

Memory Support Guide

**Information and
Services covering the
Grampians Pyrenees
Region Victoria**

**A
comprehensive
guide to
support people
to live well with
memory
changes and
dementia**



2020

ACKNOWLEDGEMENTS

In November 2012, *Grey Matters: A Guide for living well with Memory Loss and Dementia in the Grampians Region* was produced with funding provided by the Department of Health and Human Services. The 'Grey Matters' guide has been a valuable source of information for consumers however with the national Aged Care reforms in 2016, the document did not reflect the many changes in the service system and the impact on assessment and referral pathways.

In 2018, the Grampians Regional Dementia Provision Forum (supported by the Grampians Sector Development team) identified a need to update the 'Grey Matters' guide and provide information on services available across the Grampians region. As such, *The Memory Support Guide: A comprehensive guide to support people to live well with memory changes and dementia* was developed.

Wimmera Primary Care Partnership led this work and developed the new document. Contributions to this guide were made by members of the Grampians Regional Dementia Provision Forum. Special thanks go to Dementia Australia for their assistance and for providing access to resources and information. Specific regional information was provided by Central Highlands Primary Care Partnership and Grampians Pyrenees Primary Care Partnership.

With more changes to the aged care and disability sectors, this guide was reviewed in May 2020 by the PCPs and Dementia Australia and changes were made to reflect the current service system in the three catchment areas.

This guide has been developed with the support of the Grampians Sector Development team. Although funding for the printing of this guide has been provided by the Commonwealth and State Governments, the material contained herein does not necessarily represent the views or policies of either government.

HOW TO USE THIS INFORMATION

This guide has been developed to help assist any person with memory changes and their family and carers to access relevant information and support in the Grampians Pyrenees Region of Victoria that is specific to living well with memory loss and dementia.

All information was accurate at the time of publishing and may be subject to change.

Services listed in this guide might require a fee payment and it is best to consult each individual agency for fee information.

Although this document is not provided in any other language than English, Dementia Australia has a variety of help sheets, tip sheets and resources available to be downloaded from their website in other languages.

A copy can be obtained by emailing your local Primary Care Partnership at admin@gppcp.org.au.

The Memory Support Guides are available in PDF format on the three Primary Care Partnership (PCP) websites www.chpcp.org, www.wimmerapcp.org.au and www.grampianspyreneespcp.org.au

It is also available on the Grampians Sector Development website www.csdgrampians.org.au

If you have feedback about this document, please email admin@gppcp.org.au.

THE GRAMPIANS PYRENEES REGION OF VICTORIA



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What is Dementia?

Dementia affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person's normal social or working life. The hallmark of dementia is the inability to carry out everyday activities as a consequence of diminished cognitive ability.

The cognitive functions affected can include memory, language skills, understanding information, spatial skills, judgement and attention. People with dementia may have difficulty solving problems and controlling their emotions. They may also experience personality changes.

With many types of dementia, some of the nerve cells in the brain stop functioning, lose connections with other cells, and die. Dementia is usually progressive. This means that the disease gradually spreads through the brain and the person's symptoms get worse over time.

WHO GETS DEMENTIA?

Dementia can happen to anybody, but the risk increases with age. Most people with dementia are older, but it is important to remember that not all older people get dementia. It is not a normal part of ageing, but is caused by brain disease. Less commonly, people under the age of 65 years develop dementia and this is called 'younger onset dementia'.

There are a few very rare forms of inherited dementia, where a specific gene mutation is known to cause the disease. In most cases of dementia however, these genes are not involved, but people with a family history of dementia do have an increased risk.

Certain health and lifestyle factors also appear to play a role in a person's risk of dementia. People with untreated vascular risk factors including high blood pressure have an increased risk, as do those who are less physically and mentally active.

COMMON FORMS OF DEMENTIA

Alzheimer's Disease: the most common form of dementia, accounting for around two-thirds of cases. It causes a gradual decline in cognitive abilities, often beginning with memory loss.

Vascular Dementia: a cognitive impairment caused by damage to the blood vessels in the brain. It can be caused by a single stroke, or by several strokes occurring over time. The symptoms of vascular dementia can begin suddenly after a stroke, or may begin gradually as blood vessel disease worsens. Vascular dementia may appear similar to Alzheimer's disease, and a mixture of Alzheimer's disease and vascular dementia is fairly common.

Lewy Body Disease: characterised by the presence of Lewy bodies in the brain. These abnormalities cause changes in movement, thinking and behaviour. People may experience large fluctuations in attention and thinking. They can go from almost normal performance to severe confusion within short periods. Visual hallucinations are also a common symptom.

Three overlapping disorders can be included with Lewy body disease:

- Dementia with Lewy bodies
- Parkinson's disease
- Parkinson's disease dementia

Frontotemporal Dementia: involves progressive damage to the frontal and/or temporal lobes of the brain. Symptoms often begin when people are in their 50s or 60s and sometimes earlier. There are two main presentations of frontotemporal dementia – frontal (involving behavioural symptoms and personality changes) and temporal (involving language impairments). However, the two often overlap.

People with frontotemporal dementia often have problems maintaining socially appropriate behaviour. They may be rude,

neglect normal responsibilities, be compulsive or repetitive, be aggressive, show a lack of inhibition or act impulsively.

There are two main forms of language variant of frontotemporal dementia. Semantic dementia involves a gradual loss of the meaning of words, problems finding words and remembering people's names, and difficulties understanding language. Progressive non-fluent aphasia is less common and affects the ability to speak fluently.

CAN DEMENTIA BE INHERITED?

This will depend on the cause of the dementia, so it is important that the person with memory issues have a firm medical diagnosis. The majority of cases of dementia are not directly inherited and likely arise from a combination of genetic and environmental effects.

Entirely inherited dementia due to a family link is a rare form of dementia and accounts for fewer than 5% of cases. It is often subject to very early onset, occurring in people in their 30's or 40's.

YOUNGER ONSET DEMENTIA

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

A person with younger onset dementia will have different needs because the dementia appears at an earlier stage of their life when they are likely to be more physically and socially active. When diagnosed they may be:

- In full time employment
- Actively raising a family
- Financially responsible for the family
- Physically strong and healthy

Changed behaviours that are associated with dementia may be more difficult to accept and manage in a younger person. For the family members who are caring for someone with younger onset dementia, there are a number of issues that may arise:

Loss: The sense of loss for the person with younger onset dementia and their family can be enormous. Unplanned loss of income if the person with dementia was earning an income can be a major problem for the family. This can be made worse by the loss of self-esteem that comes if employment ceases, and the loss of a purpose in life. Future plans, perhaps for travel and retirement, or time with children or grandchildren, may no longer be viable.

Changes: Carers who are partners, may have double the responsibility of caring for the person with dementia, as well as possibly raising children and managing finances. Sometimes families and carers have to reduce or give up work altogether to care for the person with dementia. These changes can be significant.

Attitudes: An added difficulty can be the attitude of other people. It can be difficult to accept that a younger person can have dementia, particularly when no obvious physical changes can be seen. It may appear that no-one else in the family or carer's age group understands what is happening. Most people affected by the illness find that friendships may fade as the dementia progresses, but a younger person's friends may break away even earlier.

Children: Children may react differently to the disease, but are likely to have strong reactions. At a time when they are trying to cope with their own growing up, they find that they also have to cope with a family member who is unwell. They may become angry, resentful and withdrawn. Some young people may have problems talking with their parents because they don't want to worry them or are afraid of making them sad, or of being an extra burden. They may prefer to talk to people their own age or to a counsellor.

RISK FACTORS

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

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

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

High cholesterol: Cholesterol is essential to brain function – however, studies have shown that, high cholesterol in mid-life and late-life can increase the risk of Alzheimer's disease. Subsequent studies have indicated that cholesterol lowering drugs may lower the risk of developing Alzheimer's disease.

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

Genetic: Some risk factors predisposing to dementia are associated with genetic inheritance, for example: Genes associated with Alzheimer's disease or One gene (Apolipoprotein E) has been associated with an increased risk of late onset Alzheimer's disease while three additional genes (Amyloid Precursor Protein, presenilin 1 and Presenilin 2) are associated with early onset Alzheimer's disease.

Family history

A family history of dementia may increase one's risk of developing dementia particularly when combined with the other risk factors.

Head injury

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

HOW TO REDUCE RISK

Visit a GP regularly

All adults from the age of 18 years should have their blood pressure checked regularly and follow their doctor's advice about having their blood cholesterol and blood glucose levels tested.



Find a GP - www.healthdirect.gov.au

Western Victoria PHN - www.westvicphn.com.au

Connect with Others

To help look after a person's own brain health it's important to be social with people whose company they enjoy and in ways that interest them. Spending time with friends and family creates better brain function and reduces risk of chronic diseases such as dementia.

