Aim and learning outcomes
The aim of this section is for participants to learn about dementia, types of dementia, and its impact on the person, their family and community.
Participants will be able to:
• Explain what dementia is.
• List the most common types of dementia.
• Explain the impact of dementia on the person, their family and the community.
• Identify and/or provide support and services in their community.

Associated materials
• Flip Chart: Your Brain and Dementia.
• Brochure: Your Brain and Dementia.
• PowerPoint presentation: 10 Dementia 2007.
• PowerPoint presentation: Meet Dementia: The Bad Hawk that Steals.
• PowerPoint presentation: 10.6 Impact 2007.
• Video: A Tale of Dementia: Lily’s Story (not included in kit).
• 10.2 Exercise: Brain Puzzle (preparation required).
• 10.3 Exercise: Imagine if you had dementia ...
• 10.5 Exercise: Emotional Needs
• 10.6 Exercise: Resources
• 10.1 Case Study: Wellbeing: a) Percy & B) Lucy.
• 10.2 Case Study: Rachael.
• 10.1 Handout: Types of Dementia.
• 10.2 Handout: Factors that Influence a Person who has Dementia.
• 10.3 Handout: Assistance may be required.
• 10.4 Handout: Emotional Needs.
• 10.5 Handout: Ten Key Points for Maintaining a Person Centred Approach.
• 10.6 Handout: State and Territory Contacts.

10.1 Exercise: What words do we use?

Purpose
To explore terms commonly used in the participants’ communities to refer to dementia.

What is required
Ask participants what thoughts come to mind when they hear the word dementia? What labels and descriptions pop into their heads and what beliefs do they think most people in their community hold about dementia?

Write on the whiteboard a list of words that are used to talk about or describe dementia in their community. Invite people to name English words and Aboriginal Language words that may be commonly used.

Prior to the training, facilitators should find out words used by local Aboriginal communities that may be relevant here, and seek permission to name them in the group.

Discussion points

Facilitator note
It is important to recognise the impact of language use and how it can lead to negative perceptions and stigma.

Without judgement, consider with the group what the terms are and how they might be used, for example, as descriptive terms, whether they show a lack of understanding of dementia, are a way of dealing with a sense of hopelessness about dementia, or have a symbolic meaning.

Facilitator note:
Keep the list for future reference. It may be helpful to use or relate to some of these terms as you work through the session(s).

10.1 Dementia is not ...
Dementia is not normal ageing, nor is it temporary confusion, or mental illness. Sometimes other illnesses may look like dementia, but these can be treated and the person will often get better.
Examples of other conditions are:

- acute confusion or delirium; that is confusion due to another cause such as fever, infection or dehydration
- depression
- side effects of some medications
- vitamin deficiencies.

It is, therefore, important for a person showing any changes in memory, thinking and behaviour to be assessed by a doctor or health worker to find out the cause and decide what can be done.

10.2 What is dementia?

A person who has dementia will forget things, repeat things, get lost or confused, and not be able to do the things they have always done – they will need help from others. But what is dementia, and what causes it?

In the world of medical science, dementia is a general term used to describe a physical condition or illness that results in significant loss of abilities such as memory, problem solving, planning and thinking, that is severe enough to interfere with what a person is able to do and how they live their everyday life. It is caused by many different diseases, or trauma that affects the brain. It is an acquired disorder that generally progresses over time rather than one that is present at birth.

Once the brain has dementia-related damage it will not get better. In most cases, the damage to the brain will continue to get worse until the brain is no longer able to send messages that drive the body. Eventually the there will be so much damage that death will occur. (It is important to note the difference between chronic and progressive forms of dementia. While deterioration continues with progressive forms, chronic forms will remain static, for example, dementia related to alcohol consumption will not progress if alcohol consumption ceases.)

The World Health Organisation’s International Classification of Diseases (10th Revision) describes dementia as ... a syndrome due to disease of the brain, usually of a chronic or progressive nature in which there is disturbance of multiple cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement.

Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded by, deterioration in emotional control, social behaviour or motivation.

This syndrome occurs in Alzheimer’s disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.

10.2 Exercise: Brain Puzzle

Purpose:
In this exercise we are looking for a connection with people who have dementia: how they feel, think, and respond when they know “something is missing” or their brain is sick and not functioning as it should. However, diverse and rich learning opportunities will be provided by the many and varied response that arise from each group of participants.

What is required
2 x large piece puzzle
1 x small piece puzzle

Facilitator note
This exercise needs to be set up before the session commences.

Preparation before session begins:

- Remove the limbic system from one large piece puzzle.
- Remove the frontal lobe piece from other large piece puzzle.
- These puzzle pieces MUST be hidden around the room before the session begins.
- The third small piece puzzle must have all the pieces intact.
- Place the remaining pieces of each puzzle in a bag ready for use.

Task
- Group the participants into three groups. (If the group is small divide into two groups and use only two puzzles.)
- Allocate a bagged puzzle to each group.
- Each group is to complete their puzzle in 5 minutes.

After building the puzzle and realising pieces are missing, all participants then search for the missing pieces.
When pieces are found, the appropriate pieces are to be given to the appropriate group.

If after 2 minutes pieces are not found, facilitator may give hints, until all pieces are found. When puzzles complete, participants return to the larger group.

Debrief 1 (to reinforce the functions of the brain)
Ask each group the following questions:

What piece was missing – what are the functions of that part of the brain?

What impact would it have if that part of the brain was damaged?

How might a person feel if that part of the brain was damaged?

How might a person behave if that part of the brain was damaged?

Debrief 2 (to explore feelings, thinking and actions)
Write three columns on the whiteboard and label them “feel”, “think” and “do”. Ask the group for responses to following questions, and record their responses in the appropriate column.

1. What did you 1. feel, 2. think 3. do when you realised you had pieces of your “brain” missing?

2. What did you 1. feel, 2. think, 3. do when you realised you must look for the missing pieces to your brain?

3. What did you 1. feel, 2. think, 3. do when you couldn’t find the missing piece?

4. What did you 1. feel, 2. think, 3. do when you found the missing piece?

Responses can be interpreted in a number of ways. As responses are given, use the opportunity to gently relate what participants felt, thought and did in the following:

• “did nothing” = refusal to participate
• “thought nothing” = withdrawal in difficult/unfamiliar circumstances
• “felt nothing” = inability to identify/label a feeling
• “couldn’t be bothered looking” = too difficult/gave up.

Ask the group how we can relate this exercise to our interactions with people who have dementia. You will be looking for:

• connection between missing piece of a puzzle to the experience of people with dementia and their families to missing stories, experiences, etc

• connection between an emotional response to a situation (first) and then thought and then action

• observation of different responses (feelings, thoughts and actions) to the same experience and circumstances

• exploration (even at a basic level) of the same types of diverse reaction and responses of participants to the situation, and those of people with dementia to challenging/new circumstances

• connection between each person’s personality, life story and previous experiences to their response to the activity

• connection between the person, family and community.

Signs and symptoms of dementia

When a person has dementia, one or more parts of the brain are damaged and changes will depend on where the damage occurs. Changes usually occur slowly, but may sometimes occur quickly and will also affect people differently.

The changes in the brain are called cognitive changes and how these show in a person are called signs and symptoms. There are many signs and symptoms and together they are called a syndrome.

