthy range.

## **High cholesterol**

Cholesterol is essential to brain function – it is a component of cell membranes (structures that enclose nerve cells), and it is required for the repair and establishment of new connections between nerve cells. However, studies have shown that, high cholesterol in mid-life and late-life can increase the risk of Alzheimer's disease. Subsequent studies have indicated that cholesterol lowering drugs may lower the risk of developing Alzheimer's disease.

## **High homocysteine levels**

Homocysteine is a by-product of many metabolic reactions occurring in our body. Some studies have found that high homocysteine levels are associated with an increased risk of Alzheimer's disease and other dementias. Adequate intake of vitamin B and folate can help reduce homocysteine levels.

***Some risk factors predisposing to dementia are associated with genetic inheritance or previous life events, for example:***

### ***Genes associated with Alzheimer's disease***

One gene (Apolipoprotein E) has been associated with an increased risk of late onset Alzheimer's disease while three additional genes (Amyloid Precursor Protein, Presenilin 1 and Presenilin 2) are associated with early onset Alzheimer's disease.

Apolipoprotein E (ApoE) carries and delivers cholesterol to the nerve cells which use it for the repair and establishment of new

connections. There are three common variants of the ApoE gene. The ApoE 3 variant is the most common, the ApoE 4 variant is thought to increase the risk of Alzheimer's disease while the ApoE 2 variant appears to have a protective influence.

Mutations in the Amyloid Precursor Protein (APP), Presenilin 1 and Presenilin 2 cause the inherited form of Alzheimer's disease. However, a majority Alzheimer's disease cases appear to be sporadic and only a small number of cases are known to be inherited.

The APP gene makes a protein that is present on the surface of nerve cells and may help them grow and move. The presenilin 1 and 2 genes make proteins that are required for the correct functioning of the APP protein. Mutations in any one of these genes can cause the APP protein to be cut off from the surface of nerve cells. When this happens APP tends to accumulate in amyloid plaques which are a hallmark of Alzheimer's disease.

### **Family history**

A family history of dementia increases one's risk of developing dementia. This is probably due to genetic factors that have not yet been discovered.

### **Head injury**

A study of World War II veterans indicated that moderate to severe head injury increased risk of developing Alzheimer's disease and other dementias. Another study found that this risk is further increased if the head injury resulted in loss of consciousness.

Some of the risk factors associated with dementia can be managed through lifestyle changes or appropriate medical treatments.

There are three key areas to help you live a brain healthy life: look after your Brain, Body and Heart.

All these are important in looking after your brain health.

Following the Your Brain Matters guide is particularly important once you reach middle age, as this is when changes in the brain start to occur. But it's even better if you follow them throughout life. It's never too late either, as brain function can be improved at any age.

- Keeping your brain active matters: Keep your brain challenged and be socially active
- Being fit and healthy matters: Eating healthily and participating in regular physical activity are important for a healthy body and a healthy brain
- Looking after your heart matters: What's good for the heart is good for the brain – avoid smoking, manage your blood pressure, cholesterol, blood sugar and body weight

Dementia cannot yet be prevented or cured, so it's important for us to be aware of what we can do to reduce the risk of developing dementia.

### **How can I find out more**

What are some of the things to look out for, what are some of the tests used for diagnosing dementia and how do you go about telling someone they have dementia...all these questions and more are answered in this section.

## **Warning signs of dementia**

The early signs of dementia are very subtle and may not be immediately obvious. Early symptoms also vary a great deal. Usually though, people first seem to notice that there is a problem with memory, particularly in remembering recent events.

*(\*based on information from Alzheimer's Association USA)*

1. ***Memory loss that affects day-to-day function***  
It's normal to occasionally forget appointments or a friend's phone number and remember them later. A person with dementia may forget things more often and not remember them at all.
2. ***Difficulty performing familiar tasks***  
People can get distracted from time to time and they may forget to serve part of a meal. A person with dementia may have trouble with all steps involved in preparing a meal.
3. ***Confusion about time and place***  
It's normal to forget the day of the week - for a moment. But a person with dementia may have difficulty finding their way to a familiar place, or feel confused about where they are.
4. ***Problems with language***  
Everyone has trouble finding the right word sometimes, but a person with dementia may forget simple words or substitute inappropriate words, making sentences difficult to understand.
5. ***Problems with abstract thinking***  
Balancing a cheque-book can be difficult for anyone, but a person with dementia may have trouble knowing what the numbers mean.
6. ***Poor or decreased judgment***  
A person with dementia may have difficulty judging distance or direction when driving a car.
7. ***Problems misplacing things***  
Anyone can temporarily misplace a wallet or keys. A person with dementia may put things in inappropriate places.
8. ***Changes in personality or behavior***  
Everyone becomes sad or moody from time to time. Someone with dementia can exhibit rapid mood swings for no apparent reason. They can become confused, suspicious or withdrawn.
9. ***A loss of initiative***  
It's normal to tire of some activities. But dementia may cause a person to lose interest in previously enjoyed activities