Social activity might include involvement in groups such as Men's Sheds, Rotary, Probus, Over 50s or senior citizens clubs. Visits to friends, card or coffee groups, or spending time with family may also be rewarding.



Australian Men's Shed Association - 1300 550 009 -

www.mensshed.org

Neighbourhood Houses Victoria - (03) 9602 1228 -

www.nhvic.org.au

Probus - 1300 630 488 - www.probusouthpacific.org

 **Rotary Club Finder** - <https://my.rotary.org>
Senior Citizens Club – contact you local council to find your nearest Senior Citizens Club
Ararat Rural City - (03) 5355 0200
Northern Grampians Shire - (03) 5358 8700
Pyrenees Shire - 1300 797 363
U3A Network – University of the 3rd Age - (03) 9670 3659 - www.u3avictoria.com.au

Challenge Your Mind

Keeping a person's mind active is important to keep it functioning well. Challenging the mind with new activities helps to build new brain cells and strengthens connections between them.

There is no one activity linked to better brain health so it is recommended that everyone incorporate a variety of mentally stimulating activities into their day. Choose activities that can be started at an easier level but provide the opportunity to further challenge themselves as they become better at that activity.

Some activities that people may wish to consider are:

- A hobby such as painting, carpentry, craftwork or collecting
- A course such as gardening, computers, cooking, woodwork
- Reading the newspaper or different styles of books
- Writing poetry or keeping a diary
- Playing new board games
- Learning to dance, play a musical instrument or speak another language
- Getting involved with a local club or local community group
- Doing jigsaws, crossword or number puzzles
- Researching a topic that is of interest using the internet or the local library

Food for Life

A healthy, balanced diet can help in maintaining brain health and functionality and there are specific foods that can help to reduce the risk of dementia. There is evidence from recent studies in Europe that the age-specific rates of dementia may be modifiable. It is possible that environmental and lifestyle factors, such as diet and exercise, could make a significant contribution to reducing the risk of developing dementia. The changes in the brain that lead to dementia begin up to 20 years before symptoms first appear. People of all ages can make simple lifestyle changes that may reduce their risk of dementia, such as increasing physical activity and controlling blood pressure and cholesterol.

➔ **Heart Foundation** - 13 11 12 - www.heartfoundation.org.au

Enjoy Being Active

Being physically active stimulates your brain and strengthens your heart it is also associated with better brain function and reduced risk of cognitive decline and dementia.

Physical activities might include walking, gardening, mowing the lawn, golf, bowls, tennis, exercise classes, stretching exercises at home, yoga or tai chi.

To find out what is happening in your community, contact your local community health centre or local government office.

➔ **Ararat Rural City Council** - (03) 5355 0200 - Cnr Vincent & High Streets Ararat - www.ararat.vic.gov.au

Grampians Community Health - (03) 5358 7400 –
8–22 Patrick Street Stawell - www.gch.org.au

Northern Grampians Shire Council - (03) 5358 8700 –
59 Main Street Stawell - www.ngshire.vic.gov.au

Pyrenees Shire Council - 1300 797 363- 5 Lawrence Street
Beaufort - www.pyrenees.vic.gov.au

Risk Reduction Resources

Dementia cannot yet be prevented or cured, so it's important for us to be aware of what we can do to reduce the risk of developing it. Dementia Australia has resources that promote a 'brain healthy' lifestyle, and also provides advice on how you can reduce your risk of developing dementia.

 **Risk Reduction Resources** - www.dementia.org.au

DEMENTIA AUSTRALIA

Dementia Australia represent the 459,000 Australians living with dementia and the estimated 1.6 million Australians involved in their care. They advocate for the needs of people living with all types of dementia, and for their families and carers, and provide support services, education and information.

Dementia Australia are committed to a strong consumer focus and deliver national dementia programs and services including:

- The National Dementia Helpline
- Early intervention programs such as *Living with Dementia*
- Dementia and Memory Community Centres
- Counselling
- Carer support groups
- Education for family carers
- Public awareness activities
- A national resources program

Through their work they are committed to ensuring that people:

- Be treated with courtesy and respect
- Have their personal beliefs and privacy respected
- Be informed of the range of services provided by Dementia Australia
- Be informed of services provided by other organisations that may be of assistance
- Select the services they wish to use

- Be informed of their rights and responsibilities
- Have a person of their choice accompany them or act on their behalf
- Have access to interpreter services
- Have access to their records and be informed as to how information may be used.



Dementia Australia - 1800 100 500 - www.dementia.org.au

Dementia Resources & Help Sheets - www.dementia.org.au - Help Sheets



Pathways to Diagnosis

DIAGNOSING DEMENTIA

Initial concerns about memory should be discussed with your family. People may also feel comfortable discussing their concerns with other workers who may be involved in supporting them such as a district nurse or community care worker. Memory issues become a problem if they notably disrupt a person's everyday life.

There are a number of conditions that produce symptoms similar to dementia. These can often be treated.

It is essential that a medical diagnosis is obtained at an early stage when symptoms first appear to ensure that a person who has a treatable condition is diagnosed and treated correctly. If the symptoms are caused by dementia, an early diagnosis will mean early access to support, information and medication should it be available.

Because the diseases that cause dementia develop gradually, the early signs may be very subtle and not immediately obvious. Early symptoms also depend on the type of dementia and vary a great deal from person to person. There is no rush to make a diagnosis immediately. Time can be used to help identify changes and make adjustments.

Common early symptoms include:

- Memory problems, particularly remembering recent events
- Increasing confusion
- Reduced concentration
- Personality or behaviour changes
- Apathy and withdrawal or depression
- Loss of ability to do everyday tasks

Sometimes people fail to recognise that these symptoms indicate that something is wrong. They may mistakenly assume that such behaviour is a normal part of ageing, or symptoms may develop so

gradually they go unnoticed for a long time. Sometimes people may be reluctant to act even when they know something is wrong. For the person experiencing the symptoms, the very nature of these changes within the brain may mean that the person is unable to recognise that there are changes.

Warning signs

This is a checklist of common symptoms of dementia. Go through the list and tick any symptoms that are present. If there are several ticks, consult a doctor for a complete assessment.

- Memory loss that affects day-to-day function** - A person with dementia may forget things often or not remember them at all.
- Difficulty performing familiar tasks** - A person with dementia may have trouble with all the steps involved in preparing a meal.
- Disorientation to time and place** - A person with dementia may have difficulty finding their way to a familiar place, or feel confused about where they are, or think they are back in some past time of their life.
- Problems with language** – A person with dementia may forget some words or substitute inappropriate words, making them difficult to understand. They might also have trouble understanding others or complain of a hearing difficulty
- Problems with abstract thinking** - A person with dementia may have trouble knowing what numbers mean or what to do with them.
- Poor or decreased judgement** - A person may have difficulty making appropriate decisions, such as what to wear in cold weather.

Problems with spatial skills - A person with dementia may have difficulty judging distance or direction when driving a car.

Problems misplacing things - A person with dementia may often put things in inappropriate places.

Changes in mood, personality or behaviour – Some people with dementia may exhibit rapid mood swings for no apparent reason or become confused, suspicious or withdrawn. Some can become disinhibited or more outgoing.

A loss of initiative - Dementia may cause a person to lose interest in previously enjoyed activities.

A correct diagnosis is important

Consulting a health professional (doctor, district nurse, practice nurse) at an early stage is critical. Only a medical practitioner can diagnose dementia. A complete medical assessment may identify a treatable condition and ensure that it is treated correctly, or it might confirm the presence of dementia.

An assessment may include the following:

- Medical history
- Physical examination
- Laboratory tests
- Neuropsychological or cognitive testing
- Brain imaging
- Psychiatric assessment

People can:

- Take a relative or friend with them
- Ask questions and request further explanations if they don't understand
- Take notes during the visit
- Discuss the option of a second opinion

It may take several consultations over weeks or months. Diagnosing dementia is a lengthy and often frustrating process and people need to be patient and not expect an immediate answer.

If the person will not visit the doctor

Some people may be resistant to the idea of visiting a doctor. One of the best ways to overcome this problem is to find another reason to visit the doctor. Perhaps suggest a blood pressure check or a review of a long-term condition or medication. Another way is to suggest that it is time for the person and their partner/family member to have a physical check-up. A calm attitude at this time can help overcome the person's worries and fears.

If the person still won't talk to a doctor someone else can ask their own doctor or the person's doctor for advice. If you feel the doctor is not taking concerns seriously, consider seeking a second opinion.

SPECIALIST ASSESSMENT SERVICES

The doctor may refer a person with memory issues to see a geriatrician, neurologist or psychiatrist at the Cognitive Dementia and Memory Service (CDAMS). Specialists in CDAMS have expertise in the diagnosis of memory issues.

