

# UNDERSTANDING DEMENTIA AND WHAT YOU CAN DO ABOUT IT

## PART 1: Dementia - What is it and where do you start?



Photo from Visual Hunt

The word **dementia** refers to more than 100 different diseases of the brain all of which cause problems with day to day functioning. The most common type of dementia is **Alzheimer's disease**. It accounts for 50-70% of cases of dementia worldwide. A person can be unlucky enough to have more than one type of dementia.

The second most common dementia is **vascular dementia**. It accounts for 15-20% of cases and is due to reduced blood flow to the brain. There are several subtypes of vascular dementia each with a different cause and a different pattern of symptoms. The two most common types of vascular dementia are **multi-infarct** dementia and **Binswanger's disease**. Both of these result from from having strokes, high blood pressure or abnormal heart rhythms.

Other relatively common types of dementia include:

1. (Diffuse) Lewy body disease - one of the few dementias that are more common in men than women - some of the symptoms of this dementia resemble Parkinson's disease
2. Frontotemporal - previously referred to as Pick's disease - there are several subtypes of this dementia
3. Alcohol-related
4. HIV- associated
5. Syphilis-associated

450 000 Australians are currently living with dementia and 1.5 million people are caring for someone with dementia. Every day, 250 Australians are diagnosed with dementia - that means 10

people every hour. One more person will receive the diagnosis by the time you have finished reading this.

But there's also **good news**. There are many, many things we can do to keep our brains healthy and reduce our risk of getting dementia. Top of the list of **protective activities** are:

1. 30 minutes of physical exercise a day - walking, dancing, swimming, cycling, vigorous housework, gardening or whatever sport takes your fancy
2. Continue to set meaningful goals and learning new skills
3. Stay socially active
4. Do volunteer work
5. Get 7-9 hours of good quality sleep per night
6. Quit smoking
7. Limit alcohol to less than 2 standard drinks a day for men and one drink per day for women
8. Avoid junk food, fast food and processed food
9. Avoid all soft drinks, whether they contain sugar or artificial sweeteners
10. Keep sugar consumption to less than 6 teaspoons per day - Read my **Sugar Series** by clicking on the words in red.
11. Avoid eating seed oils (often misnamed 'vegetable oils') such as cottonseed, safflower, sunflower, rice bran oil, corn oil, soybean oil and canola (rapeseed) oil
12. Learn to let things go and manage stress effectively - meditation actually changes the structure of the brain in a very positive way
13. Spend time in nature and sunshine - at least 10 minutes a day

### **Is dementia hereditary?**

Most cases of dementia are not hereditary.

One gene that has been linked to Alzheimer's disease is called Apolipoprotein E4 or ApoE4 for short. If you don't have this gene variant, the general risk of Alzheimer's disease is about 9%.

If you inherit this gene from one parent your risk goes up to 30% and if you inherit it from both parents your risk is over 50%. However studies in the US have shown that even people who have two copies of the gene can avoid getting dementia by implementing a brain-boosting program.

Frontotemporal dementia is hereditary in 10-15% of cases and it is then known as Familial FTD caused by a genetic mutation.

### **At what age does dementia typically strike?**

Currently 1 in 100 people aged 60-64 years have dementia. The risk increases with age and doubles every 5 years after you reach 60. In other words:

- I) 1 in 50 people aged 65-69 have dementia
- II) 1 in 25 people aged 70-74 have dementia
- III) 1 in 12 people aged 75-79 have dementia
- IV) 1 in 6 people aged 80-84 have dementia
- V) 1 in 4 people over age 85 have dementia

Note that this means the majority (75%) of people over age 85 do NOT have dementia.

Certain types of dementia known as **younger onset** or **early onset dementia** can occur in 30 to 50 year olds but they are much less common.

## How is dementia diagnosed?

The most common question I am asked about dementia is: 'Where do I start? I am worried that my parent/spouse/relative might be developing the disease but how do I get an accurate diagnosis?' Here is an overview of the process of diagnosing dementia. I emphasise the word 'process' because it isn't a disease that has a definitive test that reveals yes or no. There is a lot of research into developing such a test but as yet there is nothing available.