Only a medical practitioner such as your local doctor or specialist can diagnose dementia. If a firm diagnosis has been made, it is helpful to find out about dementia and the support that is available to help you manage.

The early signs of dementia are very subtle and may not be immediately obvious. Early symptoms also vary a great deal. Usually though, people first seem to notice that there is a problem with memory, particularly in remembering recent events.

## Worried about your memory?

Feeling forgetful or confused? Finding out what is wrong is the first step to getting help.

Have you become concerned about increasing lapses in memory, or other changes in your thinking or behaviour? Changes in memory and thinking have a number of possible causes that may include:

- Stress
- Depression
- Pain
- Chronic illness
- Medication or alcohol, and
- Sometimes early dementia.

Major changes in memory are not normal at any age and should be taken seriously. If you are experiencing these kinds of difficulties it is better to see your doctor sooner rather than later.

## Talking to your doctor

There is no single specific test that can show whether someone has dementia. A diagnosis is made by talking to you and perhaps a relative or friend to find out more about your difficulties with

memory and thinking. You will also need a physical and neurological examination which will look at all other possible causes.

### **During the visit**

- Take your list of concerns with you - it will provide a useful basis for further discussion and tests
- Talk to your doctor about your concerns honestly and openly, including how long you have been experiencing these problems
- Bring a list of the medications that you are taking including the doses (or bring all your tablets in a bag). Don't forget inhalers, creams and herbal medications and vitamins.

### **Remember, you can:**

- Ask for a longer appointment
- Take a relative or friend with you
- Ask questions and request further explanations if you don't understand
- Take notes during the visit
- Discuss the option of further assessment by a specialist.

### **The earlier you act the better**

Your symptoms may not be caused by dementia, but if they are, earlier diagnosis will be helpful. An early diagnosis means that you can have access to support, information and medication. People with a diagnosis of dementia should have an opportunity to participate in planning the rest of their lives and their finances as well as indicating their wishes regarding future care. *"It was a relief to get the diagnosis, the worst was not knowing."* - Fred - diagnosed with Alzheimer's disease

*"We are glad we had that early diagnosis as we have been given the chance to change our lifestyle activities to match my capabilities and to make definite plans for the future."* - Maria - diagnosed

with vascular dementia :

*"For me, the medication has helped a lot it's lifted the fog."* - John - diagnosed with Alzheimer's disease.

Feeling forgetful or confused? Finding out what is wrong is the first step to getting help.

## Tests used in diagnosing dementia

### Assessment

The first step towards a diagnosis is to talk to your doctor about your concerns. It is a good idea to take a close family member or friend along to help provide the doctor with all the information they need.

It is also a good idea to take along a list of the memory and thinking changes that have been concerning you, including when you first noticed them and how often you notice them. You should also take a list of the medications you are taking or take your medications with you.

Your doctor may assess you and/or may refer you to a specialist such as a geriatrician (a specialist in illnesses and disabilities in older people), a neurologist (a specialist in disorders of the brain and nerves), or a psychiatrist (a specialist in disorders of emotion and behaviour).

**Assessment for dementia usually includes the following:**

#### 1. Personal history

The doctor usually spends some time discussing your medical history and gathering information about your changes in memory and thinking.

## **2. Physical examination and laboratory tests**

The symptoms of dementia can be due to a number of other possible causes, such as vitamin deficiency, infection, metabolic disorders and side effects from drugs. These other causes are often easily treated. Therefore, an early step in diagnosing dementia is to rule out these causes through a physical examination, blood tests and urine tests.

Routine laboratory tests used in the diagnosis of dementia include:

- Blood tests to investigate:
  - Anaemia
  - Infection
  - Electrolyte balance (salt and water)
  - Liver function
  - Vitamin B12 deficiency
  - Thyroid function
  - Drug interactions and dosing problems
- Urine tests to investigate infection.