If a referral for further assessments is required it is important that the person ask their doctor about what to expect. Some questions they could ask are:

- What tests will be conducted and how long will they take?
- Will there be a cost involved?
- What follow-up will be necessary?
- How will I be informed of the test results and the diagnosis?
- Who else will be told of their results and diagnosis?
- Will the doctor be given information about them?
- Who will give them information on supports available if they are given a diagnosis of dementia?

COGNITIVE DEMENTIA & MEMORY SERVICE

The aim of the CDAMS clinic is to assist people experiencing early changes to their memory and thinking by providing assessment and diagnosis of dementia, its causes, and the associated psychological, medical and social difficulties. An Assessment may include a visit to the person's own home.


A CDAMS assessment will usually include an initial nursing assessment, medical assessment, feedback session and follow-up. About half of the patients will have a neuropsychological assessment. Where a diagnosis is unclear assessments will often be repeated. There may be several months wait between assessments. CDAMS provides initial short-term support and referral to other programs and services after diagnosis but doesn't provide ongoing treatment or case management.

The CDAMS clinic for the Grampians Region is in Ballarat and an outreach service operates in Horsham.

CDAMS will make contact to arrange appointments following receipt of the referral from the GP.

CDAMS clinics require pre-appointment tests and full history and the doctor will generally be the one to handle this.

More information about the diagnosis of dementia (the steps/questions) can be found on the Dementia Pathway Tool www.dementiopathways.com.au.

 **Cognitive Dementia & Memory Service** - (03) 5320 3704
Queen Elizabeth Centre, 102 Ascot Street South, Ballarat
www.bhs.org.au - [Cognitive Dementia & Memory Service](http://www.bhs.org.au)

THE COMPLEX GERIATRIC CLINIC

Diagnosing complex geriatric problems for older people is available through this service. The clinic is a geriatrician lead, MBS funded clinic, that requires a GP referral. It will evaluate, discuss and prioritise with the person (and their families), their various health issues taking into account all medical, physical, psychological and social factors.

A written report will be provided to the treating General Practitioner with recommended actions or strategies aimed at improving the person's health and life.

The service is available for people in Residential Aged Care Facilities across the Grampians region. The clinic will be provided by telehealth unless a face to face consultation is essential.



The Complex Geriatric Clinic - (03) 5320 3791 - Queen Elizabeth Centre, 102 Ascot Street South, Ballarat

SPECIALIST GERIATRICIAN

A referral for further investigation and diagnosis can also be made directly to a geriatrician, neurologist or an aged care psychiatrist if a person does not have access to the CDAMS clinic. A referral by a doctor is required in most instances for people to obtain a Medicare rebate and to seek diagnosis and qualification for access to subsidised medical treatment. Your doctor will have a list of suitable specialists when required.

DEMENTIA BEHAVIOUR MANAGEMENT ADVISORY SERVICE & SEVERE BEHAVIOUR RESPONSE TEAMS

Dementia Behaviour Management Advisory Service (DBMAS)

The DBMAS supports staff and carers in community, residential, acute and primary care settings with information, advice, assessment and short term case management interventions.

Services include:

- Assessment of the person with dementia and their carer/ support network;
- Clinical support, information and advice
- Care planning, case conferences, referrals and short term case management;
- Mentoring for care providers and clinical supervision;
- Capacity and knowledge building for care providers;
- Help to link to current research, literature and evidence based practice guidelines;
- Translation and interpreting services for clients from culturally and linguistically diverse backgrounds;
- Behaviour consultants with Aboriginal and Torres Strait Islander and CALD portfolios;
- Advice and support that is relevant to other special needs groups (eg. Younger/Working Age Dementia, learning disability and dementia)
- Referrals to the SBRT (Severe Behaviour Response Teams).

 **Dementia Support Australia** - 1800 699 799 (24 hr) - www.dementia.com.au

Severe Behaviour Response Teams (SBRT)

The SBRT are a mobile workforce available to provide timely expertise and advice to Commonwealth funded approved Residential Aged Care Facilities, Multi-Purpose Services, or Flexibly Funded Services requiring assistance.

They include nurse practitioners, nurses, allied health and specialist staff and address the needs of people with severe and very severe Behavioural and Psychological Symptoms of Dementia (BPSD).

 **Dementia Support Australia** - 1800 699 799 (24 hr) - www.dementia.com.au



Support

&

Assessments

MY AGED CARE

My Aged Care is an Australian Government initiative to help people over the age of 65 years or over 50 years for Aboriginal & Torres Strait Islander people, or 50 years or older (45 years or older for Aboriginal and Torres Strait Islander people) and on a low income, homeless or at risk of being homeless find out what aged care services may be available to help them.


A person may be eligible to receive some supports such as assistance with home based services.

To access this support a person must ring My Aged Care. They will be asked questions over the phone to help work out their needs and care arrangements – this takes at least ten minutes. When making a phone call for the first time they will need their Medicare card. If they would like someone to call My Aged Care for them, they will need to give them their consent.

My Aged Care may then arrange for a trained assessor to come to the person's home. With the person's consent the assessor will determine their care needs and eligibility for services and work with them to develop a support plan which addresses their needs, goals and preferences. Someone else can be with the person during this visit.

My Aged Care and service providers can give people information about the cost of services.

The Service Finder on the My Aged Care website can help people locate and compare service providers in their area once they know which type of care they are eligible for. Their assessor and My Aged Care can also help people find a service provider(s) in their local area that meets their needs.

 **My Aged Care** - 1800 200 422 - www.myagedcare.gov.au

THE HACC PROGRAM FOR YOUNGER PEOPLE

The HACC Program for Younger People (HACC PYP) offers a range of support services that can enable people to live independently at home and remain socially connected to their community. HACC PYP is for people under the age of 65 and Aboriginal and Torres Strait Islander people under the age of 50 who need assistance with daily activities including personal care, dressing, preparing meals, house cleaning, property maintenance, community access and using public transport.

People can approach a funded service provider themselves for a particular service such as personal care, or with their permission a referral can be made by family, their doctor or other allied health professions.

Under this program, a Living at Home Assessment is required. This is a broad, strengths based assessment that seeks to identify a person's needs and priority for assistance. It also takes into account carer need for support and further assistance.

The assessment is undertaken in a person's own home, with their carer or family member and it explores the things that people can do (strengths), what they would like to continue doing (interests) and links them to new activities that can assist them to live well with dementia.

The focus is to promote independence and maintain skills. It also focuses on the strengthening of family, community and social connections. Periodic reviews are undertaken or as needs change throughout the progression of dementia.

Please consult with your nearest assessment service for more information.

 **Ararat Rural City Council** - (03) 5355 0200 - Cnr Vincent & High Street Ararat - www.ararat.vic.gov.au
Northern Grampians Shire Council - (03) 5358 8700 - 59 Main Street Stawell - www.ngshire.vic.gov.au
Pyrenees Shire Council - 1300 797 363 - 5 Lawrence Street Beaufort - www.pyrenees.vic.gov.au

NATIONAL DISABILITY INSURANCE SCHEME

If a person is under 65 years of age and has a diagnosis of dementia, they may also be eligible for services through the National Disability Insurance Scheme (NDIS). The NDIS provides individualised support and services for eligible people living with younger onset dementia (a diagnosis under the age of 65 years).

They can access the NDIS if they are under 65 years old, are an Australian citizen or a permanent resident, and have a diagnosis of dementia.

To apply for the NDIS, call the National Disability Insurance Agency or visit your Local Area Coordination (LAC) service.

Once a person is approved for the NDIS they will participate in a planning conversation meeting to discuss their needs and goals. Once a person's plan has been approved, they can ask for assistance from their support coordinator (if you have one) or your Local Area Coordination (LAC) Service to help find the services they need.

 **National Disability Insurance Agency (NDIA)** - 1800 800 110 - www.ndis.gov.au
NDIS Local Area Coordination – LaTrobe Community Health Service –1800 242 696 - www.lchs.com.au - **NDIS**

AGED CARE ASSESSMENT SERVICES

The Grampians Aged Care Assessment Service (ACAS) is the Victorian Commonwealth funded service which assesses the care needs of older people to assist them to access the most appropriate types of care, including approval for Australian Government subsidised care services.

This regional team of health professionals assess the needs of frail older people and younger people with disabilities (where required) to facilitate access to care services appropriate to their needs. The assessor, with the person's permission, may seek to consult their doctor or other health professionals already involved in their care, to gain more information during the assessment process. The comprehensive assessment can be conducted in home or in hospital.

A person may be approved to receive one or more of the following types of care:

- Residential Care
- Residential Respite Care
- Home Care Package
- Transition Care Program
- Short Term Restorative Care

The assessor may also provide information and refer clients to services that are appropriate and available, including facilitating access to broader community services such as Commonwealth Home Support Programme (CHSP) to meet their needs and preferences.

