



Look after your brain

A guide to dementia for Aboriginal people



**Family &
Community Services**
Ageing, Disability & Home Care



In compiling this dementia information resource, Ageing, Disability and Home Care undertook consultations and field testing with a range of agencies including:

- Aboriginal Access and Assessment Team and Ngangana Home Care Branch, Ageing, Disability and Home Care
- Aboriginal Health and Medical Research Council of NSW
- Booroongen Djugun Aged Care Facility
- Gilgai Aboriginal Centre
- Dementia Education and Carer Support, New England Division of General Practice
- Katungal Aboriginal Corporation
- Koori Growing Old Well Study, Neuroscience Research Australia
- NSW Ministry of Health
- South Eastern Sydney Local Health District
- Rose Mumbler Residential Aged Care facility
- School of Psychiatry, University of New South Wales
- Southern NSW Local Health District
- Western Australian Centre for Health and Ageing
- Wyanga Aboriginal Community Aged Care Programme Inc.

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Introduction

Respecting and caring for the Elders and older people in our community has always been an important part of our culture.

If you are reading this booklet it probably means the issue of dementia is touching your life, or the life of a person in your immediate or extended family. That person is probably an older person or Elder.

This booklet guides you through the many questions you may have, so you can confront the issue of dementia in your life with knowledge and dignity.

It is important that you do not rely on this booklet as medical advice (although it has been developed in close consultation with medical advisors). Like any illness or sickness, dementia needs to be treated under the close guidance of a health professional.

Respecting and caring for the Elders and older people in our community has always been an important part of our culture.



What is dementia?

Dementia is a disease of the brain that makes it difficult for you to remember, think and plan.

You get sicker over time. As dementia gets worse you may find it hard to keep doing the things you used to do each day.

There are many types of dementia.



The most common types of dementia

Alzheimer's disease	Vascular dementia	Parkinson's related dementia	Dementia with Lewy Bodies	Alcohol related dementia	Frontotemporal dementia
This is when some of the nerve cells in the brain stop working and lose connections with other cells. These nerve cells eventually die.	This is a type of dementia associated with problems of circulation of blood to the brain.	This type of dementia can occur in the later stages of Parkinson's disease. Parkinson's occurs when certain nerve cells in a part of the brain die or become impaired.	This is another form of dementia that causes loss of cells in the brain.	This type of dementia is linked to severe drinking of alcohol.	This can cause dementia in younger adults. Damage to the brain cells begins in the frontal and/or temporal lobes of the brain.

What are the signs of dementia?

All dementias can make it hard for you to remember, think and plan.

If you are very sick with dementia, you might forget the people in your family, or important things about yourself. You can also have physical problems, like not being able to move properly.

Not all older people get dementia, but it's important if you, or someone you love, show any of the signs of dementia, to get it checked out. Across NSW there is a network of Aboriginal Medical Services and Aboriginal Health Workers.

A doctor can help tell you whether the signs are just a normal part of growing old, or if there is something wrong. It is better if you seek treatment early. It will help you manage things better.

The first sign of dementia can be memory loss. You might forget things like someone's name, places you've been, who visited you yesterday or what you have to do tomorrow.

When you have dementia, you may forget things: your stories, what someone told you, where you left your keys or people's names. You might remember other things from when you were young.

Forgetting someone's name, stories, places you've been, who you visited yesterday, or growing a lot may be signs of dementia.

When you have dementia, you might:

- go for a walk and forget where you are going or where you've been
- feel worried
- not want to go out, or visit your friends and family, or do the things you used to do
- find it hard to solve problems
- feel something isn't quite right with your brain
- get cranky and say and do things you wouldn't have before
- have trouble doing the shopping properly
- have trouble paying bills or handling money properly
- have trouble looking after yourself and eating a good diet regularly, or you might notice you are losing weight
- forget to take your medications
- not know these things are happening but people around you might notice and say something to you or to others.



What causes dementia?