The person's GP (family doctor) is your first port of call and the first step is to exclude conditions that mimic dementia but are not dementia. Examples include thyroid disease, infections (especially of the urinary tract), vitamin and mineral deficiencies such as B1, B2, B12, folate or zinc; side effects of medications, stroke, severe stress or anxiety, depression, hydrocephalus (build up of excess fluid in the brain) or a brain tumour. It helps if the doctor has known the person for a long time because they may notice changes in brain function before they even start to do any formal tests.

It's a good idea to write up a list of symptoms and behaviours you've observed in your loved one that are causing you concern. Take the list to the doctor and ask what each symptom might mean. If you're worried about upsetting the person, you may like to have a word with the doctor on your own before you bring the person into the room. When you book the appointment explain to the receptionist that you'd like 5 minutes alone with the doctor first.

The doctor will then perform a physical examination and a series of mental tests before ordering blood tests and one or all of the following (usually not all at once but over a number of visits):

- urine test
- questionnaire to rule out a mood disorder
- brain imaging eg CT scan or MRI
- referral to a specialist geriatrician, neurologist or psychiatrist

When enough pieces of the puzzle have been assembled, a provisional diagnosis will be made and treatment options discussed. However **the most important thing is to embark on the 10 protective activities listed above**. These will go a long way to halting the progression of the disease.

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## **PART 2: Dementia - But there's nothing wrong with me!**



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### **Are there any symptoms that set off alarm bells for oncoming dementia?**

To say that someone has dementia is like saying that someone has cancer without specifying the type. The symptoms vary widely depending on the part of the brain that is affected. Even with the one person, symptoms can fluctuate from day to day and even from hour to hour.

Signs to look out for include - but are not restricted to:

- the person starts forgetting how to do things they used to be able to do
- they forget how to get somewhere they've been many times before
- loss of motivation to do things
- becoming withdrawn and not wanting to socialise
- getting confused and disoriented
- personality changes
- short term memory loss
- difficulty focusing
- problems communicating
- not being able to understand simple instructions

## **What causes dementia?**

The short answer is we don't know. Inflammation, abnormal protein accumulation, death of brain cells, compromised blood flow to the brain - these are physical changes that scientists have observed in the brains of people with dementia but we're not sure why they happen. There are several theories and medical research has been testing them for decades but there are no clear answers to date. A minority of dementias are hereditary but the vast majority are not. Certain genes may increase or decrease your risk of dementia but only to a small degree.

The following lifestyle factors appear to increase your risk of developing dementia more than the genes you carry. However I emphasise that these things are risk factors, not causes.

- Having had a serious head injury - war veterans, boxers and football players are all at increased risk if they've had a lot of head trauma. Cyclists please wear helmets!
- Type 2 diabetes
- Stroke, heart disease and high blood pressure. What's good for the heart is good for the brain.
- Smoking can increase risk of dementia by 70%.
- Excessive alcohol consumption especially regular binge drinking.
- Chronic major depression, severe stress or poor sleep throughout life - this means more than a one off bout of depression, stress or insomnia.
- Sleep apnoea
- Social isolation

## **What if my relative refuses to go to the doctor because they think they're fine?**

People are often resistant to going to the doctor for several reasons. They may have no insight that anything is wrong because the disease robs them of insight. Sometimes dementia causes paranoia so the person is suspicious of your motives for wanting to take them to the doctor. Other times the person is aware that something is amiss but they're afraid of having their fears confirmed.

My father passed through all the above stages and never wanted to see a doctor. Yes, I'm a doctor but I wanted to get a second unemotional opinion. So I'd tell him it was time we both had a check up. 'Everyone needs to see the doctor on a regular basis to get their body serviced in the same way you need to get your car serviced.' I remained upbeat and cheerful so that he saw it as just another thing to tick off our to-do list. If I were to have said 'I'm worried about you,' he would never have agreed to come to the doctor. If your relative is on medication for any other condition, you might suggest that the doctor needs to review the dose. Maybe a new/better medication has become available? It's tricky and challenging because I don't want to encourage you to be deceptive but it's important to get a diagnosis as early as possible. Many conditions like thyroid disease can be treated with medication and the person's symptoms will disappear. A brain tumour can be removed if it's small enough. And if it turns out to be dementia, medication may slow down the progression of the disease if it is caught in the early stages.

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## PART 3: Dementia - What happens after diagnosis?