Signs and symptoms will vary from person to person and can occur at different times for the one person. Early signs may not be recognised. Family and friends may notice that the person is forgetful or simply consider the person to be irritable, withdrawn or moody. Common signs and symptoms of dementia include:

• forgetting recent events
• losing things
• getting lost in a place they know well (such as where they live)
• not being able to remember what a familiar object is called
• forgetting words or getting words muddled up
• repeating the same story or question
• not being able to follow a conversation if more than one person is talking
• loss of ability to plan or sort out problems, think clearly or make decisions
• difficulty in doing new things, or everyday things they have always done
changes in mood, expressing emotions differently, such as getting angry, becoming agitated or withdrawn

acting in ways that are not considered socially or culturally appropriate

losing interest in things that were always enjoyed.

The person may have difficulty doing ordinary things, show poor judgement in buying things or making decisions. These changes become more obvious as time goes by. There is a loss of every day skills and eventually an affected person is no longer able to do the things they have always done or to take care of themselves. The rate of decline varies considerably from person to person. Some people will decline over two to three years while for others the decline may occur more gradually over ten or more years. As the disease progresses the person will need complete assistance with eating, toileting and personal care, they may no longer talk and may lose mobility. They will eventually reach a terminal state or may have other medical complications that lead to death.

ASSESSMENT TASK 3: CASE STUDY – SIGNS AND SYMPTOMS

How many signs and symptoms can you identify in this story?

Purpose: To identify the way symptoms may show in everyday situations.

What is required

Either provide participants with a printed handout of the scenario and ask them to read through and underline the symptoms they identify, or read the scenario to the group, asking them to identify the symptoms as you read.

Scenario: Two old mates

Bill and Doug have been mates for more than thirty years and are in their early seventies. They regularly get together every fortnight for a yarn and a feed.

Bill’s wife Geraldine passed away five years ago. Since his wife’s passing Bill has lived mainly with his daughter and, at times, his niece’s place.

One day Bill’s niece, Kayla, drives him to Doug’s house. She hasn’t been there before and Bill gives her directions. “Just drive down Flinders Street and turn left at the end.” His directions seem to take them every which way and at one point Bill gets a bit stroppy, “Just go the way I’m telling ya!” he says. Eventually they get to Doug’s street and Kayla recognises his old car.

Inside the house, Kayla and Maxine, Doug’s wife, start cutting up potatoes, cabbage and carrots for the meal. Maxine starts talking about old times.

Meanwhile Doug and Bill play cards like they always do. Doug wins the first few hands easily and notices Bill is throwing out useful cards. “You should’ve hung onto that one, Bill,” states Doug. Bill loses his temper and yells, “Don’t tell me how to play! I know more about bloody cards than you ever will.” Doug is a bit surprised by Bill’s show of temper. “Steady on mate, it’s only a game.”

Over dinner the conversation is easy and full of stories and laughter as some of the day’s earlier agitations are forgotten. “How come we took so long to get here today?” asks Bill. Kayla answers “Because you forgot which street was the right one. Your memory ain’t as good as it used to be, Uncle Bill.”

On the way back Bill says “How come it took us so long to get here today?” Kayla replies, “Uncle Bill, remember, I told you why it took us so long, ‘cos you forgot the way!”

10.2.1 Types of dementia

There are many different types or forms of dementia; in fact, there are more than 70 different diseases related to dementia. There are a range of causes that may result in a form of dementia, these include:

• toxic damage e.g. alcohol abuse
• strokes and mini infarcts e.g. vascular dementia
• plaques, tangles and damage to transmission of messages e.g. Alzheimer’s disease
• physical damage e.g. head injury
• infections e.g. AIDS, syphilis.

It is possible for a person to have more than one form of dementia, for example alcohol related dementia and vascular Dementia. The most common types of dementia and their typical features are summarised below.

Facilitator note:

The following tables give summary information about some of the types of dementia. They are provided for your information and included as handouts for participants.
<table>
<thead>
<tr>
<th>Type or form</th>
<th>Cause and typical features</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s disease</td>
<td>Cause: A physical disease. Abnormal materials called tangles build up in the brain cells, and plaques form outside the brain cells. These damage connections in the brain and prevent messages being transmitted. Eventually, healthy brain cells die. Onset Usually occurs in later life but may occur before 60 years of age. Onset and progression are gradual. Features: Early signs include losses in memory, language, thinking, reasoning, making decisions. As the disease progresses more abilities are lost.</td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>Cause: Problems with circulation of the blood to the brain causing damage to the blood vessels in the brain. As a consequence, a stroke or a series of small or mini strokes damage the brain. Onset: Can occur at any time in later life. Onset is sudden, deterioration occurs in steps. Features: Damage can be patchy and widespread. Signs will depend on where the damage occurs. People with vascular dementia can be distressed by the experience and show aggression or agitation related to frustration, particularly where communication difficulties are a feature.</td>
</tr>
<tr>
<td>Fronto temporal lobar degeneration</td>
<td>Cause: Shrinkage occurs in both frontal and temporal lobes. There is a strong family history. Onset Initial onset is usually unclear and generally occurs between the ages of 45 and 65 years, but can occur before 30 years of age. Features: Early symptoms are changes in behaviour such as being socially or culturally inappropriate, or withdrawal. These may not be recognised as dementia.</td>
</tr>
<tr>
<td>Lewy body dementia</td>
<td>Cause: Abnormal lumps called Lewy bodies develop inside the nerve cells in the brain causing death of brain cells. Features: Pattern is similar to Alzheimer’s disease. Visual or auditory hallucinations, delusions and paranoia are more common. Variation in cognition is common and muscular rigidity and slowness of movement also occur.</td>
</tr>
</tbody>
</table>
The following forms of dementia are related to other conditions.

<table>
<thead>
<tr>
<th>Type</th>
<th>Condition</th>
<th>Typical features</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acquired Brain Injury</td>
<td>Structural damage - trauma</td>
<td>Damage to the brain caused by trauma such as blows to the head as may occur in boxing or domestic violence that causes deterioration in cognitive functioning. Slow information processing, reduced attention span, problems with memory and problem solving.</td>
</tr>
<tr>
<td>Alcohol related dementia</td>
<td>(Korsakoff’s syndrome or Wernicke’s encephalopathy)</td>
<td>Damage to the brain, usually caused by prolonged excessive drinking of alcohol. It is unclear whether the damage is caused by the direct effect of alcohol on the brain cells or if the damaged is due to lack of thiamine (vitamin B1). It affects men and women of all ages. Features include personality changes, problems with memory, difficulty with making decisions, learning, planning and judgement, changes in social skills and problems with balance. Habits and skills learned early in life tend to be relatively unaffected. If alcohol consumption ceases, progression does not continue.</td>
</tr>
<tr>
<td>Toxic substances e.g.</td>
<td>Medications, drugs of abuse, solvents, petrol</td>
<td>Dementia applies when symptoms persist beyond intoxication, delirium and withdrawal. Features may include inability to learn new information or remember what has been learned, and language disturbance, failure to recognise objects, disturbance in planning and organising.</td>
</tr>
<tr>
<td>Secondary (to other diseases)</td>
<td>Parkinson’s disease</td>
<td>Progressive disease of the central nervous system characterised by tremors and stiffness in limbs and joints, and speech impediments. Some people may develop dementia late in the disease. Poor concentration, mental slowness, inability to plan actions and thoughts, and make decisions. Retrieval of memories difficult.</td>
</tr>
<tr>
<td></td>
<td>Huntington’s chorea</td>
<td>A degenerative brain disease that affects the mind and body characterised by involuntary muscle movement. Dementia occurs in a majority of cases, but awareness is retained until late in the illness. Difficult retrieval of memory.</td>
</tr>
<tr>
<td>Infection</td>
<td>AIDS dementia complex (ADC)</td>
<td>People who have HIV/AIDS are at risk of developing ADC. May affect younger people. It may occur in the later stages of HIV, but early and sustained antiviral treatment may prevent. Features include inattentiveness, impaired concentration and problem solving, forgetfulness tremors, slurred speech, sluggishness and social withdrawal.</td>
</tr>
<tr>
<td></td>
<td>Syphilis</td>
<td>Dementia-like syndrome late in the disease. May be prevented by early recognition and treatment.</td>
</tr>
</tbody>
</table>
10.3 Who gets dementia?