Dementia can happen to anybody, but is more common in older people. Not everyone who gets old gets dementia, but older people are more likely to get dementia than younger people.

Alzheimer's disease can cause dementia. A major stroke or mini strokes in the brain are also causes of dementia.

When you drink too much alcohol over a long time, your chance of getting dementia will increase.

Dementia can happen to anybody. It's more common in older people, but can sometimes happen to younger people.

Risk factors

A 'risk factor' is something like your habits, personal history or your family's health history that increases your chance of getting a disease.

The main risk factor for dementia is getting older. There are also vascular risk factors, such as high blood pressure, high cholesterol and diabetes.

Head injuries are also linked to dementia. You can get a head injury by knocking your head in a fall or in a car crash.

Bad habits

Bad habits can increase your risk of dementia. Smoking, being overweight and not exercising enough increases vascular risk factors, so looking after your health can help your brain stay healthy.

Eating healthy food can improve your health, help you avoid problems with your heart and blood circulation and reduce your risk of getting vascular related dementia.

If you are a very heavy drinker of alcohol, your chance of getting dementia can rise.

It is important to know the risk factors and deal with them while you are still young enough to do something about them.



How to reduce the chances of getting dementia

One of the most common types of dementia in Aboriginal people is vascular dementia. This is a dementia associated with bad blood flow to the brain, so anything that will improve blood flow is important. There are ways to reduce your risk of getting this type of dementia.

Taking the medication your doctor has prescribed is important and cutting down or stopping smoking can reduce the risk of stroke. Strokes are when the blood flow to the brain stops because of a block or rupture of a blood vessel in the brain.

If you manage any underlying vascular illnesses (conditions that affect your arteries, blood vessels and the blood flow throughout the body), you can lessen your chances of getting dementia and if you already have dementia, you can slow it down.

Some vascular illnesses include strokes, high blood pressure and heart problems. People with diabetes have a greater risk of developing problems with their body's blood flow, which can lead to heart attacks and strokes. Certain types of medication can prevent strokes, and you can manage diabetes and high blood pressure with the medications the doctor gives you.

A good way to reduce vascular risk factors is regular walking. Half an hour of walking, three times a week is a healthy and inexpensive form of exercise.

If you stop drinking alcohol and you have alcohol related dementia, the progression of dementia may stop.

Everything you can do to keep your heart healthy is also good for the brain and will help lessen your chance of getting dementia.

Reduce your chance of getting dementia

- Get regular health checks.
- If you have high blood pressure, get it checked and if you are on tablets for it, take the tablets the doctor told you to take.
- Make sure you keep your diabetes under control.
- Mind your habits – smoking and severe drinking are linked to dementia.
- Get active, exercise more. Walk regularly.
- If you are overweight, losing weight can help.
- Go out with friends and family.
- Keep your brain active. Learn something new and keep learning.
- Keep talking and communicate with your family and share your stories.
- Eat good foods – fresh fruit, vegetables and lean meat are all good sources of nutrition.



One of the most common types of dementia in Aboriginal people is vascular dementia.

Caring for someone living with dementia

When someone has dementia, it's still possible to care for them in their home. There is help available for you so you aren't left to care for them by yourself.

There are medical, home and personal services and respite services to help you provide care at home.



It's also important to know how to care for someone who has dementia because they have special needs.

When the person repeats a question or tells their stories over and over, be patient. The next time they ask the question or tell a story, it will be the first time for them because they will have forgotten the last time they asked you a question or told a story.

Keep the person happy and help them feel good about themselves. Make sure they are not distressed and don't focus on the dementia.

The most important thing to remember is that it's not their fault they have dementia and no one should be *shame* because of it.





Dementia is no one's fault so:

- Keep the person active and enjoying life.
- Make sure they eat healthy, regular foods.
- Make sure they take their tablets.
- Accept the person has dementia and that it will get worse over time.
- Accept they will forget things – even your name.

A person with dementia may sometimes get muddled and tell stories that aren't exactly how things really happened. Try not to argue with them unless it's really important. Ask yourself if it really matters when they say something that may not be true.