As the person's needs change or their need for support to continue living at home increases, they may be referred to ACAS for an assessment by their current service provider, health professional or doctor. The person or their family can also self-refer for an assessment to access aged care services via My Aged Care.

Where a Geriatrician assessment is sought a written referral from a doctor is required. These referrals are to be sent directly to Ballarat Health Services Central Intake.



Ballarat Health Services Central Intake - (03) 5320 6690 –

Email: Centralintaketriage@bhs.org.au

My Aged Care - 1800 200 422 - www.myagedcare.gov.au

Grampians Aged Care Assessment Service - (03) 5320 3740 –
www.bhs.org.au - ACAS



Support Options

This chapter outlines some of the support options and services that are available within the Grampians Pyrenees Region. Many of these services are provided through government funded programs.

COMMONWEALTH HOME SUPPORT PROGRAMME

The aim of the Commonwealth Home Support Programme (CHSP) is to support frail aged people live as independently as possible – with a focus on working with the client, rather than doing the work for them. It is about working on their strengths, capacity and goals to help them remain living independently and safely at home.


Services funded under the CHSP include:

- Domestic assistance
- Transport
- Meals
- Personal care
- Home maintenance and modifications,
- Social support
- Nursing
- Allied health.

Costs

The Australian Government subsidises a range of aged care services to keep client fees reasonable and affordable. If someone is eligible, they are expected to contribute to the cost of their care if they can afford to. The person does not need an income assessment to access CHSP services and their age pension will not be affected.

The person will need to discuss and agree to any fees with their service provider before they receive services. Service providers should have a fee policy with arrangements for those who are unable to pay their fees due to hardship.

 **My Aged Care** - 1800 200 422 - www.myagedcare.gov.au


HOME CARE PACKAGES

The Australian Government's Home Care Packages Program helps people to live independently in their own home for as long as they can. The Program provides a subsidy towards a package of care, services and case management to meet their personal needs.

There are four levels of home care packages. A professional assessor will work with a person to find out if a home care package is the right service for them, which level of service they need and when they might need it.

Each level of home care package provides a different subsidy amount. This amount is paid to an approved home care provider that the person has selected. The subsidy contributes to the total cost of their service and care delivery. It is also expected that they will contribute to the cost of their care where their personal circumstances allow.

Approved home care providers will work in partnership with the person to tailor care and services to best support their needs and goals.

 **My Aged Care** - 1800 200 422 - www.myagedcare.gov.au

THE HACC PROGRAM FOR YOUNGER PEOPLE

The Home and Community Care Program for Younger People (HACC PYP) offers a range of support services that can assist people to live independently at home and remain socially connected to their community.

HACC PYP services provide support with daily activities, including:

- Personal care,
- Delivered meals
- Domestic Assistance

- Respite
- Property maintenance,
- Planned activity group
- Nursing
- Allied health
- Case Management

The focus of the program is to promote independence and maintain skills. It also focuses on strengthening of family, community and social connections. Periodic reviews are undertaken or as needs change throughout the progression of dementia.

Please consult with your nearest service for more information.

-  **Ararat Rural City Council** - (03) 5355 0200 - Cnr Vincent & High Street Ararat - www.ararat.vic.gov.au
- Beaufort Skipton Health Service** – (03) 5349 1600 – 23 Havelock St Beaufort - www.bshts.org.au
- East Grampians Health Service** - (03) 5352 9300 - Girdlestone Street Ararat - www.eghs.net.au
- East Wimmera Health Service** - (03) 5477 2222 – 52 North Western Rd St Arnaud - www.ewhs.org.au
- Grampians Community Health** - (03) 5358 7400 – 8–22 Patrick Street Stawell - www.gch.org.au
- Northern Grampians Shire Council** - (03) 5358 8700 - 59 Main Street Stawell - www.ngshire.vic.gov.au
- Pyrenees Shire Council** - 1300 797 363 - 5 Lawrence Street Beaufort - www.pyrenees.vic.gov.au
- Stawell Regional Health** - (03) 5358 8500 - Sloane Street Stawell - www.srh.org.au

NATIONAL DISABILITY INSURANCE SCHEME

The NDIS provides individualised support and services for eligible people under 65 years who are living with dementia.

Once you have an NDIS plan, you can start receiving the services you need. To find an appropriate service provider you can:

- Ask your support coordinator for help (if you have one)
- Search for an NDIS registered provider on the Provider Finder on the myplace portal; or
- Call or visit your Local Area Coordination (LAC) service. In Grampians Pyrenees, the LAC is Latrobe Community Health Service.



National Disability Insurance Agency (NDIA) - 1800 800 110

www.ndis.gov.au

NDIS Local Area Coordination – LaTrobe Community

Health Service –1800 242 696 - www.lchs.com.au - [NDIS](#)

TRANSITION CARE PROGRAM

There may be occasions while living with dementia that a person will need to be treated in hospital for other medical conditions. The transition care program is designed to improve their independence and confidence after a hospital stay and is to assist them to return home instead of considering early admission to residential care.

The program has a short time frame that focuses on providing therapies such as physiotherapy, occupational therapy and social work and also includes nursing and personal care services.

Transition care can last up to 12 weeks and take place in an aged care (nursing) home, a person's home, in the community or a mix of all of these.

To access this program, a person must be assessed by the Grampians ACAS. If eligible, they must enter transition care as soon as they leave the hospital.

MEMORY SUPPORT SERVICE/NURSE

The memory support service is for people and their families living with memory loss or dementia in the community.


Living with memory loss or dementia can have a profound effect on a person's daily life and those around them. The memory support service (or memory support nurse) provides specialised and practical support to anyone living with dementia, or suspected memory loss.

This includes working with families and/or carers.

- Support is delivered in their own home
- Assistance is focused on the areas that they feel are the most important to them
- The aim is to maximise a person's independence to stay living in their home for as long as they can and wish to do so.

The memory support service (or memory support nurse) will:

- Help people to understand their condition
- Navigate support options available in the community
- Give practical strategies on how to live well with memory loss to be able to complete their day to day tasks
- Educate people on how to manage and minimise changed behaviours (for example wandering, anxiety, aggression)
- Support the family and/or carer
- Help a person to plan for the future in relation to driving, legal matters, employment, medical care and care arrangements.

 **Stawell Regional Health** - (03) 5358 8500 - Sloane Street
Stawell - www.srh.org.au - [Memory Support Nurse](#)

DISTRICT NURSING SERVICE

District Nursing is a service that offers nursing support in a person's own home. Nursing support may include assistance with personal care, such as showering, assistance with medicines and wound care.

District nurses undertake a comprehensive nursing assessment for every new client referred to their service. This may include screening for any memory related issues. If a person already receives a district nursing service and they are concerned about their memory, then they may feel comfortable discussing this with the nurse during a visit.

The District Nurse can help a person by assessing their needs and arranging a referral to their local doctor for specialist assessment if required.

District Nurses can also provide support and education to a person, their family and their carer in relation to their needs and help to find and link them with other community services if required and with their permission.

-  **Beaufort Skipton Health Service** - (03) 5349 1625 - 28 Havelock Street Beaufort and 2 Blake Street Skipton - www.bshs.org.au
- East Grampians Health Service** - (03) 5352 9300 - Girdlestone Street Ararat - www.eghs.net.au
- East Wimmera Health Service** - (03) 5477 2222 – 52 North Western Rd St Arnaud - www.ewhs.org.au
- Elmhurst Bush Nursing Centre** - (03) 5355 5000 - 36 Green Street Elmhurst - www.ebnc.org.au/
- Lake Bolac Bush Nursing Centre** – (03) 5355 8700 – 155 Montgomery Street Lake Bolac - www.lbbnc.org.au
- Maryborough District Health Service** – (03) 5461 033 - Avoca- www.mdhs.vic.gov.au
- Stawell Regional Health** - (03) 5358 8500 – Sloane Street Stawell www.srh.org.au

BALLARAT HEALTH SERVICES CARER RESPITE & SUPPORT SERVICES

Ballarat Health Services Carer Respite and Support Services is a **Carer Gateway** service provider and also provides services under the Victorian Support for Carers Program.

Carers and families make a valuable contribution in the life of their loved ones with dementia. Carer Respite & Support Services aim to support carers in their caring role.

Carers can access online, over-the-phone and in-person support including:

- Coaching
- Counselling
- Peer support
- Short-term individual case management
- Assistance to access short-term, occasional and emergency respite
- Information and advice
- Education sessions, support groups and programs
- Carer newsletter

Anyone caring for a family or friend with a disability or mental illness, or is frail, aged or has a chronic condition may be eligible for support.