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If you've been given a diagnosis of dementia in Australia or have found yourself in the caring role, I suggest you contact two organisations:

1. Alzheimer's Australia - [fightdementia.org.au](http://fightdementia.org.au) or 1800 100 500. This is where you will find all the information you need on all of the different dementias. There are over 100 Fact Sheets that you can download or ask to have posted to you. The Fact Sheets provide information about every aspect of dementia including advice for carers about how to manage specific symptoms and behaviours. Alzheimer's Australia also offer courses for carers and health professionals, run support groups for carers, and organise activities for those with dementia. They have trained counsellors with personal experience of looking after someone with dementia and they are available on the phone from 9am to 5pm every weekday. The counsellors are there to answer any questions or to lend a listening ear. They are wonderful and helped me enormously, even if it was just to say, 'I understand what you're going through.'
2. My Aged Care - [myagedcare.gov.au](http://myagedcare.gov.au) or 1800 200 422. This is an Australian Government website and phone line that helps you find out what services are available to assist you in maintaining the best quality of life, either in your own home or in an aged care facility. The service is not only for people with dementia but anyone who has a physical or mental health issue that interferes with their ability to live independently. In order to access any services, the person will need to undergo a friendly assessment. You can go online and arrange for an assessment yourself but the process is complicated to say the least. I recommend you ask your GP to make the referral for you. Most GPs will do this without prompting but in case they don't, ask them to organise an ACAT (Aged Care Assessment Team) to visit you at home. I believe it's critically important to have a support person present while the assessment is carried out because a person with dementia may struggle to comprehend what is going on and may not remember what happened afterwards.

ACAT will speak with you about what you need in order to live well and stay safe. With your permission, they will see if you might benefit from having rails installed, trip hazards removed or other home modifications that will make daily life easier. They will determine whether you need someone to help you clean, cook, shop, shower, remind you to take medications or provide social stimulation. They will also inform you of local services that provide meals, social activities or transport. The government will subsidise the cost of your required services so that they remain within your means. If you wish to move into a residential care facility, ACAT can also help you find one that is best suited to you.

Another brilliant Australian initiative is the National Companion Card Scheme. This is not only for people with dementia but anyone who has a permanent disability and needs a carer or companion to accompany them when attending particular events, activities or venues. A Companion Card means that your companion can attend the event free of charge because without them you wouldn't be able to go. Eligible events include movies, opera, ballet, musicals, theatre, parks and much more. Public transport services also accept the Companion Card so your companion doesn't have to pay when travelling with you on buses, trains or ferries. Whenever you want to go somewhere that charges an entry fee or requires you to purchase a ticket, ask if they accept the Companion Card. Visit [companioncard.gov.au](http://companioncard.gov.au) to download an application form. Your doctor will need to complete one section of the form.

It can be exhausting setting everything up but it's worth the initial effort. Don't be afraid to ring a friend, an Alzheimer's counsellor or Lifeline 13 11 14 (24 hours, 7 days a week). In my experience, the biggest barrier to receiving help is not asking for it.

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## PART 4: Dementia - Can't I just pop a pill?



Photo from Visual Hunt

There are currently two types of medications available for dementia. More are undergoing clinical trials.

The first are known as cholinesterase inhibitors ( eg Rivastigmine or Exelon) and they're used to treat people with mild to moderate Alzheimer's or Lewy Body Dementia. They work by reducing the breakdown of a chemical called acetyl choline which is important for learning and memory. In people with Alzheimer's disease, the brain cells that produce acetyl choline start dying off so there isn't enough of it in their brain. The drug increases levels of acetyl choline and it can slow down the progression of the disease in some people but it won't reverse the damage that has already been done. Its effect seems to wear off after 3-5 years and it can take 3 months to start working. It comes in the form of capsules or a patch that you stick on your skin.

The second group of drugs are called N-methyl-D-aspartate (NMDA) receptor antagonists (eg Memantine or Ebixa) and they're used in people with moderate to severe Alzheimer's disease. These drugs block the action of a chemical called glutamate. People with Alzheimer's have too much glutamate. This causes excessive amounts of calcium to enter their brain cells and damage them. The drugs help some people but only for a few years.

A person can take both drugs at the same time because the two medications work in completely different ways.