Keep them safe in the home and in the community. People with dementia can go for walks and forget where they are, so let them keep to their routine wherever possible and make sure they're safe. There are bracelets that you can get to identify the person when they're lost.

If you are concerned about someone's ability to keep track of their money or to make decisions about their own health and care, address this problem early. The NSW Guardianship Tribunal can help. You can call them on 1800 463 928.

**Dementia is no one's fault
so don't be *shame*.**

Make sure you plan family gatherings or visits so that everybody doesn't arrive at the same time. Older people may love the young people deeply but their voices and constant questions may cause anxiety and distress for someone with dementia.

When engaged in conversation ensure that everyone doesn't talk at once. Slow down the speed of the conversations, and turn off televisions and radios in the background that cause distraction and interference.

Make sure they take their medication. The chemist can package up all the pills by time and date (called Webster packs), so it makes it easier for them to take their pills or for you to give them out. Webster packs are critical to effective treatment.



There may be times throughout the dementia when the person wanders away from your home. The important thing to remember is to make your home as safe as you can.

Delirium

Sometimes a person may suddenly become more confused. This may mean they are sick inside and have delirium.

Delirium affects a person's mental function. The most common causes are infections, or a new medication or drug. It can occur in someone who has dementia and also someone who hasn't got dementia and it is more common the older the person gets.

It's important that you seek medical help quickly for them so that the cause of the delirium can be treated.



It's important to care for yourself as well.

- Join a carers support group. Many people find it very helpful to talk to others who are going through the same things.
- Find out what dementia is, what can happen as the dementia gets worse and how you can reduce the impact of dementia.
- Know the risks to the person's safety – for example, they may put something on the stove and go away and leave it.
- Find someone to talk to. Caring can be hard work, especially when you've got other family to look after.
- Use respite as often as you can. Respite is when you place the person into short-term care, so you can have a break from caring.
- Accept that as the dementia enters its last stages you may need to place them in long-term care so that medical help is close by.
- Accept they need you and you will be no good to anyone if your health fails due to the pressures of caring.

**Don't be *shame* to ask for help.
Help is available. You don't have
to care for them by yourself.**



Lynnie and Phylis' story

The world changed for Lynnie when she got a phone call that her mum Phylis had fallen down the stairs at the local shops.

As well as breaking her arm, glasses and spraining her ankle, Phylis had trouble answering a lot of questions when the ambulance arrived. The ambulance officer had known Lynnie since she was a child growing up in country NSW. The ambulance officer phoned Lynnie who was living in Sydney at the time (a four-hour drive away) to tell her there was something not quite right with her mum. Her mum was having trouble remembering what was going on around her. Lynnie rushed home immediately.

Phylis was a strong, proud, independent Aboriginal woman in her early seventies and the backbone of all her four children's lives. She had worked hard all her life.

When Lynnie saw her mum in the hospital, her mum was confused, scared and very anxious. There were many questions running through Lynnie's mind.

Is this permanent?

Can it be fixed?

How bad is it?

Is there treatment?

Looking around at home while her mum was in hospital, Lynnie realised that Phylis hadn't been caring for herself like she used to. Her normal, in-control mum, needed help.

When Phylis got out of hospital, Lynnie took her mum to the Aboriginal Medical Service. Lynnie told the doctor that her mum was having trouble with her memory and stressed that she had gone from being a little bit forgetful to a serious problem.


They were referred to a centre that specialised in dementia and an assessment process took place over about eight weeks.

Phylis was diagnosed with early-stage memory loss, which was most likely brought about by vascular deterioration and anxiety. It was confirmed that Phylis' condition was dementia.

Lynn timer and her three brothers took the time to research dementia, and what their options were as a family.

It took 12 weeks to get Phylis back to health after her fall. During that time, all four children were rostered to monitor her doctor's visits, her day-to-day health and home care. They had to focus on their mum and make sure that she was getting the best assistance possible. Phylis didn't think she needed help at all and was very resistant to even talking about her memory. Phylis just wanted everything to go back to the way it was before the fall.