## **3. Cognitive testing**

Cognitive tests are used to measure and evaluate cognitive, or 'thinking', functions such as memory, concentration, visual-spatial awareness, problem solving, counting and language skills.

Most doctors use short cognitive screening tests when assessing these functions. If more detailed testing is required you will be referred to a neuropsychologist – a psychologist specialising in the assessment and measurement of cognitive function.

Cognitive tests are vital in the diagnosis of dementia and are often used to differentiate between types of dementia. They can also be used to assess mood and may help diagnose depression, which can cause symptoms similar to those of dementia.

Special arrangements can be made for testing people whose first language is not English or who have communication difficulties. Your doctor can give you advice about this.

This page explains the more common tests and assessments doctors currently use to diagnose dementia. There is no one diagnostic test for Alzheimer's disease or for most other causes of dementia. Doctors use a number of different tests to determine whether

symptoms fit a certain diagnosis and to rule out other possible causes of symptoms.

### **Informing the person with dementia**

Whether or not to tell a person with dementia about their diagnosis is likely to be a difficult and emotional issue for all concerned. Improved diagnostic techniques mean that increasingly dementia is being diagnosed at an early stage of the illness. This means that people with dementia are more likely to be able to understand the implications of the disease than has been the case in the past.

### **Preparing for the diagnosis**

Wherever possible, the person undergoing the assessment for dementia should be allowed to decide if they want to know if the diagnosis is confirmed. In general, if a person is aware that they are going for a diagnosis they will be able to make that choice.

Some doctors will always tell their patient the outcome of the diagnosis, so it is important to discuss this issue prior to proceeding with the diagnosis.

If the person is not in a position to understand the implications of receiving a diagnosis of dementia, you need to make some judgments, based on your understanding of what the person's wishes would be. What would their choices have been if they were able to understand the implications? Have they ever given an indication at some time in the past as to what they would have preferred in a similar circumstance?

This is an important and difficult decision to be making on behalf of another person. Talking to family and friends, as well as to the doctor or specialist beforehand may help.

### **To tell or not to tell?**

Should I tell the person with dementia about the diagnosis?

There are many reasons for telling a person with dementia about their condition:

- It is now widely accepted that people have a right to know any medical information about themselves, if this is not to their detriment

- Many people are already aware that something is wrong. The diagnosis of dementia can come as a relief, as they now know what is causing their problems
- Knowing the diagnosis can help a person understand their situation, and make important plans for the future, particularly about legal and financial matters
- Knowing about the disease allows for an honest and open discussion of the experience of dementia between family and friends
- Access to information, support and new treatments are helped when the person knows about their condition.

However, there are a number of reasons sometimes given for not sharing the diagnosis with a person with dementia:

- The very nature of the dementia changes the ability to understand and remember information. It can also affect people's abilities to deal with emotional issues. The person may not understand the diagnosis, or may not remember it
- It may be felt that the person will become very distressed by the discussion. Families naturally feel very protective of their relative and wish to spare them the trauma.

## **Remember**

It is generally recommended that a person with dementia be told of their diagnosis. However, a person has a right not to know their diagnosis if that is their clear and informed preference.

## **How to share the diagnosis**

Sharing the initial news of the diagnosis may come from any one of a number of people. The doctor or specialist, assessment team or members of the family may talk to the person about the diagnosis either individually or as a group. You might like to consider having someone present at the time of telling to provide extra support.

Planning ahead about the best way to share the diagnosis will make it easier. As individual responses will be different, careful consideration must be given to every individual situation. However, there are some considerations that will be generally helpful when talking with a person about their diagnosis:

- Ensure that the setting is quiet and without competing noise and distractions
- Speak slowly, clearly and directly to the person
- Give one message at a time
- Allow time for the person to absorb the information and to form questions. Information may need to be added later
- Written information about dementia can be helpful to take away and provides a helpful reference. Alzheimer's Germany has information written specifically for people with dementia. Helpline on 01803-17 10 17
- Ensure that someone is available to support the person after being told about the diagnosis.

## What information to share

As a general guideline a number of things will need to be explained. These will include:

- An explanation as to why the symptoms are occurring
- A discussion of the particular form of dementia, in terms that are appropriate to the person's level of understanding
- Any possible treatment for symptoms
- The specialised services and support programs that are available for people with dementia.