Dementia is a growing health and social issue in Australia. While the risk of dementia increases with advancing age, it is not part of normal ageing. Dementia mostly affects people over 70 years of age, but it does occur in people under the age of 60 years and can occur in people aged in their 40s or younger.

The number of people with dementia is predicted to increase significantly in the years ahead. This prediction assumes the number of older people in our population will continue to increase because people will live longer and there will be no significant advance in ability to prevent, delay the onset, or cure dementia.

At present, little is known about the prevalence and impact of dementia in Aboriginal and Torres Strait Islander communities. A small survey of Aboriginal people living in North Queensland found dementia rates were 20 percent amongst Aboriginal people aged over 65 years. However, this survey included only a small percentage of the Aboriginal population and further research is needed to determine the needs of Aboriginal people, their carers and communities. Aboriginal and Torres Strait Islander people have a shorter life expectancy but may experience diseases of ageing at an earlier age. As Pollit noted, because mortality of Aboriginal and Torres Strait Islander people is so high, few people reach old age. However, as with other diseases such as cardiovascular disease, dementia may be a problem at earlier ages.

The types of dementia that are identified as being more prevalent in people aged in their 70s or 80s may be experienced by Aboriginal and Torres Strait Islander people 10 or 20 years earlier. Furthermore, many Aboriginal and Torres Strait Islander people are at higher risk of the types of dementia that are largely preventable, that is, Acquired Brain Injury (dementia that is a consequence of injury to the head, long term alcohol abuse or exposure to toxic substances) and vascular dementia. There is also an emerging awareness of health issues experienced as a consequence of homelessness and associated risk of dementia.

These forms of dementia can occur at a younger age. It is well recognised that general improvement of the social and emotional health and wellbeing of Aboriginal and Torres Strait Islander communities is needed. Indeed, the vision of the reporting framework of the Council of Australian Governments (COAG) is that:

"Aboriginal people will one day enjoy the same overall standard of living as other Australians. They will be as healthy, live as long and participate fully in the social and economic life of the nation."

Indeed it is suggested that the health and life span of Aboriginal and Torres Strait Islander people is improving. Interestingly, any increase in life expectancy may lead to an increase in the prevalence of dementia because more people will live to the age where the prevalence of forms of dementia such as Alzheimer's disease is highest.

Incidence of dementia

Australia's population is living longer and increasing numbers of people are reaching an older age where the likelihood of dementia increases. Estimates of numbers of people with dementia in the broader Australian community, by age group, are:

- under 64 years of age 1 in 1000
- 65 – 70 years of age 1 in 25
- 70 – 80 years of age 1 in 10
- over 80 years 1 in 4.

The total number of people with dementia in Australia is expected to increase from 200,000 in 2005 to 730,000 by 2040. There is a lack of reliable information about dementia amongst Aboriginal and Torres Strait Islander people. While in the non-Aboriginal population Alzheimer's disease is the commonest form, it is understood that in Aboriginal and Torres Strait populations, 90% of dementia is from causes that are preventable. These are:

- alcohol related dementia
- vascular dementia
- trauma.

Alzheimer's disease accounts for a much smaller percentage.
Presentation: Meet Dementia:
The Bad Hawk that Steals

Facilitator note:
For some groups the hawk is a sacred totem with particular cultural significance and it may not be appropriate to use this resource. Remember to check with local Aboriginal and Torres Strait Islander Community before using this story.

The story Meet Dementia The Bad Hawk That Steals is included in the resource materials as a PowerPoint presentation. It is an option that may be used in culturally appropriate contexts. The story, written by Brian Lampton an Aboriginal man from Queensland is about alcohol related dementia and introduces the early symptoms, deterioration and final stages of loss of memory and health. The story can be easily understood and used across all generations.

After the story discuss with the group the messages that were raised. Provide an opportunity for participants to reflect on their own experiences with dementia in their Community.

10.4 Risk reduction
Changes in our brain can begin a long time before any symptoms appear. While it is not possible to prevent or cure many of the forms of dementia, it is possible to keep our brain healthy and reduce the risk of dementia. We are not able to change risks like getting older, but there are some risks we can reduce by changes to our lifestyle and habits.

Alcohol
Patterns of alcohol use among Aboriginal and Torres Strait Islander peoples have been shaped by history. Aboriginal and Torres Strait Islander people were not allowed to drink so to avoid being caught, they would buy large quantities of alcohol and drink it quickly. Alcohol was often consumed in groups which allowed people to be with family, hear what was happening, speak their language, sing songs and tell stories. This provided a sense of belonging and identity. Sharing alcohol became a part of wider cultural practice which has had both positive and negative consequences on the wellbeing of Aboriginal and Torres Strait Islander people.

The problematic use of alcohol is recognised as being a major health issue for Aboriginal and Torres Strait Islander people. As with all social groups, the use of alcohol and other drugs is both the cause and effect of much suffering. The community level alcohol is a contributor to problems including violence and family breakdown. At an individual level alcohol is related to dementia and other conditions such as liver disease, high blood pressure and stroke. Alcohol related brain damage has been one of the major causes of dementia amongst Aboriginal and Torres Strait Islander people. Alcohol related dementia is related to chronic and extreme levels of drinking and can affect men and women of any age. However, it is important to put this into perspective. While some Aboriginal and Torres Strait Islander people drink alcohol at risky levels there are many who choose not to drink any alcohol at all.

How alcohol affects the brain will depend on:
- how much and how long the person drinks alcohol
- if they drink every day or binge drink
- the age, sex and health of the person
- associated nutritional problems.

Alcohol related dementia affects four main areas:

Thinking
confusion and loss of memory, especially recent memory
loss of ability to plan and organise
inability to recognise the consequences of one’s own behaviour

Behaviour
impulsive
boredom
returning to old habits
suspicious or paranoid

Emotions
anxiety
depression
loss of confidence and self esteem

Balance and movement
staggering walking
weakness or paralysis of eye movement
Key point

Alcohol related dementia can be prevented by not drinking alcohol or following recommendations for low risk alcohol consumption.

Australian Alcohol Guidelines provide the following recommendations for low risk alcohol consumption:

For men
- No more than 6 standard drinks* in one day** and no more than 28 in any week
- One or two alcohol-free days per week

For women
- No more than 4 standard drinks* in one day** and no more than 14 in any week
- One or two alcohol-free days per week

* A standard drink contains 10 grams of alcohol.
** These drinks should be spread over several hours. For example, men should have no more than 2 standard drinks in the first hour and 1 per hour after that. Women should have no more than 1 standard drink per hour.