“Finding out what the story is with dementia is really difficult,” Lennie told her good friend one night. “There’s some info on the internet, and a few friends offered confidential advice as well, but what do we actually do? What happens when we leave mum? Mum needs help but doesn’t see it. Everything is going around in one big circle,” Lennie said.

Meanwhile, there were a few basic steps Phylis’ children took. Number one was that their mum needed to feel loved, safe and protected and Phylis needed to feel confident that any admission of her having a problem would not lead to her being put in a home.

As a result of her memory loss, love, respect and support were needed daily. The family realised they could not close ranks around their mum. They needed to face Phylis’ dementia as they would any other illness. They also realised the dementia was going to get worse, much worse, month by month.

After a family meeting, it was decided that Lennie would move closer to her mum to ‘keep an eye on things’ and her brothers would all contribute as much as they could. The family read that caring for a person with dementia can really take its toll, so sharing the responsibility is critical. Phylis was very lucky that her cousin Daphne was also around to lend a hand, and would drop in every day with the local paper, to say hello.

Today, Phylis is still living in her own home and the family have got Home Care and a more structured schedule of family visits. Phylis understands what is going on. She has started writing everything down in a diary that Lennie and her brothers update daily.

Phylis is happy and still in control of her life. The family realised if they do a bit for Phylis, then Phylis can do a lot more for herself and stay in her own home in the medium and even longer term.

Lynn timer is likewise very happy. She and Phylis sit down and talk for hours. They talk about their family history, who is related to who, and how everyone is related. That has been an unexpected upside for Lynn timer.

“A diagnosis of dementia isn’t as scary, once everyone knows what is going on and understands the illness,” Lynn timer told her good friend some months after Phylis’ diagnosis.

“The whole family should make it their business to care for our older people. That’s the way it has always been.”

A diagnosis of dementia isn’t so scary, once everyone knows what is going on and understands the illness.



Seeking help – the first step

If you're worried about dementia, tell someone. You can go to your local doctor and say: "I'm forgetting things and something doesn't feel right."

If you are worried about someone who is forgetting things you might want to go with them to the doctor or Aboriginal Medical Service and tell them you are worried and why.

If you have Home and Community Care or Aboriginal Home Care services come to your house to help you with housekeeping and personal care, you can tell your care worker.

When you talk to your doctor, he will ask you a few questions and he may send you to a specialist dementia doctor for an assessment. Some things that seem like dementia, such as depression, are treatable so it is very important to have an assessment done.

Having this assessment done means that they will know whether or not you have dementia and what stage it's at.

If someone you love has been diagnosed with dementia, you might wonder how to tell them they have dementia. At the time of diagnosis the doctor or other health professional can tell the person they have dementia in a way that they can best understand. They will also involve families and carers.

If the person asks about it later on, you need to respond in a way that they can best understand. Importantly you need to make sure they feel loved and supported and accepted.

In some cases you might not need to tell the person they have dementia. It all depends on your situation. You should talk to your doctor if you're unsure about what to do if the person asks about dementia. As a family, keep the lines of communication open.



Where to go for more information or help

You should talk with your family and friends – the people you can trust. You can also talk to your:

- Aboriginal Medical Service
- Aboriginal Health Worker
- Doctor
- hospital
- chemist where you get your pills, if you are taking any
- Aboriginal Home Care service.

Aboriginal Home Care

Provides domestic and personal care to people to maintain their independence at home and in the community. For more information about Aboriginal Home Care Service eligibility and referrals, phone:

Aboriginal Access and Assessment Team
Tel **1300 797 606**

Aboriginal Medical Service (AMS)

Look up the address of your local AMS on the Aboriginal Health and Medical Research Council of NSW website **www.ahmrc.org.au** or Tel **02 9212 4777** (business hours).