Informing a person that they have dementia is a serious matter, which needs to be handled with great sensitivity, calmness and dignity. It can be a very stressful time for everyone. Don't forget to look after yourself. Alzheimer's Australia offers confidential counselling and support for families, carers and people with dementia.

## How is dementia treated.

### Drug treatments & 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 functioning. It is a broad term to describe a loss of memory, intellect, rationality, social skills and what would be considered normal emotional reactions. Dementia causes significant impairment in a person's day to day functioning.

### Drugs to treat the cognitive symptoms of dementia

A number of drugs are currently available in Australia for use by people with dementia. These drugs fall into two categories, cholinergic treatments and Memantine.

### Cholinergic treatments

Cholinergic treatments offer some relief from the symptoms of Alzheimer's disease for some people for a limited time. Drugs known as acetylcholinesterase inhibitors work by blocking the actions of an enzyme called acetylcholinesterase which destroys an important neurotransmitter for memory called acetylcholine. Current cholinergic treatments are approved for use for people with mild to moderate Alzheimer's disease. A number of the acetylcholinesterase inhibitors are available as subsidised medicines under the Australian Pharmaceutical Benefits Scheme.

People may receive these drugs at nominal cost if a physician or psychiatrist has found them to have a diagnosis of Alzheimer's disease. They must show improvement on a commonly used test of mental function in the first six months of treatment in order to receive further supplies of subsidised medication.

## **Memantine treatments**

Memantine targets a neurotransmitter called glutamate that is present in high levels when someone has Alzheimer's disease. Memantine blocks glutamate and prevents too much calcium moving into the brain cells causing damage. It is the first in a new class of therapies and acts quite differently to the acetylcholinesterase inhibitors that are currently approved for treatment.

Memantine is currently approved for use for people with moderately-severe to severe Alzheimer's disease. It is available at subsidised rates under the Pharmaceutical Benefits Schedule for those who meet the criteria for diagnosis and stage of disease.

## **How to get treatment**

It is important that the person has a firm diagnosis of Alzheimer's disease, not another form of dementia and to determine which stage the disease is in. A specialist, such as neurologist, psychogeriatrician, geriatrician or psychiatrist, will usually be involved in the prescription of these drugs.

## **Treating the accompanying symptoms of dementia**

Dementia often causes a number of behavioural and psychological symptoms which can be very distressing. These may include depression, anxiety, sleeplessness, hallucinations, ideas of persecution, misidentification of relatives or places, agitation and aggressive behaviour. These symptoms may respond to reassurance, a change in the environment or removal of the source of any distress such as pain. However, sometimes medication may be required for relief.

## **Major tranquillisers**

Major tranquillisers, also known as neuroleptics or anti-psychotics, are used to control agitation, aggression, delusions and hallucina-

tions. Haloperidol (Serenace) is one commonly used drug. In modest doses this drug tends to cause symptoms similar to Parkinson's disease such as stiffness, shuffling gait and shakiness, and older people are very prone to these side effects. Some are unable to tolerate even low doses of Haloperidol.

Newer tranquillisers such as Risperidone (Risperdal) have fewer Parkinson's like side effects and have been studied more intensively in people with dementia than Haloperidol has. Risperidone appears to be helpful for the treatment of aggression and psychosis, but may be associated with a slight increase in risk of stroke.

Olanzapine (Zyprexa) and Quetiapine (Seroquel) are sometimes used, but have been less comprehensively studied in the treatment of dementia, and there is some evidence that Olanzapine may also be associated with increased risk of stroke.

### **Drugs for treating depression**

Symptoms of depression are extremely common in people with dementia. Depression can usually be effectively treated with antidepressants, but care must be taken to ensure that this is done with a minimum of side effects.

### **Drugs for treating anxiety**

Anxiety states, accompanied by panic attacks and unreasonable fearfulness can be very distressing for a person with dementia and place considerable stress on family and careers. Short-lived periods of anxiety may be helped by a group of drugs known as benzodiazepines. While benzodiazepines are very effective for reducing anxiety in the short term, most individuals rapidly become used to their effects and they become less beneficial with time. Withdrawal of benzodiazepines is often associated with a rebound of anxiety symptoms and should not be undertaken without medical advice.

## **Drugs for treating sleep disturbances**

Persistent waking at night, and night time wandering can cause a lot of difficulties. Many drugs commonly prescribed for dementia can cause excessive sedation during the day, leading to an inability to sleep at night. Increased stimulation during the day can reduce the need for sleep inducing medications at night.