Key Point:

At an early stage of the disease problems may be reduced if the affected person stops drinking alcohol and their diet is improved, especially with thiamine (vitamin B1).

It is important to treat underlying alcohol dependence or addiction. However, alcohol dependence and addiction are complex issues and there are many reports, plans and strategies in the field of Aboriginal and Torres Strait Islander use of alcohol. The reference group for the National Drug Strategy reviewed policy papers and reports to develop the following six common principles.

1. The use of alcohol, tobacco and other drugs must be addressed as part of a comprehensive, holistic approach to health that includes physical, spiritual, cultural, emotional and social wellbeing, community development and capacity building.
2. Local planning is required to develop responses to needs and priorities set by local Aboriginal and Torres Strait Islander communities.
3. Culturally valid strategies that are effective for Aboriginal and Torres Strait Islander peoples must be developed, implemented and evaluated.
4. Aboriginal and Torres Strait Islander peoples must be centrally involved in planning, development and implementation of strategies to address the use of alcohol, tobacco and other drugs in their communities.
5. Aboriginal and Torres Strait Islander communities should have control over their health, drug and alcohol and related services.
6. Resources to address the use of alcohol, tobacco and other drugs must be available at the level needed to reduce disproportionate levels of drug related harm among Aboriginal and Torres Strait Islander peoples.

Petrol and solvents

Solvent use can also cause brain damage. Solvents are drugs or chemicals, usually liquids or gasses that give off fumes. Solvents are used in more than 250 products, for example, glues, paints, paint thinners, spray cans, lighter fluid and petrol.

How a solvent affects a person depends on things like:
- what sort of solvent they sniff (glue, paint, petrol)
- how they sniff (using plastic bag or direct)
- how much they sniff
- how often they do it
- how long they have been sniffing
- how fit and healthy they are.

The effects of solvents are felt faster than the effects of alcohol. The solvent’s fumes are taken directly into the sniffer’s body and immediately start affecting their ability to function. The fumes go from the lungs into the blood and carry the chemicals to all parts of the body. Some of these chemicals collect in the brain and cause damage.

Chronic use of solvents can cause permanent damage and serious health problems.
Brain damage due to solvent misuse will cause problems such as:

• confusion, crazy talk
• seeing things that aren’t there (hallucinations)
• depression
• mood swings – a person may become more irritable, hostile or violent
• short term memory loss, forgetting stories
• thinking and learning difficulties.

Damage to the brain is permanent, so it is better to prevent the damage by dealing with solvent misuse. While there are no easy answers it is necessary to strengthen Aboriginal and Torres Strait Islander culture so that this thing can be beaten with strong bodies, strong spirit, strong Country, strong relationships, strong stories and strong culture.6

Some communities will develop a community action plan that will consider:

• what they will do
• how they will do it
• who will do it
• when they will do it.

**Facilitator note:**
The above are significant issues and a full exploration of the issues and preventative strategies is beyond the scope of this resource.

Further information:

National Indigenous Drug Strategy

Aboriginal Drug and Alcohol Council (SA) Inc  www.adac.org.au

Alcohol Go Easy: Low-Risk Drinking
http://www.dassa.sa.gov.au/site/page.cfm?u=90Eprint=1

Additional resource:
The Brain Story: A kit depicting the brain damage caused by solvent abuse

Developed by the Alcohol and Drug Resource and Education Service (ADRES) Funded by the Commonwealth Department of Human Services and Health


**Vascular dementia**

Vascular dementia is a consequence of disease of the blood circulation system and is not limited to the brain. It be caused in several different ways. Most commonly there is a blockage of small blood vessels somewhere in the brain. Blockages may be caused by plaque build-up on the inside of the artery wall, or by blood clots. Clots can form as a result of abnormal heart rhythms or other heart abnormalities. Also, a weak patch on an artery wall can balloon outwards and form an aneurysm, which can burst and deprive the brain cells of oxygen.

Risk factors include:

• high blood pressure (hypertension)
• cigarette smoking
• high consumption of alcohol
• high blood fat (high levels of the bad type of cholesterol)
• being overweight (obesity)
• heart disease
• high blood sugar (diabetes).

The best way to reduce the risk of vascular dementia is to reduce these risk factors by:

• not smoking
• exercising regularly
• eating a healthy diet
• limiting alcohol intake
• reducing the amount of salt and fat in the diet
• managing stress through relaxation techniques or meditation
• having a blood pressure check at least once a year
• having blood fat and blood sugar levels measured periodically.

Medications can control high blood cholesterol, high blood pressure, diabetes and heart disease.
Brief episodes of numbness and temporary loss of vision, speech, or strength may indicate a mini-stroke (TIA), or be a warning sign of a stroke. It is advisable to seek medical help if these symptoms are experienced.

Education, lifestyle changes and adequate medical advice are the best safeguards. Know the warning signs and start making the necessary life adjustments. The most important thing is to begin!

Trauma

Head injury, particularly severe (such as that causing unconsciousness) or repeated injury (as experienced by boxers) has been shown to be a risk factor for dementia. Risk can be reduced by reducing the incidence of violent or accidental head injury.

Trauma can be reduced by:

- protecting your head from accidental injury by wearing seat belts in cars and wearing protective head gear when required, such as when rollerblading, riding a bike or a horse
- reduction of incidence of community and domestic violence.

10.5 Diagnosis

Early signs of dementia can develop very gradually, be subtle, and vary a lot from one person to another. A problem with memory, particularly recent memory, tends to be one of the first signs noticed. Other signs can be confusion, changes in personality, or withdrawal. Symptoms may not be noticed or they may be assumed to be part of the ageing process. Or symptoms may be ignored, denied or covered up.

However, early assessment and accurate diagnosis is important because it enables:

- management of treatable conditions that are not dementia
- initiation of therapy
- planning for future disease management and care
- financial and legal decisions to be made.

Other important benefits of diagnosis include:

- When dementia is alcohol, related if alcohol consumption stops, the disease may become static, or some recovery may be possible.

- In some forms of dementia (primarily Alzheimer's type dementia) drugs called cholinesterase inhibitors may be used. Their benefits include temporary stabilisation of the rate of decline in cognition and improvement in function – the person may experience improved ability to think clearly and function in daily activities such as dressing. However, these improvements have been shown to decrease as the disease progresses. Additionally, in about one fifth of people the drugs will have adverse effects such as nausea, diarrhoea and insomnia, particularly if the dose is increased rapidly.

A clear diagnosis requires evidence of changes in memory and one or more other cognitive changes such as:

- language disturbance
- failure to recognise or identify objects
- disturbance in ability of planning, organising, sequencing
- impaired ability to carry out motor functions.

A complete medical assessment may identify a treatable condition or confirm the presence of dementia.

Assessment will include:

- a detailed medical history, provided by the person with the symptoms and a family member or friend
- a physical examination, including tests of the senses and movement functions, laboratory tests of blood and urine
- tests to assess cognitive functions such as memory, and identify abilities and problems related to comprehension, insight and judgement.