To access Carer Gateway please call 1800 422 737 or visit www.carergateway.gov.au.

RESPITE CARE

Respite care can support a person and their carer with a break for a short period of time. This gives carers the chance to get to everyday activities or go on a planned break. Respite care may be given informally by family, friends or neighbours, or by formal respite care services.

Formal respite care may be for a few hours, days or for longer periods. It can take place in the home, an overnight respite cottage, a day centre or an aged care home.

There are different types of respite care to suit any situation depending on the person's needs, eligibility and what services are available in the area:

- Community based respite care
- Residential respite care (short stays in aged care homes).

Community based respite care

There are a range of respite services to support a person and their carer so that regular carers can take a break or continue working or training. Community based respite can be on a planned or emergency basis.

Types of respite care include:

- **In-home respite** usually involves a paid carer coming to a person's home so that their carer can go out for a few hours. They may also take them for an outing for a few hours while their carer has a break. This type of respite is available during the day or overnight.
- **Centre-based day respite** usually takes place at a planned activity group or club. It offers structured group activities or outings that give people a chance to do things that they enjoy and talk with other people. Day respite often runs from 10am to 3pm and may include transport to and from the centre.
- **Community access respite** provides activities and outings to give people a sense of independence and some social interaction, while giving their carer a break. This may be provided individually or as part of a group.

Access to community based respite care

A person will need an assessment to work out if they are eligible for planned respite care.

You can contact the Carer Gateway on 1800 422 737 for advice and help in finding a service in your area.

If a person has an NDIS plan, they may be able to access these services as part of their plan. For assistance in finding an appropriate service provider you can:

- Ask your support coordinator for help (if you have one)
- Search for an NDIS registered provider on the Provider Finder on the myplace portal; or
- Call or visit your Local Area Coordination (LAC) service. In the Grampians Pyrenees, the LAC is Latrobe Community Health Service.



Ararat Rural City Council - (03) 5355 0200 - Cnr Vincent & High Street Ararat - www.ararat.vic.gov.au

Carer Gateway - 1800 422 737 – www.carergateway.gov.au

Grampians Community Health - (03) 5358 7400 - 8 – 22 Patrick Street Stawell - www.gch.org.au

My Aged Care - 1800 200 422 - www.myagedcare.gov.au

National Disability Insurance Scheme (NDIS) - 1800 800 110 www.ndis.gov.au

NDIS Local Area Coordination – LaTrobe Community Health Service –1800 242 696 - www.lchs.com.au - NDIS

Northern Grampians Shire Council - (03) 5358 8700 - 59 Main Street Stawell - www.ngshire.vic.gov.au

Pyrenees Shire Council - 1300 797 363 - 5 Lawrence Street Beaufort - www.pyrenees.vic.gov.au

VMCH Western Region – 1300 971 720 – Shop 4/5, 56 High Street Ararat - www.vmch.com.au

RESIDENTIAL RESPITE CARE (SHORT STAYS IN AGED CARE HOMES)

If a person needs help from their carer every day, they may need to have a short stay in an aged care home. This is called 'residential respite care' and can be provided on a planned or emergency basis. This type of respite services may be used if their carer is away, is unwell or unable to provide care for any other reason. Once the carer is back, the person will return home.

Care available

An aged care facility may provide a range of care and services, depending on the person's needs.



Carer Gateway - 1800 422 737 – www.carergateway.gov.au

Ballarat Aged Care - (03) 5320 3620 -
www.ballaratagedcare.org.au

Grampians Community Health - (03) 5358 7400 - 8-22 Patrick Street Stawell - <https://gch.org.au>

This list is not exhaustive. To find other residential respite options in your area contact:

My Aged Care - 1800 200 422 - www.myagedcare.gov.au

National Disability Insurance Scheme (NDIS) - 1800 800 110
www.ndis.gov.au

NDIS Local Area Coordination – LaTrobe Community Health Service –1800 242 696 - www.lchs.com.au - NDIS

COTTAGE RESPITE HOUSES

Cottage respite is an option appreciated by carers as it provides a short weekend break, day and night, which is not based in residential respite care and does not require an ACAS assessment beforehand.

It is available to primary carers of people living with dementia in the community and offers a supervised overnight or weekend stay in a comfortable home-like environment.

The Cottage Respite Program provides small group person-centred care for people not requiring higher-level residential care support. A needs assessment will be completed beforehand by an experienced program coordinator. It is preferred if the person with dementia is already accessing the week-day social support program prior to booking the respite stay to ensure they are familiar with the environment and staff before longer overnight stays away from their home and family.

The cottages in Ballarat and Horsham provide a warm and friendly environment with skilled staff and volunteers, a range of activities, fresh home cooked meals and some assistance with personal care.

A person does not have to live locally to access the cottage respite program but may be more comfortable if familiar with the environment, facility and staff first.



Grampians Community Health - (03) 5358 7400 –
8–22 Patrick Street Stawell - www.gch.org.au

SOCIAL SUPPORT GROUPS (FORMALLY PLANNED ACTIVITY GROUPS)

Social Support Groups (SSGs) provide an opportunity for people to meet other people in a supported social setting and give the carer a break from their normal caring role.

SSG's aim to foster a person's abilities, interests and strengths. They provide an opportunity to share experiences, learn new skills and form new friendships.

The SSG environment is one that encourages people to maintain skills needed for everyday living, their well-being and support their ongoing participation in the community.

Through a person's participation in a SSG, their care and progress is planned and monitored with them, their carer, family and supporting teams.

There are a variety of SSGs available across the region and to attend a person will need to be independent with their mobility and need to be able to cope within a group setting.

There are some dementia specific SSGs throughout the region. As a person's needs change with dementia, these groups may be more appropriate.

Generally referrals will be made by their doctor, health worker or assessment service but a person or their family can also self-refer.



East Grampians Health Service - (03) 5352 9326 - Girdlestone Street Ararat - www.eghs.net.au

East Wimmera Health Service - (03) 5477 2222 – 52 North Western Rd St Arnaud - www.ewhs.org.au

Elmhurst Bush Nursing Centre - (03) 5355 5000 - 36 Green Street Elmhurst - www.ebnc.org.au



Grampians Community Health Centre - (03) 5358 7400 -
8–22 Patrick Street Stawell - www.gch.org.au

My Aged Care - 1800 200 422 - www.myagedcare.gov.au

Lake Bolac Bush Nursing Centre - (03) 5355 8700 –
155 Montgomery Street Lake Bolac - www.lbbnc.org.au

Pyrenees Shire Council - (03) 5358 8700 - 5 Lawrence Street
Beaufort - www.pyrenees.vic.gov.au

Stawell Regional Health - (03) 5358 8500 - Sloane Street
Stawell - www.srh.org.au

SUPPORT FOR CARERS PROGRAM

The Support for Carers Program provides respite, other services and supports for all Victorian carers (including Young carers - carers under 25 years), who are caring for someone who:

- Is older with care needs
- Has a mental illness
- Has a chronic illness
- Has a disability
- Has dementia (including younger-onset dementia)

The program focuses on person-centred care and supports through:

- One-off or short-term support for carers including goods and equipment, that can add to other services or fill service gaps
- Support to people in a care relationship, and at the same time and at the same place if people want to be together while having the support service
- Supporting people's wellbeing - quality of life, physical and mental wellbeing, social activity and or social connections. For example, carers can get respite with social, health and other support.



Annecto – Emergency After Hours Response Service

(EARS) A free telephone support service for any in-home, unplanned non-medical emergency during out of business hours, over the weekend and during public holidays - 1300 487 017

Grampians Community Health Centre - (03) 5358 7400 - 8–22 Patrick Street Stawell - www.gch.org.au

Uniting Grampians - (03) 5352 3836 – 34 Viewpoint Street Ararat www.unitingballarat.org.au

For more information, you can call the Carers Victoria Advisory Line on 1800 514 845 - www.carersvictoria.org.au

CARER SUPPORT GROUPS AND PROGRAMS

For some of us, the chance to meet with people who are dealing with a similar experience is very important and beneficial. Carer support groups provide the opportunity to meet others in the caring role and to share our experiences, our feelings, and our thoughts.

In some areas there are support groups held specifically for people caring for someone with dementia. The opportunity to talk and listen to other carers can help lighten the load and provide them with the strength they need to continue in their role.

Joining a carer support group not only provides an opportunity to receive practical information, tips and resources but it also gives them the chance to form new friendships with people who understand the pressure of caring.



Grampians Community Health - (03) 5358 7400 – 8–22 Patrick Street Stawell - www.gch.org.au

East Wimmera Health Service & St Arnaud Neighbourhood House - 03 5495 3300 - 34 Alma St, St Arnaud - www.stanhi.wixsite.com/stanhi

➔ **Uniting Grampians** - (03) 5352 3836 – 34 Viewpoint Street
Ararat www.unitingballarat.org.au

Carer respite and support services across the Grampians region can assist in linking carers with local support groups and community services.