Medication to treat sleep disturbances should be a last resort, as people may become dependent on these and withdrawal of the medication may be followed by rebound sleeplessness and anxiety.

### **Remember**

- All drugs can have side effects, some of which may make the person's symptoms worse
- Always ask the doctor why the drug is being prescribed and what side effects might occur
- A drug which is useful may not continue to be effective indefinitely because of the progressive changes to the brain caused by dementia
- Do not expect immediate results. Benefits may take several weeks to appear particularly with anti-depressants. Discuss this with the doctor
- It is important that treatment is reviewed regularly
- Keep a record of all medications, including alternative medications. Take this record to medical appointments
- Many people with dementia take a number of medications for different symptoms. It is important to discuss with the doctor any impact that medications may have on each other.

### **Questions to ask the doctor if drugs are prescribed**

- What are the potential benefits of taking this drug?
- How long before improvement may be noticed?

- What action should be taken if a dose is missed?
- What are the known side effects?
- If there are side effects, should the drug be stopped?
- If the drug is stopped suddenly, what happens?
- What drugs (prescription and over-the counter) might interact with the medication?
- How might this drug affect other medical conditions?
- Are there any changes that should be reported immediately?
- How often will a visit to the doctor who prescribed the drug be needed?
- Is the drug available at a subsidised rate?

This page broadly discusses some of the drug treatments currently being used in the treatment of dementia. This includes new drugs which may have a temporary effect in improving mental functioning and drugs used to treat accompanying symptoms such as depression and anxiety. It also suggests questions that people with dementia, their families and carers should ask their doctor before being prescribed any of these drugs.

## Drugs used to relieve behavioural & psychological symptoms of dementia

**Avoid drugs unless they are really necessary. Before any of the drugs mentioned on this page are prescribed it is essential to ensure that the person with dementia is physically healthy, comfortable and well cared for.**

Whenever possible, the person should be helped to lead an active life, with interesting and stimulating daily activities. Behavioral and psychological symptoms of dementia can often result from unreported pain, other illnesses, drug interactions and environmental factors.

It is important to address these factors in the first instance before resorting to medication. By minimising distress and agitation it is usually possible to avoid the use of drugs altogether. If, after trying non-drug treatments, drugs are considered to be necessary remember:

- All drugs have side-effects that may worsen symptoms. It is important to weigh the benefits against the likelihood of side effects when considering the use of drug treatments.
- Always ask the prescribing doctor why the drug is being prescribed, what the side effects may be and what you should do if they occur.
- Don't assume that a drug that has proved to be useful at one time will continue to be effective. Dementia is a degenerative condition. The chemistry and structure of the brain will change during the course of the illness.
- Many people with dementia take a number of different medications. Certain combinations of drugs may counteract each other or act to make memory and thinking worse. Remind your doctor if other medications are being taken.
- If a drug is prescribed, check with your doctor that there is a clear plan to review the medication and to stop it as soon as possible. There should be defined treatment goals and careful monitoring as well as a clear timeline for drug withdrawal. Usually a trial of stopping drugs is recommended after three months.

## **Taking drugs**

Drugs will be more effective if they are taken exactly as prescribed by the doctor, in the correct dose and monitored regularly for side-effects. If symptoms are difficult to control, the doctor may refer to a specialist for further advice.

- Some drugs need to be taken regularly to have an effect – for example, antidepressants and antipsychotics (sometimes called major tranquillisers or neuroleptics). These drugs are not helpful when given on an 'as needed basis'.

Other drugs, such as hypnotics or anxiety-relieving drugs, may be more effective when taken on an as needed basis. This should only be done after discussion with the doctor.

- Do not expect immediate results. Benefits may take several weeks to appear, particularly with antidepressants and antipsychotics.
- Side-effects may occur early or late in the course of treatment – it is important that you ask the doctor what to expect.
- Side-effects are usually related to the dose given (i.e. higher doses are usually associated with a greater chance of side effects). The doctor will usually 'start low and go slow', gradually increasing the dose until the desired effects are achieved.
- Once treatment has been established it is important that it is reviewed regularly. Take all medications to clinic and hospital appointments.
- Remember that some of the drugs taken to control behavioural symptoms can be dangerous if accidentally taken in large quantities. Make sure medicines are kept safe and secure.