Facilitator note:


Additional resources:

ASSESSMENT TASK 4: WHAT IS DEMENTIA

Describe dementia and explain how you might use this knowledge in the care of a person with dementia.

10.6 The impact of dementia on person, family and community

Now that we have explored dementia and its causes we will shift our focus to the person with dementia, their family and community.

Older people are looked up to and have an essential role in kinship, community, in transmitting cultural knowledge. Dementia impacts on this role and has consequences for the person, the family and community. The model below (Figure 10.2) illustrates that the person with dementia is part of the community and is supported by family, networks and services. Relationships between the person with dementia, their family and community hold special significance. All are interdependent. Illness is not viewed as discrete. Wellbeing is an holistic and collective issue, with specific individual health problems being part of wider social, spiritual and community health. From an Aboriginal and Torres Strait Islander people’s perspective health “is viewed within an holistic and community lifestyle framework, which is related to both past and present issues, and it is not necessarily individualised or compartmentalised.”

FIGURE 10.2 MODEL DEPICTING INTERCONNECTION OF PERSON WITH DEMENTIA, FAMILY, SERVICES AND COMMUNITY

Dementia affects people differently. Throughout this section it is important to take an holistic approach that considers the impact and implications for the person, their family and community.
10.3 Exercise: Imagine if you had dementia…

**Purpose**
To develop empathy with the experience of dementia.

**What is involved**
Distribute handout and ask participants to write their responses to the questions or divide the group into pairs to discuss their responses to the questions.

Inform the group that you will ask them to share their response.

**Questions**
If you had dementia …

What would you want from people who were caring for you?
What would you not want from them?

**Debrief**
Ask the group to share their responses to the questions.

You can expect that there will be some similar responses and some that will be different.

Write the responses on the whiteboard.

**Points to be covered**
- Discuss how the group has some similarities but also some differences.
- Explain how people with dementia have similar preferences.
- Discuss what this might mean for providing care and support for persons who have dementia.

10.7 Factors influencing the experience of dementia

Each person is very different from all the others. Each person’s experience of dementia will also be different, as it is influenced by the factors that make each person different. These factors are identified in the table that follows.

<table>
<thead>
<tr>
<th>TABLE 10.2 FACTORS THAT INFLUENCE A PERSON WHO HAS DEMENTIA</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Personality</strong></td>
</tr>
<tr>
<td>Personality develops throughout our lives and includes the way we deal with all sorts of things, including the sort of coping skills that we have developed.</td>
</tr>
<tr>
<td>It is important to have an understanding of a person’s personality.</td>
</tr>
<tr>
<td><strong>Life story</strong></td>
</tr>
<tr>
<td>A person’s life story is who they are and all the things they have done and experienced; it includes Country, family, kin, spirituality and culture. There may be happy and sad experiences.</td>
</tr>
<tr>
<td>Knowing about the person’s story means that we can assist them to maintain the way of life that is important to them.</td>
</tr>
<tr>
<td>In addition, how the person’s culture defines and responds to behaviours that demonstrate dementia will greatly influence their experience of the illness.</td>
</tr>
<tr>
<td><strong>Physical health</strong></td>
</tr>
<tr>
<td>A person’s physical health can influence a person’s ability. For example if a person has a fever their confusion may increase, if they are in pain they may withdraw or call out because they are not able to tell us about the pain.</td>
</tr>
<tr>
<td>It is important to assess physical health so problems can be treated.</td>
</tr>
<tr>
<td><strong>Changes in the brain (cognitive impairment)</strong></td>
</tr>
<tr>
<td>Changes in the brain will be progressive or chronic. We are not able to influence these changes but we need to take them into account.</td>
</tr>
<tr>
<td><strong>Environment: social, psychological and physical</strong></td>
</tr>
<tr>
<td>These are important areas and we can make a difference for the person by keeping strong links with Country and Community, maintaining trusting relationships, assisting the person to maintain social and cultural networks and ensuring their physical environment is safe and suits them.</td>
</tr>
<tr>
<td><strong>10.8 Respecting the person and their story</strong></td>
</tr>
<tr>
<td>As dementia progresses it will have a huge impact on the person and how they are able to live their life. They will need more and more assistance from others. Common areas where people with dementia require assistance are included right:</td>
</tr>
</tbody>
</table>
TABLE 10.3 ASSISTANCE MAY BE REQUIRED

| Memory loss | The person may feel frustrated because they cannot remember. They may forget how to do everyday things and not be able to learn new things. |
| Orientation to place, people and time | The person may not know where they are or who other people are or what the time period is. They may feel lost and insecure. |
| Communication | They may not be able to tell you what they want or how they feel, and become frustrated or angry. |
| Changed behaviour | Changes in behaviour such as aggression, agitation, or abusive language can be the way a person with dementia communicates that something is wrong. While we can find the behaviours challenging we need to remember that it has meaning for the person and try to work out what they are feeling and communicating. |
| Looking after themselves | The person may forget to eat or drink, or forget that they have just eaten. They may not remember where the toilet is and they may get sick because of poor hygiene. |
| Safety issues | The person may be at risk because they may not be able to recognise dangers (e.g. traffic, being in the hot sun for long periods of time, boiling water, fire) and may be injured. |

Focusing on the person, or a person centred approach, is about respecting and valuing the person with dementia as unique, and acknowledging each individual’s life story, culture, personality, and network of relationships.

A person centred approach strives to assist the person to maintain their dignity, wellbeing, sense of self and personhood. Professor Tom Kitwood described personhood as the status that is given to one human being, by others, in the context of relationship and social being.

Aboriginal and Torres Strait Islander people may see dementia as “a ‘soreness of the spirit’ caused by loss of social and family network, destruction of kinship and family, dislocation from ancestral lands, and the conflict between tradition and the pressures of trying to exist within and alongside Western culture”.

10.4 Exercise: Being treated as a person – experiencing personhood

Purpose
To identify the feelings experienced in positive/good or negative/bad situations that can maintain or diminish personhood.

What is required
Ask participants to work in pairs and discuss the following:

• Tell each other about an instance when they were not treated as a person and how they felt and responded in this situation. (For example: You walked into a room and were ignored by the people in the room.)
• Tell each other about an instance when they were treated as a person and how they felt and responded in that situation. (For example: You walked into a room and were greeted warmly by the people in the room.)

Before you bring the group back together make two columns on the whiteboard – the first heading “BAD” the second “GOOD”.

Bring the group back together and ask participants how they felt in each situation (the feelings part of the questions above) and write on the whiteboard under the appropriate heading.

Discussion points
• How we respond in positive or negative situations.
• The strength of our feelings and the behaviour this may trigger.
• Ask/suggest why they think being treated as a person does not occur.
• Relate this to a person who has dementia, cannot rationalise what is happening and will respond or act according to how they feel.

10.1 Case Study: Maintaining wellbeing

Purpose:
To identify ways of supporting a person with dementia to maintain sense of self, dignity and wellbeing.

Facilitator note
Select one of the following two case studies.
A: Percy

Percy is an 85 year old Aboriginal man, who was living in a remote Community. Percy has several medical conditions. He has been on blood pressure medication for seven years. Recently he had a stroke and was diagnosed with vascular dementia. His family aren’t able to care for him because he is unable to walk and needs two people’s help to stand up to move from his wheelchair to his bed. Their house isn’t built for a wheelchair to move around in. The local old people’s hostel is unable to care for Percy because it is already full. Percy has moved to the closest regional centre and is staying in a non-Indigenous nursing home. His behaviour has become withdrawn, sometimes staff see him crying. He refuses care and tells the staff to leave him alone.