Carers Australia Vic also provide support to carers including training and workshops to support carers.

➔ **Carer Gateway** - 1800 422 737 - www.carergateway.gov.au
Carers Australia Vic - 1800 514 845 - www.carersvictoria.org.au

CARER CARD PROGRAM

The Carer Card Program gives recognition, understanding and support to Victorian carers.

Participating businesses agree to offer a wide range of discounts and benefits on goods and services exclusively for carers. All offers are easy to use and understand, but also offer genuine value to carers.

➔ **Victorian Government Carer Card Program** - 1800 901 958 -
www.carercard.vic.gov.au

EDUCATION PROGRAMS

Education and knowledge are key to living well with dementia. The benefits of accessing education programs early in a person's diagnosis will help them to build their awareness of the disease and its progression as well as help them to accept and manage the disease as well as possible

The individual will have the opportunity to obtain information and have questions answered, meet and talk confidentially with others in

a similar situation and discuss experiences and focus on maintaining and enhancing skills and abilities.

Education programs also help carers to provide care effectively while at the same time giving them the knowledge to take care of their own health and well-being.

Sessions are delivered by professional educators and counsellors in a supportive environment.

Dementia Australia runs a range of sessions and group programs in regional locations across Victoria. These are offered to families, friends and carers of people living with dementia. To see what sessions and programs are available in your region go to www.dementia.org.au/education/list/carers or call 1800 100 500.

Sessions currently being offered include:

- Understanding Dementia
- Communication & Dementia
- Coping with Changes in Behaviour
- Transition to Respite & Residential Care
- What's it like for EDIE
- How Dementia Friendly is your home
- Driving and Dementia
- Activities at Home
- Mild Cognitive Impairment

 **Dementia Helpline - 1800 100 500**

LIVING WITH DEMENTIA PROGRAM

The Living with Dementia program is a flexible 4-6 week program for people with early stage dementia and their support person.


There are Living with Dementia group programs for people with specific needs:

- Living with Dementia for people with Alzheimer's Disease
- Individual programs for people who have dementia with Lewy Bodies (Lewy Body Disease), mild cognitive impairments, memory loss, and fronto-temporal dementia
- A specialized Living with Dementia Program for people with younger onset dementia.

Living with Dementia is a group program usually held in six weekly sessions or as a residential retreat. Programs are run in both metropolitan and regional locations at no charge to the participants.

The program is very flexible, and options can be discussed with the Dementia Australia team.

The program offers the opportunity for support people and people with dementia to separate into groups, facilitating discussion in small, supportive peer groups of people with similar issues.

 **Living with Dementia** - (03) 9815 7800 - www.dementia.org.au
- [Living with Dementia Program](#)

CREATIVE WAYS TO CARE

This program is delivered specifically for the carer, family or friends and provides them with the opportunity to learn and experience a range of diversional activities to use at home to support them to live positively with dementia.

The program is delivered as a two and half day retreat and aims to provide additional knowledge, skills and resources for carers, family and friends that is supportive of their caring role. The care recipient also attends the retreat and enjoys facilitated activities while the carer attends the education sessions.

 **Grampians Community Health** - (03) 5358 7400 - 8-22 Patrick Street Stawell - www.gch.org.au

MEMORY LANE CAFÉ AND MEMORY SUPPORT GROUPS

These programs are available for people with dementia and their family members or friends.

These cafés and groups provide an opportunity for people with dementia and their family members to enjoy time together with some refreshments and entertainment, in the company of people in a similar situation to themselves.

Anyone can join a group by themselves or through an agency referral.



East Grampians Health Service – Memory Support group -
(03) 5352 9326 - Girdlestone Street Ararat - www.eghs.net.au
Pyrenees Shire Council - Memories & Melodies (Avoca) -
1300 797 363 - 5 Lawrence Street Beaufort
www.pyrenees.vic.gov.au

CONNECTING WITH OTHERS & FRIENDLY VISITING SERVICES

Social support plays an important part in our lives and there is a lot of evidence that suggests daily social activity improves our brain function and helps to lessen decline in our function and physical abilities.

Receiving a weekly visit or phone call from a volunteer can help us to maintain our sense of belonging. It can also help us to retain our self-awareness which is important for overall quality of life and satisfaction.

There are a variety of organisations across the Grampians Pyrenees Region that provide visiting programs. The programs encourage positive social contact that can help to defeat loneliness and isolation.

Some programs may also provide volunteer support to appointments for medical and related services.



Community Visitors Scheme - (03) 9845 2729

East Wimmera Health Service – Volunteer Visiting Scheme

St Arnaud - (03) 5477 2222 - 52 North Western Road

St Arnaud - www.ewhs.org.au

Grampians Community Health – Do Care visiting program

(03) 5358 7400 - 8-22 Patrick Street Stawell - www.gch.org.au

My Aged Care - 1800 200 422 - www.myagedcare.gov.au

National Disability Insurance Scheme (NDIS) - 1800 800 110

www.ndis.gov.au

NDIS Local Area Coordination – LaTrobe Community Health

Service – Ararat & Stawell – 1800 242 696

Switchboard – A free service reducing social isolation in the

LGBTI+ community throughout Victoria - 1800 184 527 -

www.switchboard.org.au - [Out & About](#)

Uniting Grampians - (03) 5352 3836 – 34 Viewpoint Street

Ararat www.unitingballarat.org.au

COUNSELLING & SUPPORT

Dementia Australia Victoria provides counselling to people living with dementia and those affected by or concerned about dementia.


Counselling is provided throughout Victoria by telephone, in person in the family home, at one of our metropolitan or regional offices and via email or video conference by visiting www.helpwithdementia.org.au.

This service is confidential & sensitive.

Dementia counselling can assist by:

- Helping a person gain an understanding of the impact of dementia
- Identifying strategies for coping and living with dementia
- Planning how to care in the future when dementia changes

- Dealing with feelings of stress and a mixture of emotions
- Helping families reach agreement on dementia-related issues
- Making referrals for relevant assistance and services


 **Dementia Australia** - 1800 100 500 - www.dementia.org.au

RESIDENTIAL AGED CARE SERVICES

Residential aged care is for older people who can no longer live at home. Services provide continuous supported care ranging from help with daily tasks and personal care to 24-hour nursing care.

Residential aged care services can provide high and low levels of care to meet the person's needs. Considering long term accommodation and care can be stressful so exploring the options early can ensure that the person knows what they can expect as well as giving them a good understanding of the process involved to access residential care.

Some residential aged care services are specifically designed to cater for people with dementia which include specialised furnishings and equipment. They also provide staff to assist the person with all aspects of personal care (showering, grooming and dressing), eating and nutritional requirements, recreational and social activities, specialised therapy programs and nursing services.

 **My Aged Care** - 1800 200 422 - www.myagedcare.gov.au

OCCUPATIONAL THERAPY

Occupational therapy may improve a person's ability to perform daily activities and reduce the burden on their carer. The focus of occupational therapy is to promote independence, community

engagement and involvement in social activities so that a person can experience a better quality of life for a longer period of time.

An occupational therapist will evaluate a person's current situation in their home environment and then recommend changes, make modifications or assist the person to develop new routines that will enhance their safety and capacity to undertake daily activities.

- ➔ **Beaufort Skipton Health Service** - (03) 5349 1625 – 28 Havelock Street Beaufort - www.bshs.org.au
- East Grampians Health Service** - (03) 5352 9327 - Girdlestone Street Ararat - www.eghs.net.au
- East Wimmera Health Service** –(03) 5477 2222 - 52 North Western Road St Arnaud - www.ewhs.org.au
- Stawell Regional Health** - (03) 5358 8500 - Sloane Street Stawell - www.srh.org.au

This list is not exhaustive. To find Occupational Therapy and other Allied Health service providers in your area contact:

- My Aged Care** - 1800 200 422 - www.myagedcare.gov.au
- National Disability Insurance Scheme (NDIS)** - 1800 800 110 www.ndis.gov.au
- NDIS Local Area Coordination - Latrobe Community Health Services** – 1800 242 696 - www.lchs.com.au - NDIS
- National Health Service Directory** - www.healthdirect.gov.au
- Better Health Channel** – www.betterhealth.vic.gov.au

AIDS & EQUIPMENT

Aids and equipment can be essential and may make life easier and safer for people and their carers. There are many types of equipment available. A person might need equipment and aids for daily tasks like moving, showering or feeding.

People can talk to a doctor, physiotherapist, occupational therapist or allied health professional about getting the right equipment.