## **Names of drugs**

All drugs have at least two names – a generic name, which identifies the substance, and a proprietary (trade) name, which may vary depending upon the company that manufactured it. Generic names are used in this information sheet – at the end you will find a list of drugs in common use, giving both the generic and proprietary names.

## **Drugs for treating agitation, aggression and psychotic symptoms**

Antipsychotics (also known as neuroleptics or major tranquillisers) are drugs that were originally developed to treat people with schizophrenia. The use of antipsychotics in people with dementia re-

mains controversial and clinical trials are in progress to better determine their effectiveness.

### ***Side-effects***

Side-effects can include excessive sedation, dizziness, unsteadiness and symptoms that resemble those of Parkinson's disease (shakiness, slowness and stiffness of the limbs). Some antipsychotics are particularly dangerous for people with dementia with Lewy bodies or Parkinson's disease, being very likely to cause severe stiffness. Some studies have suggested that sudden death may be a rare complication of giving older antipsychotics to people with dementia with Lewy bodies or Parkinson's disease. If such a person must be prescribed an antipsychotic, it should be done with the utmost care, under close supervision, and should be monitored regularly.

A new generation of antipsychotics called atypical antipsychotics may be less prone to produce troublesome side-effects. However, while there is some indication that atypical antipsychotics such as risperidone and olanzapine can be beneficial, it is important to balance the potential benefit against possible side effects, which may include increased risk of stroke and death.

Whichever drug is used, treatment with antipsychotics should be regularly reviewed and the dose reduced or the drug withdrawn if side effects become unacceptable. Excessive sedation with antipsychotics may reduce symptoms such as restlessness and aggression at the expense of reducing mobility and worsening confusion.

Some studies have suggested that antipsychotic use may be associated with faster cognitive decline in people with dementia, but this finding is controversial and not supported by some other research. What may occur is that mental function is slowed in people with dementia who take antipsychotics so that they appear to have deteriorated, though this deterioration may be reversible if the drug is ceased.

Anticonvulsant drugs, such as sodium valproate and carbamazepine, are sometimes also used to reduce aggression and agitation.

## **Drugs for treating depression**

Symptoms of depression are extremely common in dementia. In the early stages they are usually a reaction to the person's awareness of their diagnosis. In the later stages of the illness, depression may also be the result of reduced chemical transmitter function in the brain. Simple non-drug interventions, such as an activity or exercise programme, can be very helpful. In addition, both types of depression can be treated with antidepressants, but care must be taken to ensure that this is done with the minimum of side-effects.

Antidepressants may be helpful not only in improving persistently low mood but also in controlling the irritability and rapid mood swings that often occur in dementia and following a stroke. Once started, the doctor will usually recommend prescribing antidepressant drugs for a period of at least six months. In order for them to be effective, it is important that they are taken regularly without missing any doses. Improvement in mood typically takes two to three weeks or more to occur, whereas side-effects may appear within a few days of starting treatment.

### ***Side-effects***

Tricyclic antidepressants, such as amitriptyline, imipramine or dothiepin, which used to be widely used to treat depression, are likely to increase confusion in someone with dementia. They might also cause a dry mouth, blurred vision, constipation, difficulty in urination (especially in men) and dizziness on standing, which may lead to falls and injuries. For these reasons their use by all age groups is in decline and they are not recommended for use in people with Alzheimer's disease except when they have found to be the only effective treatment for previous depressions in that individual.

Newer antidepressants are preferable as first line treatments for depression in dementia. Drugs such as fluoxetine, paroxetine, fluvoxamine, sertraline, citalopram and escitalopram (known as the selective serotonin re-uptake inhibitors) do not have the side-effects of tricyclics and are well tolerated by older people.

They can produce headaches and nausea, especially in the first week or two of treatment. There is very limited information about the use of other newer antidepressants such as mianserin, mirtazapine and venlafaxine in people with dementia. Moclobemide is well tolerated by people with dementia and was found to be helpful in one large study of individuals with depression and cognitive impairment.

### **Drugs for treating anxiety**

Anxiety states, accompanied by panic attacks and fearfulness may lead to demands for constant company and reassurance.

Short-lived periods of anxiety, for example in response to a stressful event, may be helped by a group of drugs known as benzodiazepines. Continuous treatment in excess of two to four weeks is not advisable because dependency can occur, making it difficult to stop the medication without withdrawal symptoms.