Percy has never left his remote Aboriginal community; anything he ever wanted was there, Country, family and community. In his younger days, he used to hunt, and all his life he has eaten traditional foods. He speaks simple English and Creole, but his first language is an Aboriginal Traditional language.

Before he became ill he used to tell stories and talk about traditional culture to the children by making drawings in the dirt. Younger people would often ask his advice on life and ceremonies.

He is a very well respected Elder, when people in the community spoke to Percy, they had certain cultural protocols to follow.

B: Lucy

Lucy is a 64 year woman who moved from an Aboriginal community to the city when she was 16 years old looking for work. She meet her partner a Torres Strait Islander man when she was 18, they have lived together for 39 years, her husband passed away 7 years ago. They raised a family of six children, these days she’s a great-grandmother. While raising their family in the city they had strong community links with the Aboriginal and Torres Strait Islander people (family and friends), she had only one non-Indigenous friend from her husband’s work.

She was diagnosed with head injury dementia four years ago, after a car accident. Her family are very supportive, but now they have families of their own. They can not handle the aggressive behaviour their mother shows, when she was growing them up she was a very patient lady and only sometimes showed her temper. Now she gets angry without being provoked, they can’t understand why, so they moved her to a non-Indigenous hostel, her angry behaviours are getting worse. Lucy’s children are also starting to fight amongst each other. The hostel has one Torres Strait Islander carer who seems to be able to calm Lucy easily, when she talks Creole to her and brings in some Torres Strait Islander food.

This carer is starting to explain to the children what type of dementia their mother has, and asking Lucy’s children what she used to like before the dementia.

Discussion points

After reading the case study above discuss the following questions or points:

• How would leaving their community affect an older Aboriginal and Torres Strait Islander person, their family and community?

• What would be important to the Aboriginal and Torres Strait Islander older person?

• How could you help to improve their sense of self, dignity, and wellbeing?

Emotional needs

Every person has emotional needs. When a person has dementia they still have emotional needs but are less able to seek ways to meet their own needs and may need assistance from others. Emotional needs are described in the table below.

**TABLE 10.4 EMOTIONAL NEEDS**

<table>
<thead>
<tr>
<th>Comfort</th>
<th>Tenderness, closeness, the soothing of pain and sorrow, the calming of anxiety, the feeling of security which comes from being close to another.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attachment</td>
<td>The bonds and attachments each person forms throughout their life that give a sense of belonging and security.</td>
</tr>
<tr>
<td>Inclusion</td>
<td>To be part of a group or to be social with others. No one likes to be excluded.</td>
</tr>
<tr>
<td>Role and social obligations</td>
<td>The need to be involved in activities that are personally significant and draw on our abilities and experience.</td>
</tr>
</tbody>
</table>
Identity
The need to know who we are and where we come from. It is also about having a connection with our past and having a story to tell.

Love
As an all-encompassing need.

We can show our respect for the person with dementia by maintaining their personhood and sense of wellbeing. A person centred approach guides us to do this. Ten key points for maintaining a person centred approach are described in the table that follows.

<table>
<thead>
<tr>
<th>TABLE 10.5: TEN KEY POINTS FOR MAINTAINING A PERSON CENTRED APPROACH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attend to the whole person</td>
</tr>
<tr>
<td>It is essential that all aspects of the person are considered; their physical wellbeing, their thoughts, feelings, culture and spirituality.</td>
</tr>
<tr>
<td>See each individual as special</td>
</tr>
<tr>
<td>It is so easy to lose sight of how special each person is, especially when some aspects of that person may be changing. It is very easy for people to become stereotyped and clumped together. It is easier to see a group of problems instead of a group of people with a range of difficulties requiring different kinds of support.</td>
</tr>
<tr>
<td>Give respect to the past</td>
</tr>
<tr>
<td>It is the past which has created the person we see today. It is essential that we gain insight into relationships, critical events, key roles, routines and habits, which may well explain some of the behaviour being observed.</td>
</tr>
<tr>
<td>Focus on the positives</td>
</tr>
<tr>
<td>It is essential to know what abilities the person has. This enables us to ensure that maximum independence is maintained. It also means that the person is not set up to fail because our expectations are too high.</td>
</tr>
<tr>
<td>Stay in communication</td>
</tr>
<tr>
<td>A very small amount of communication is dependent on the actual words we use. Far more information is received through the non-verbal content of voice tone, facial expression, and sensory input other than hearing. People with dementia may not be able to say the words, but they are very sensitive to the information received at the feeling level.</td>
</tr>
<tr>
<td>Nourish attachments</td>
</tr>
<tr>
<td>People form strong bonds or attachments with others and with their Land. These attachments provide security and reassurance necessary to a sense of wellbeing. Attachments support feelings of trust and security which help prevent some of the anxiety associated with the changes that are occurring.</td>
</tr>
</tbody>
</table>

10.5 Exercise Meeting emotional needs

Purpose
To raise awareness of emotional needs, what it would be like if these needs are not met, and how another person can support the emotional needs of a person with dementia.

What is required
Distribute the Emotional Needs Handout and Exercise sheet (or you may choose to draw model on whiteboard and work with the group.)

Task
Working in groups of two or three, ask participants to identify ways they meet each of the emotional needs. Report back to the main group. Write responses on the whiteboard/flipchart.

Discussion points
- Discuss what it might mean for our wellbeing if we are not able to meet our emotional needs.
- Relate this to people who have dementia.
- How might we assist a person with dementia to meet their emotional needs?
Create community
We are social beings designed to live in community. Membership adds value, recognition, and supports our feelings of identity. A sense of belonging for people with dementia is an important way of reaffirming their self worth and value.

Choices and risk taking
The person who develops dementia is subject to a number of losses, such as choice about personal routines, independence in decision making, and what they can do. This loss of independence and increase in control by others can create problems.

Physical, chemical and psychological restraint used as a form of control can have negative consequences. These can include loss of mobility, muscle weakness, constipation and physical injury. It is important that all limitations and legal ramifications be considered.

On the other hand, by reducing the controls, it is possible to achieve a marked reduction in the negative kinds of behaviour that are just assumed to be due to the dementia.

Give and receive
Everyone has a need to both give and receive.

Maintain an environment of trust
This means a situation where trust and value are created for each person. The person with dementia needs to know that they can rely on and trust their carers, in the same way we need to trust our family members. Anxiety as a result of lack of this trust will often lead to the problem behaviour shown by someone who is insecure and overburdened with a feeling of anxiety.

Key point:
Caring for a person who has dementia is not an easy task and requires a lot of understanding and patience. However, rather than concentrate on the illness and what the person is not able to do, it is important to know the person, the abilities they have, and to assist them with what they can do.

10.9 Family and community

10.2 Case Study: Rachael
Facilitator note: The case study exercise "Rachael" is provided as an example and is intended to enable participants to relate their learning to their real world context. You can use this story, or you may choose to write a different story that is more suitable for your participants.

Purpose:
To explore
• relationships between life events, the pattern of alcohol consumption and the consequence of dementia,
• identify the impact of dementia on the person, her family and community.