Aged Care Assessment Team

Provides an assessment that helps work out which services you may be eligible for and how well you're able to cope with daily living activities and your own care.

Tel **1800 500 853**
www.agedcareaustralia.gov.au

Alzheimer's Australia

Alzheimer's Australia has a National Dementia Hotline and you can ring for information, education, counselling and support. The service is available to someone living with dementia, or anyone caring for someone living with dementia. They also offer a Dementia Advisory Service where you can go to get support and counselling and a Living with Memory Loss Program.

If you are living with early stage dementia or are a family carer for someone with dementia, you are welcome to join the early intervention program.

You will get information and support through sharing your experiences with a small group of others in a similar situation.

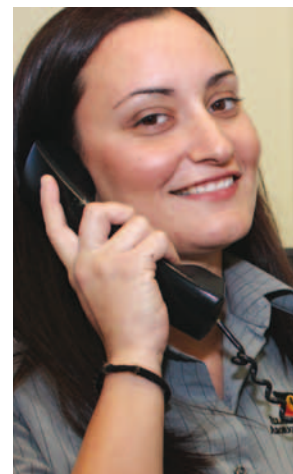
Alzheimer's Australia has free events and workshops to help carers understand dementia and care for a person living with dementia.

Tel **1800 100 500**
www.alzheimers.org.au

Centrelink

You may be able to get help with daily care or when a carer is unable to support themselves through full participation in the workforce.

Tel **132 717**
www.centrelink.gov.au



Where to go for more information or help

Commonwealth Respite and Carelink Centre

The service provides free and confidential information on community aged care, disability and other support services available locally, interstate or anywhere within Australia.

Tel **1800 052 222**
(business hours)
Emergency respite support outside standard hours.
Tel **1800 052 222**

Dementia Behaviour Management Advisory Services

Dementia Behaviour Management Advisory Services, funded by the Australian Government, are available to support people caring for someone with dementia who is demonstrating behavioural and psychological symptoms of dementia which are impacting on their care.

Tel **1800 699 799**

Specialist Mental Health Services for Older People

This community team provides specialised assessment and consultation, treatment and time-limited case management for older people with mental health and social and emotional wellbeing issues, including depression, anxiety and severe behavioural disturbances due to dementia. Contact your local community health or mental health team for more information.

The National Respite for Carers Program (NRCP)

NRCP allows carers of older people needing palliative care and people with a disability to have a break to look after their own health and wellbeing, with the comfort of knowing that their dependants are well looked after.

Information about respite services in your local area can be obtained by phoning Commonwealth Respite and Carelink Centre.

Tel 1800 052 222

(business hours)

Emergency respite support outside standard business hours. **Tel 1800 052 222**

The NSW Guardianship Tribunal

Its primary role is to make guardianship and financial management orders for people aged 16 years and over with decision-making disabilities, such as dementia.

Tel 1800 463 928

Your local hospital

You can also go to your local hospital for advice.

Summary

What types of dementia are there?

Dementia can happen to anybody, but is more common in older people. Some common types of dementia are:

- Alzheimer's disease
- vascular related dementia
- alcohol related dementia
- frontotemporal dementia.

What are the signs of dementia?

Forgetting someone's name, your stories or places you've been, who you visited yesterday, or *growing* a lot may be signs of dementia.


What are the risk factors for dementia?

Your risk of dementia rises as you get older. Other factors that might increase your risk of getting dementia include:

- high blood pressure
- high cholesterol
- diabetes
- smoking
- heavy drinking
- being overweight and not enough exercise
- head injuries.

How can I reduce my risk of dementia?

- Get regular health checks.
- Get your blood pressure and diabetes checked often.
- Try and cut down or stop smoking and drinking.
- Get active and exercise more.
- Go out with friends and family.
- Keep your brain active.
Keep learning.
- Eat good foods like fresh fruit, vegetables and lean meats.



For more information, please call the
Aboriginal Access and Assessment Team
on 1300 797 606 for a confidential discussion.

**Ageing, Disability and Home Care
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