In addition, benzodiazepines are associated with a range of side-effects that make them particularly problematic for older people and should not be recommended other than for very short term use. Where an individual has used benzodiazepine drugs for a long period prior to the development of dementia withdrawal may be difficult, but the decision about whether to continue their use or to slowly reduce the dose should be addressed with the doctor treating the person with dementia.

## ***Side-effects***

There are many different benzodiazepines, some with a short duration of action, such as lorazepam and oxazepam, and some with longer action, such as chlordiazepoxide and diazepam. All of these drugs may cause excessive sedation, unsteadiness and a tendency to fall, and they may accentuate any confusion and memory deficits that are already present. The long term use of benzodiazepines for neuropsychiatric symptoms is not recommended, but they have a limited role in the short term treatment of agitation in people with dementia (Woodward 2005).

Antipsychotics (see above) are often used for severe or persistent anxiety. If taken for long periods some of these drugs can produce a side-effect called tardive dyskinesia, which is recognised by persistent involuntary chewing movements and facial grimacing. This may be irreversible, but is more likely to disappear if it is recognised early and the medication causing the problem stopped.

## **Drugs for treating sleep disturbance**

Sleep disturbance, and in particular persistent wakefulness and night-time restlessness, can be distressing for the person with dementia and disturbing for carers. Many of the drugs commonly prescribed for people with dementia can cause excessive sedation during the day, leading to an inability to sleep at night. Increased stimulation and activity during the day can reduce the need for sleep-inducing medications (hypnotics) at night. Hypnotics are generally more helpful in getting people off to sleep at bedtime than they are at keeping people asleep throughout the whole of the night. They are usually taken 30 minutes to one hour before going to bed.

## ***Side-effects***

If excessive sedation is given at bedtime, the person may be unable to wake to go to the toilet and incontinence may occur, sometimes for the first time. If the person does wake up during the night

despite sedation, increased confusion and unsteadiness may occur.

Hypnotics are often best used intermittently, rather than regularly, when the carer and person with dementia feel that a good night's sleep is necessary for either or both of them. The use of such drugs should be regularly reviewed by the doctor.

## **Cholinesterase inhibitors and other drugs**

The new generation of cholinesterase inhibitor drugs (donepezil, galantamine and rivastigmine) were originally developed to improve memory and the ability to carry out day-to-day living activities in people with Alzheimer's disease.

Evidence suggests that these drugs also have slight beneficial effects on behavioural symptoms, particularly apathy (lack of drive), mood and confidence, (and in people with dementia with Lewy bodies) delusions and hallucinations. Taking cholinesterase inhibitor drugs may therefore reduce the need for other forms of medication. However, in higher doses these cholinesterase inhibitor drugs may occasionally increase agitation and produce insomnia with nightmares.

Memantine is the most recent antidementia drug to be developed. It works in a different way to the anticholinesterase drugs and is the first drug approved for those in the middle to later stages of Alzheimer's disease.

There is some evidence that memantine has a positive effect on mood, behavior and agitation.

People with dementia may at some point in their illness develop symptoms such as depression, anxiety, agitation, sleep disturbance, aggressive behavior and psychosis (delusions and hallucinations). While it is important to try to understand and address the

underlying reasons for these problems, it may be necessary at times to prescribe medication if the symptoms are distressing, persistent and have not responded to psychological treatments. This page describes the different types of drugs that may be prescribed.

## What kinds of questions should you ask your doctor about any drug being prescribed?

- What are the potential benefits of taking this drug?
- How long before improvement may be noticed?
- What action should be taken if a dose is missed?
- What are the known side-effects?
- If there are side-effects, should the dosage be reduced or should the drug be stopped?
- If the drug is stopped suddenly, what happens?
- What drugs (prescription and over-the-counter) might interact with the medication?
- How might this drug affect other medical conditions?
- Are there any changes that should be reported immediately?
- How often will a visit to the doctor who prescribed the drug be needed?
- Is the drug available at a subsidised rate?

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Das **Netzwerk Demenz** ist ein Projekt des **Landratsamts Ravensburg**.

Das Netzwerk Demenz bietet für organisierte NachbarschaftshelferInnen, Ehrenamtliche und pflegenden Angehörige qualifizierte und praxisnahe Fortbildung, sowie einen erfahrungsbezogenen Austausch an.

Die **akademie südwest** des ZfP Südwürttemberg führt jährlich die rund 45 Veranstaltungen durch. Sie finden in verschiedenen Städten und Orten im ganzen Landkreis Ravensburg statt.

Der Eintritt ist **kostenfrei**.

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