Case study
Rachael was born on an Aboriginal Community in 1966. She started drinking alcohol when she was 15 after her father passed away. Rachel would go out with her cousins every weekend and occasionally during the week and get drunk. At first Rachael drank beer and wine, but as the years went by she was drinking spirits, rum, bourbon and vodka.

At 19, Rachael got a job as a domestic maid on an outback homestead near Arkaroola. Nine months later she was fired for theft and her drunkenness during work hours. Rachael never worked again.

By the time Rachael was 25, she had four children under the age of eight years and an abusive husband who was in jail for domestic violence. Rachael was still drinking heavily and Grannie Pat was caring for her kids.

In 1992, Rachael was diagnosed with diabetes and her eldest son was killed in a car accident. Unable to cope with this, Rachael drank even more. She was now drinking every day from the time she woke up until she passed out.

At 34, Rachael’s behaviour had started to change, she was becoming aggressive. She was forgetting things and having difficulties planning her day.

When Rachael was 35 years old she was diagnosed with dementia due to alcohol related brain damage. At the age of 37, Rachael was placed in a residential facility as her care needs were extremely high.
1. Discussion points
• What was the cause of Rachael’s dementia?
• Could the dementia have been prevented?
• If so, what was needed and when did that need to occur?

2. Discussion points
If you were one of Rachael’s family members, what would be useful to tell the doctor, health workers or care staff at the facility?

3. Discussion points – choice of care
Why was residential care chosen?
• Identify the people who were affected by the choice of care.
• In what ways were they affected?
• Could Rachael be cared for in the Community? Consider:
  • advantages and disadvantages
  • personal resources
  • carer resources
  • community resources.

Impact on family and community
Support for Aboriginal and Torres Strait Islander people with dementia may come from various community, government and professional organisations, but family and friends tend to be the most commonly available sources of support.

Over time, a person with dementia will require more and more support and care from family, friends and community members. These people play an important role in the lives of people with dementia by providing a circle of support and links to past experiences. Caring for a person with dementia is constant and often demanding and can have an impact on the physical and emotional health of those who provide care. Carers may experience difficulty in dealing with changes in the person with dementia and also with the change in their relationship with the person, as well as additional physical care requirements. These demands can affect feelings or emotions, and carers may experience depression, anxiety and even physical illness.

Video: Lily’s story: A Tale of Dementia
Details for obtaining this video are:
Call Number: VID 94 A
Available from Bynoe Community Advancement Cooperative Society Phone. (07) 4745 2333

A Tale of Dementia: LILY’S STORY is an Aboriginal and Torres Strait Islander based story written by participants at a Good Practice in Dementia Care Demonstration Workshop in Normanton, Queensland. The story is about Lily, an Aboriginal woman with Alzheimer’s Disease. It reflects on her life and experiences to explain her behaviour as a result of dementia. The story of a young man, Barry, who has alcohol related dementia is also told to demonstrate how excessive alcohol consumption has resulted in dementia and affected his life.

After viewing the story prompt the group to discuss the following questions.
• What was the impact of dementia of each of the people in the story?
• How did dementia impact on their family and Community?
• Are there people like Lily and Barry in their Community?
• How do families and Community deal with dementia?
10.9.1 Loss and grief

**Facilitator note:**

This section is sensitive and is to be facilitated by an Aboriginal or Torres Strait Islander trainer.

The content of this section may raise strong feelings in individuals or the group. It is important that you gauge the potential for distress and either adapt the content of this session or ensure that you have the time and the skills necessary to adequately work through/debrief any strong/distressed feelings that may emerge.

Loss has been described as “being deprived of or coming to be without something” and grief as “a deep or intense sorrow”. The experiences of grief and loss in relation to dementia have been described in the stories about Rachael and Lily.

As well as the losses experienced by the person with dementia, there can be many losses for family and community as they become aware of the dementia related changes. These include:

- effects of the illness
- changes in personality of the person with dementia
- changes in relationships
- changes in the caring role
- anticipated decline in the health of the person with dementia
- inability of the person to carry out significant cultural roles or fulfill cultural obligations – older people play a crucial role in maintaining cultural knowledge.

Family and carers may also experience loss:

- sharing plans and activities
- hopes for the future
- social life
- communicating, relationship and intimacy
- changes in role
- personal time.

The sense of loss may be strong. When we experience loss our feelings can be a bit mixed up. We may feel resentment, anger, sadness and guilt at the same time. Or we may just feel numb. These feelings may start when the person is diagnosed and remain long after the person dies.

**Responding to loss and grief**

The feelings of loss and grief are not just one feeling but a whole lot of different feelings that will be felt in different ways by each person and for different lengths of time. These feelings can be complicated even more by the ongoing needs of the person being cared for.

As well as these unique and often profound individual responses, for Aboriginal and Torres Strait Islander people there is also a collective grief about losses relating to our culture, community and traditional values. In her work with Aboriginal and Torres Strait Islander people on grief and loss, Rosemary Wangooneen identified different sorts of losses. These can be for example, historical losses, recognised losses (that can be seen, such as land and family members), and unrecognised losses (things that cannot be seen, such as sense of power, confidence, dignity, pride and inner strength). In many Aboriginal and Torres Strait Islander communities, family and community funerals are an all-too-common event – as is death from preventable causes. Each loss is likely to compound feelings of the generalised underlying grief.

**Common symptoms of loss and grief**

When we are going through the process of loss and grief we can have many different feelings and may even feel depressed, like it is too hard to keep going. We can find it hard to do the normal things like eating, sleeping and talking to friends. We may even experience some physical effects. Some of the common symptoms include:

- loss of energy
- inability to concentrate
- making mistakes
- hopelessness
- mood changes
- loss of appetite or eating all the time
- loss of interest in every day activities
- changed sleeping patterns such as broken sleep or wanting to sleep all the time
- sadness
- depression
- headaches and strange feelings in our head
- body pains.
Key point
Not doing anything and just hoping that these feelings and symptoms will go away may not work.

What can we do?
Even though we all have different feelings, we all need to grieve. Our feelings can be pretty overwhelming and if we don’t find ways to grieve we may get angry and take it out on family and friends or, just as Rachael did, we may turn to alcohol or drugs and that adds shame and just makes it all worse.

It is important to understand that there is not one best way to grieve – just as the feelings experienced are different, so the way we grieve will be different. It may be helpful to:
• acknowledge your feelings, cry if you need to
• talk and share with someone else
• let go of anger and resentment
• keep a journal
• find your own comfort
• put decisions on hold
• be kind to yourself
• accept help from others.

Most of us can get help from our families and friends.

Sitting down and talking with other people who have a similar experience is a good way to lighten the load.

It is also important to remember that special help is also available from health workers, counsellors, doctors, or religious ministers.

It is important that carers are supported to recognise their own needs and develop strategies to take care of their own health. These may include:
• learning about dementia
• continuing with interests or hobbies
• joining a support group
• taking a break
• staying healthy – going for regular walks, practicing relaxation, regular medical checks
• maintaining good nutrition
• keeping in contact with friends
• seeking/accepting assistance
• professional counselling.

What services are available in the Community to support people with dementia and their carers?