Independent Living Centres Australia has a [National Equipment Database](#) that provides information about aids and equipment options across Australia.

Commonwealth government-subsidised schemes

Equipment can be expensive to buy. A person or the person being cared for might be entitled to free or government-subsidised equipment and devices. Look into:

- [National Disability Insurance Scheme](#) (NDIS)
- [Continence Aids Payment Scheme](#)
- Commonwealth-funded [home care packages](#)
- [Rehabilitation Appliances Program](#) (Department of Veterans Affairs)
- [Australian Hearing Services](#)
- A person may also be able to get assistance with the cost of running [essential medical equipment](#), such as oxygen equipment or a home dialysis machine.

State and territory equipment schemes

Each state and territory have its own equipment schemes, although these vary. Equipment is usually loaned free or at low cost. These schemes are often means-tested. In some states there are waiting lists, and a person might not be able to get what they want at the time they want it.

- Victoria: [Aids and Equipment Program](#)

Equipment assistance from non-government organisations

Some non-government organisations also provide and loan equipment or have aids and equipment to purchase.



Independent Living Centres Australia - 1300 885 886 - www.ilcaustralia.org.au

State-wide Equipment Program - 1300 747 937 - PO Box 1993 Bakery Hill - www.swep.bhs.org.au

Vision Australia – 1300 847 466 - www.shop.visionaustralia.org

HOME MEDICINES REVIEW

A Home Medicines Review (HMR) is a free comprehensive clinical review of a person's medicines in their home by an accredited pharmacist on referral from the person's general practitioner (GP). The person may choose to be referred to their local pharmacist or a private pharmacist who meets their needs.


The service involves cooperation between the GP, pharmacist, other health professionals and their patient (and, where appropriate, their carer). A HMR service improves a person's and their health professionals' knowledge and understanding about medicines, facilitates cooperative working relationships between members of the health care team in the interests of patient health and wellbeing and provides medication information to the person and other health care providers involved in their care.

The pharmacist can also show the person how to use and look after any medical devices they may need, such as inhalers, blood pressure monitors and blood glucose monitors.

The pharmacist will write a report and send it to the person's GP. After going through it with the person, the GP will then give them a 'Medication Management Plan'. This should be shared with their healthcare providers.

ABORIGINAL HEALTH SERVICES

The local Aboriginal Health Service deliver health and wellbeing services to their Aboriginal and Torres Strait Islander community and are dedicated to building cultural pride and ensuring their services respect Aboriginal culture, history and experience.

 **Budja Budja Aboriginal Cooperative** - (03) 5356 4751 –
20–22 Grampians Road Halls Gap - www.budjabudjacoop.org.au



Therapies & Activities

REMINISCENCE THERAPIES

There are many ways that we can reminisce with a person with dementia, either one on one, in a group setting, using objects from a memory box or during everyday activities such as mealtimes, shower times, bed times etc.

For the person with dementia, encouraging the act of reminiscence can be extremely beneficial to their feelings of belonging, importance, value and identity. It provides the opportunity to increase social interaction through the sharing of experiences and encourages them to regain an interest in hobbies and past times.

Importantly, reminiscence allows them to take on a teaching role through the sharing of their stories. Reminiscence involves exchanging memories between them and young people, friends and relatives, with caregivers and professionals.

Themes are a good way for people to initiate conversation with a person with dementia during daily tasks. Reminiscing about 'turning 21', their childhood home, heroes, work or other relatives can help to build up their personal 'life history' with them. It provides them with the opportunity to communicate and express themselves.

MEMORY BOXES

Having familiar objects around can be reassuring when living with dementia. A memory box can represent some of the greatest times in their life.

A memory box is a useful way to assist with memory recollection from the past and provides family, friends and care workers with a meaningful activity that can be undertaken when spending time with a person with dementia.

It is best to begin putting together a memory box as soon as the person has a diagnosis of dementia. That way they can be involved in deciding what to include.

Typical items that can be included are photographs of family and friends at gatherings and special occasions, pieces of jewellery, tickets and programmes to events that they may have attended and even mementos that were used by them in their working life.

They may want to include items that have an interesting texture such as fabric or a soft toy. A favourite perfume can trigger wonderful memories. A CD with their favourite music can provide an activity that can help improve mood and thoughts. It can even get the person singing and dancing.

For women, they may have enjoyed wearing nail polish in the past, so having a few colours in the box can provide an activity to share with the person visiting.

For men, they may have enjoyed playing marbles or spinning tops as a boy. Holding these familiar objects can help calm anxiety and trigger warm emotions and recollection of their history.

A memory box can help someone figure out where they belong in a world that can feel turned almost upside down. Their memory box can serve as a temporary anchor and help people see another side of them or the person they care for.

LIFE BOOKS

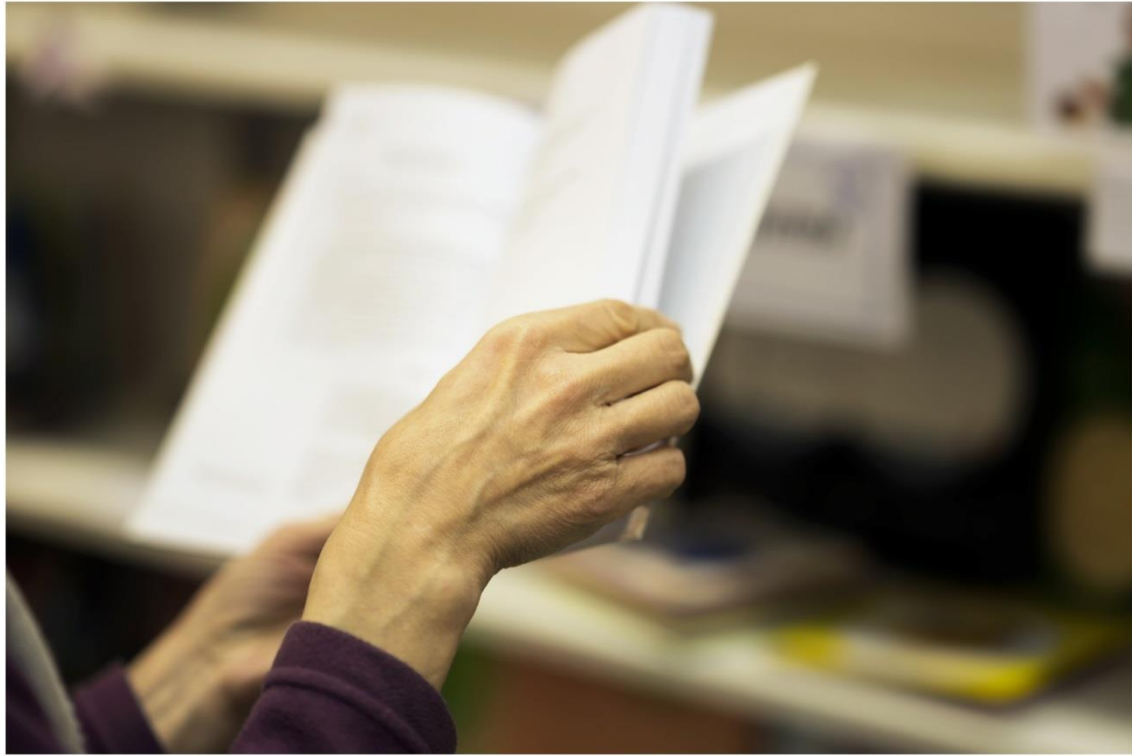
Everyone's life and life story is important. Creating a book or journal of precious moments, past interests and employment, likes and dislikes, important people and events can help improve a person's quality of life, improve their sense of identity and help staff and family to communicate in a meaningful way.

A life book not only helps to involve family and care givers in the person's care but it can move with the person when they receive different services such as planned activity group, or various types of respite.

It gives new people the opportunity to get to know them as a person and to explain why they may do the things that they do. Life books help others to see past a person's dementia and helps them to see them as a person with a past filled with many experiences, accomplishments and triumphs.

Many people with dementia and their families enjoy putting together a life book. The format is entirely up to each person and their family. Some people like to use a computer and make a magazine-style life book, while others like to add other bits and pieces with photos in the form of a scrap book or a photo album. Other people use plastic pockets to form a book so pages can be added as required.

Whatever a person decides, their carer, family or staff will enjoy helping them to put together a detailed history of their life, their current preferences and routines and their wishes for their future care.



Planning for the Future

Throughout life we make decisions about our finances, health and lifestyle choices. Some decisions impact on our day to day lives while others are more far reaching as we aim to secure our future.

With a diagnosis of dementia and the changes associated with decision making, the need to plan for the future is very important while a person still has the ability to actively do so.

Planning for the future consists of financial security (pensions and incomes) wills and powers of attorney (financial and medical) and an advanced care directive (medical).