Recently there's been optimism around a potential drug for a specific type of dementia called frontotemporal dementia or FTD. About 11 500 Australians have FTD and it tends to strike at a much younger age than Alzheimer's. Symptoms can begin as early as 45 years (though usually the person is in their 50s or 60s) and 10-15% of cases are due to a gene mutation that can be passed



on from one generation to the next. The University of Melbourne is conducting a trial in which patients are given sodium selenate tablets for 12 months and tested for improvements in brain function.

If you've picked up on the word selenate - a form of selenium - and know that Brazil nuts are a rich source of selenium, it doesn't mean licence to start hoeing through packets of Brazil nuts because getting the dose right is critical. Three Brazil nuts a day is plenty. Too much selenium can be toxic.

As for supplements that may be helpful in people with dementia, I gave my father vitamin D, omega-3 and curcumin (the active ingredient in turmeric). Research suggests they may improve cognition and there appears to be no harm in taking them.

### **Are there any particular brain-boosting foods?**

Top of my recommendations would be to eat plenty of fresh vegetables every day, especially your greens and purples. Purple fruits and vegetables - like eggplant, beetroot, purple sweet potato, blueberries (which are actually purple), cabbage, black rice, purple grapes - contain an anti-oxidant flavonoid called anthocyanin. Apart from having strong anti-inflammatory properties (which is good for both your heart and your brain) anthocyanin-rich foods have been observed to improve cognition and memory in adults and children.

In general, the brighter or darker the colour of fruits and vegetables the higher their anti-oxidant content. Purple sweet potatoes for instance can have 4 times the anti-oxidant concentration of other varieties of potatoes.

However all vegetables and fruits confer health benefits - so get colourful! Each different colour tends to represent a different nutrient - and by fruit and colourful I don't mean fruit loops!

Other brain-boosting foods include:

- Omega-3 fatty acids found in cold water deep sea fish like wild salmon, mackerel and sardines; chia seeds, linseeds, walnuts, soy beans and dark leafy greens
- Vitamin D-rich foods such as mushrooms, fatty fish, egg yolks, cheese and beef liver
- Turmeric and coconut oil are both being studied and scientists are cautiously optimistic about these two foods playing a protective role.

**Vitamin B12** deficiency can also lead to dementia. B12 is only found in animal products like fish (especially shellfish and crab), dairy, liver, meat and poultry so if you're vegan, take supplements or injections or find foods that are fortified with B12 - for instance, tofu often has B12 added to it. Your liver can store B12 and it may take 5 years or so to run out so it can creep up on a person very slowly.

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## PART 5: It's never too late (or too early) to start boosting your brain



Photo from Pixabay

Contrary to what I was taught in medical school several decades ago, we continue to grow new brain cells throughout our lives. In fact **we make about 5000 new brain cells every day**.

Our brains are also constantly changing (or 'rewiring') in response to everything we do, think, feel and believe. The term for this is **neuroplasticity**.

This gives us enormous personal power and allows us to adapt to an ever-changing world. It also enables us to sharpen our thinking and improve the functioning of our brain at any age or stage of life. We are not passive victims of our genes, our habits or our environment.

By rewiring your brain you can think better, learn better, create better, relate better and achieve far more than you ever thought possible. Neuroplasticity opens avenues for change we never previously knew existed. Your brain runs the show of your life. Use it or lose it. Train it and regain it.

Research has uncovered three of the most powerful determinants of a long healthy life:

1. having a positive attitude to ageing
2. continuing to set meaningful goals
3. looking forward to what each new day will bring with excitement and enthusiasm.

Our attitude and mindset have a physical effect on our brain and body. They also help protect us from developing dementia.

One final point is that your health is not just about you. A study by Harvard psychologist Ellen Langer discovered another important factor that contributed healthy ageing: having sprightly grandparents.

When you were a child, if you had contact with older people who were active and capable, you are more likely to age well. Therefore your health and vitality influence the health of your grandchildren - not because they inherit your genes but because of the role model you present to them - and to any young people with whom you are in contact.

Your health, happiness and engagement with life are not just about *your* quality of life but the quality of life of the people you most care about. That's how important you are.

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To learn more about neuroplasticity and how you can boost your brain, read ***In Search of My Father – Dementia is no match for a daughter's determination***

The book is a warm and humorous account of how we can build a better brain at any age or stage of life.