Additional resources:
National Association for Loss and Grief www.nalag.org.au
(see also websites for each State and Territory)


Australian Government information: Help for family, friends and carers of people living with dementia

10.9.2 Community strategies
Each community will have their own way of supporting a person with dementia. In this section, the facilitator must ensure that local Aboriginal and Torres Strait Islander resources for supporting people with dementia and assisting with community liaison, cultural and language interpretation, and partnerships with mainstream agencies are named and explained.

ASSESSMENT TASK 5: NETWORKS AND SUPPORTS
Purpose: Participants will identify roles of key workers and supports for persons with dementia in their community.

What is involved: Make two columns on the whiteboard or flip chart. Write the list of support persons in the first column. Ask the group if there is anyone else who may be involved and add to the list in column one.

Are there any Aboriginal and Torres Strait Islander agencies or key workers?

Ask participants to describe how each one assists a person with dementia in their community.

Write responses in the second column.

Assessment: each participant must create their own written list of services and individual workers that can be partners in working with Aboriginal communities and dementia. They should include contact details and hand this in to be assessed. It can be completed after the training if further research is required.
<table>
<thead>
<tr>
<th>Support person</th>
<th>Name &amp; title</th>
<th>Contact details</th>
<th>Brief description of role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immediate family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extended family</td>
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<td></td>
<td></td>
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<tr>
<td>Community members</td>
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<td></td>
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<tr>
<td>Aboriginal health workers</td>
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<td></td>
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<tr>
<td>Aboriginal home and community care workers</td>
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<tr>
<td>Counsellor</td>
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<td>Local GP</td>
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<tr>
<td>Transport drivers</td>
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<tr>
<td>Day centre staff</td>
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<tr>
<td>Cultural or Language Interpreter</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Other</td>
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</tbody>
</table>

**Summary points**

It is important that everyone understands each other’s roles for this network to function well. Reflecting on your role and the role of others will contribute to culturally effective service delivery.
10.6 Exercise: Resources

Purpose: Participants will develop a comprehensive list of resources available in their Community and how they may access additional resources.

Brainstorming

Ask participants to identify:

- What resources currently exist in their community?
- What additional resources are needed?
- How can additional resources be accessed?

Write responses in three columns on the whiteboard or flip chart. Lead a discussion on the responses to each of the questions.

Make a list of resources that are available locally, State/Territory or Nationally.

<table>
<thead>
<tr>
<th>Local</th>
<th>State/Territory</th>
<th>Nationally</th>
</tr>
</thead>
<tbody>
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</tbody>
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10.10 Legal and Financial Planning

Facilitator note:
The way legal and financial matters are administered will vary between the States and Territories. It is important that you are familiar with local information and check local contact details. State and Territory contacts and resources are provided below; because these details may change it is important that you check them prior to using the information. It is also important to check the services available from your local Aboriginal and Torres Strait Islander legal centre.

As dementia progresses, the person’s ability to make decisions decreases. Eventually the person will be considered to have lost the capacity to make decisions about financial and legal matters.

Planning ahead will enable the person to participate in the decision making and make arrangements that they feel comfortable about. They may choose a trusted family member or friend to make financial, health and lifestyle decisions for them. However, some situations, such as managing a bank account, require legal authority. A community legal centre, the Public Trustee, Guardianship Board, a solicitor or law society can provide advice and assistance with these matters.

Areas to be considered include:

Making a will

A will provides instructions about the distribution of the estate of a deceased person. It is important for the person with dementia to make or update their will while they are capable of doing so. Without a will, there is no guarantee that the person’s wishes will be carried out after death and this can cause conflict and stress.
Enduring power of attorney

An enduring power of attorney is a legal arrangement for a person to look after another’s financial affairs if they become unable to do so themselves. It is usual for a person appointed as enduring power of attorney to deal with all assets. This means it is very important that the right person is chosen.

An enduring power of attorney continues until the person dies.

An enduring power of attorney can only be signed by a person who is legally competent at time of signing.

It is advisable that the opportunity to appoint a person as an enduring power of attorney be provided as soon as possible after diagnosis if the person has not already done so, because it is too late to appoint a person after the person with dementia has lost capacity to manage their own affairs.

Conditions of enduring power of attorney differ in each State/Territory, so it is necessary to seek advice.

Enduring power of guardianship

Enduring power of guardianship is a legal arrangement that enables a person to appoint another to be their guardian to make personal, health or lifestyle decisions for them.

A person can only sign an Enduring power of guardianship if they are legally competent at time of signing, but the appointment only comes into effect at a time when the person loses the capacity to make decisions for themselves.

In some circumstances a guardian may be appointed by a State or Territory government to act on behalf of a person who has lost the ability to make their own decisions. This may occur if there are problems in dealing with the affairs of the person with dementia, or if there is conflict in the family about the person’s best interest.

Advocacy

Advocacy in relation to a person who has dementia is about standing alongside that person and speaking or acting on his/her behalf in a way that that represents the best interest of that person.

Some of the common aims of advocacy are to:

- protect the person’s rights
- be responsive to and emphasise individual needs and wishes
- overcome barriers that restrict opportunities
- ensure appropriate societal and service delivery responses
- ensure a better quality of life.

Advocacy can be by one person for another, or it can occur through a public office or department.

Further information about public advocacy can be located on websites included in the State and Territory Contacts list.

Financial support

A person with dementia and a person who is providing full time care for a person with dementia may be eligible for some government benefits. The Carer Payment and Care Allowance provide income support payments for carers who, because of the demands of their caring role, are unable to support themselves through full participation in the workforce.

A younger person with dementia who is unable to work may be eligible for a Disability Support Pension. A Centrelink office can provide information on these benefits and allowances.

Information can also be obtained form the Department of Veterans’ Affairs about the range of financial assistance and support for veterans, war widows, their families and carers.

Other formal arrangements

In some States and Territories other formal arrangements are available, including medical guardianship, enduring power of medical guardianship and advance directives.

An advance directive may allow a person to define the medical treatment they wish to have, or refuse, should it become difficult to make these decisions later on.
State and Territory Contacts

Facilitator note
Contact details are subject to change – check the details before using

ACT
The Public Advocate (02) 6207 0707

New South Wales
Office of the Public Guardian (02) 9265 3184
Guardianship Tribunal (02) 9555 8500

Northern Territory
The Land Titles Office (08) 8999 6520 Darwin
(08) 8951 5339 Alice Springs
The Office of Adult Guardianship (08) 8999 2557

Queensland
Department of Justice (07) 3234 0870 or
and Attorney-General (07) 3234 0870

South Australia
Office of the Public Advocate (08) 8269 7575 or
1800 066 969 (country SA only)
Public Trustee (08) 8226 9200
www.publictrustee.sa.on.net/productsAndServices/legalDocuments/enduringGuardian/index.htm

Tasmania
Office of the Public Guardian (03) 6233 7608
Guardianship and Administration Board (03) 6233 3085
www.guardianship.tas.gov.au/

Victoria
Office of the Public Advocate (03) 9603 9500

Western Australia
The Department of Justice 13 12 17 or (08) 9264 1711
The Public Advocate (08) 9278 7300 or
1800 807 437

Resources:
State & Territory contacts are included below
(NOTE: check prior to using)
Alzheimer’s Australia Legal Planning, [online ]
and Resources then Legal Planning & Dementia
internet/wcms/publishing.nsf/Content/Dementia-1

Living with dementia: Links to resources on coping with dementia on a daily basis http://www.healthinsite.gov.au/topics/Living_with_Dementia