PAYMENTS & CONCESSIONS FOR OLDER AUSTRALIANS

Payments for Older Australians

The **Age Pension** provides income support and access to a range of concessions for eligible older Australians. If a person meets the age and residence requirements, the amount of Age Pension they can get will be calculated, depending on their income, assets and other circumstances.

When they receive the Age Pension, they may also be eligible to receive help with living and household costs such as rent assistance and energy supply.

The **Disability Support Pension (DSP)** provides financial help when a person has a permanent physical, intellectual or psychiatric condition that stops them from working. To be eligible for the DSP a person must meet both non-medical rules (including age, residence status, income and assets) and medical rules which assesses how their condition affects them.

Carer Payment – is an income support payment for people who provide constant care to someone who has a severe disability, illness, or an adult who is frail and aged.

To get this you must:

- be under the pension income and assets test limits
- be an Australian resident
- care for someone who is an Australian resident
- care for one or more people who have care need scores high enough on the assessment tools used for an adult or child
- care for someone who'll have these needs for at least 6 months or the rest of their life.

A carer may also be eligible for a **Carer's Allowance**. It is a fortnightly supplement for people who give additional daily care to someone who has a disability, serious illness, or is frail aged.

To get this you must:

- meet an income test
- give additional daily care to someone with a disability, severe illness or who is frail aged
- care for someone whose care needs score is high enough on the assessment tools used for an adult or a child
- care for someone who'll have these needs for at least 12 months or the rest of their life.

Concessions for Older Australians

If you receive the Age Pension, Carer Payment or Disability Support Pension, you can also get a **Pensioner Concession Card**. This concession card can help you to get cheaper medicine, bulk billed doctors' visits and help with hearing services.

It may also help you access other discounts from the Victorian State government or your local council. They may lower your utility bills, property and water rates and public transport fares. To find out more, call the Victorian Concessions Information Line on 1800 658 521 or visit www.services.dhhs.vic.gov.au/about-concessions.

If you are not able to get the Age Pension but are of Age Pension Age (currently 66 years) you may be able to apply for a **Commonwealth Seniors Health Card**. This gives you a concession card to get cheaper health care and some discounts.

To get this you must:

- be unable to get a payment from Services Australia or the Department of Veterans' Affairs
- be under the income test limit
- meet residence rules.



Australian Government – Services Australia

For help with Carers payments call 132 717

www.servicesaustralia.gov.au - Payments for Carers

For help with payments for Older Australians call 132 300

www.servicesaustralia.gov.au - Payments for Older Australians

For help with Disability Support Pension call 132 717

www.servicesaustralia.gov.au - Disability Support Pension

Or visit your local Centrelink Office

LEGAL DOCUMENTS & POWERS OF ATTORNEY

This section refers to legal documents that protect people and their wishes. They provide instructions on how a person wants to be cared for, their wishes with regard to their assets and who they want to be in control of decisions, once they can no longer make them for themselves.

In Victoria, there are four different powers of attorney. The powers of attorney cover different areas of decision-making:

- Enduring Power of Attorney (financial) allows a person to choose someone to make financial and legal decisions for them. e.g. paying bills

- Enduring Power of Attorney (personal) allows a person to choose someone to make personal decisions for them. e.g. where they live.
- Supportive Power of Attorney allows a person to choose someone to help them make decisions. This is not enduring and does not give decision making powers.
- General Power of Attorney allows a person to choose someone who will make specified financial and legal decisions for them. This power ceases if they lose the capacity to make their own decisions.
- Medical Treatment Decision Maker (MTDM) lets a person choose someone to make decisions about their medical treatment.

A will or trust is a legal document that provides details of what a person would like to happen with their belongings and assets when they die. Expressing their wishes by making a will can help a person to keep control of certain aspects of their life that they feel are important and can provide peace of mind for themselves and their loved ones.

It is strongly recommended that a solicitor assists a person in completing these documents. The Office of the Public Advocate and Legal Aid are also able to provide assistance.



Ballarat & Grampians Community Legal Service –

(03) 5331 5999 - 5 Chancery Lane, Ballarat Central -

www.bgcls.org.au

Office of Public Advocate - 1300 309 337 -

www.publicadvocate.vic.gov.au

Victoria Legal Aid - 1300 792 387 - www.legalaid.vic.gov.au

Seniors Rights Victoria - 1300 368 821 -

www.seniorsrights.org.au

Seniors Information Victoria – COTA - 1300 135 090 -

www.cotavic.org.au


ADVANCE CARE DIRECTIVE

An advance care plan, sometimes called an advance care directive is a way of documenting a person's medical and personal care instructions for family members, doctors and other healthcare workers.

An advance care plan allows a person to record the type of care and treatment they want now and in the future, if they are unable to communicate or if they lose the ability to make decisions for themselves.

Advanced care planning gives a person the opportunity to think about their beliefs, values, goals and what is important in their life. These themes should be discussed with their family and friends and the person that they choose to be their agent. Their GP or other health professional should be involved to find out more about the illness and what may occur in the future. A person's health care wishes are then written in an **advance care plan** which needs to be witnessed. One of those witnesses needs to be the person's GP.

The Advance Care Planning website explains how and why to do advance care planning and provides a step by step process.

 **Advance Care Planning** - 1300 208 582 - www.advancecareplanning.org.au - Victoria
Office of Public Advocate - 1300 309 337 - www.publicadvocate.vic.gov.au



Other Useful Contacts



Alliance for Forgotten Australians

0488 460 646 and 0419 854 980 – An estimated 500,000 people known as Forgotten Australians, experienced institutional or other out-of-home care as children and young people in the last century in Australia, many of whom suffered physical, emotional and/or sexual abuse while in 'care'. www.forgottenaustralians.org.au

Australian Hearing

1300 412 512 - The nation's leading hearing specialist and largest provider of Government funded hearing services.

www.hearing.com.au

Ethnic Communities Council of Victoria

(03) 9354 9555 - The Ethnic Communities Council of Victoria (ECCV) advocates on behalf of multicultural communities in areas like human rights, access and equity and improving services. www.eccv.org.au

GLHV – Gay and Lesbian Health Victoria

(03) 9479 8760 - Promoting the health and wellbeing of LGBTIQ Victorians. www.rainbowhealthvic.org.au

National Relay Service

1800 555 660 (Helpdesk) - The National Relay Service allows people who are deaf, hard of hearing and/or have a speech impairment to make and receive phone calls.

www.communications.gov.au - National Relay Service

Transgender Victoria

(03) 9020 4642 - Founded in the late 1990s to achieve justice, equity and quality health and community service provision for trans and gender diverse (TGD) people, their partners, families and friends. They provide support, questions, advocacy, education etc.

www.tgv.org.au

Nurse-on-Call

1300 60 60 24 - A phone service that provides immediate, expert health advice from a registered nurse, 24 hours a day, 7 days a week. *If you think your situation is an emergency, you should always call 000 or go to an emergency department at a hospital.*

www.ambulance.vic.gov.au - Nurse on Call

Medicare

132 011 - Information about payments and services for Medicare.

www.servicesaustralia.gov.au



Additional Resources

ONLINE RESOURCES

Carer Gateway

www.carergateway.gov.au

Carer Gateway is a national online and phone service that provides practical information and resources to support carers. The interactive service finder helps carers connect to local support services.

Dementia Australia

www.dementia.org.au

Information about dementia and access to a range of resources and workshops.

Dementia Australia - Helpsheets

www.dementia.org.au - help sheets

Advice on the issues most commonly raised about dementia.

Dementia Australia - Resources

www.dementia.org.au - resources

Videos, facts, guides, toolkits, helpsheets, translated information and useful resources.

Dementia Daily

www.dementiadaily.org.au

Dementia Daily keeps you up to date with research and news, and helps you find support. We're here to help you access resources and information you need to deal with dementia.

Dementia Library Catalogue

www.dementialibrary.org.au

This national catalogue contains information about items held in the Victorian collection along with other states and territories. You can visit online or call the library if you would like to check something.

Dementia Resources Blog

www.dementiaresources.org.au

Some recent posts have been dance and dementia, travelling well with dementia, younger onset dementia, films and fiction that have a theme of dementia, along with many others. Take a look and if it is of interest to you please sign up for regular posts.

Dementia Training Australia

www.dementiatrainingaustralia.com.au

Suitable for care workers, health professionals and **family carers**, it links to a range of audiovisual and text material, and includes free online courses.

Dementia Training Australia – Environmental Design Resource

www.dta.com.au - environmental design resource

A collection of resources to support those who wish to improve environments for people with dementia. The resources introduce the reader to a systematic way of looking at the built environment and provide a number of tools that guide the user to an understanding of what needs to be changed, and how the change might be accomplished.

Helpful Handbook for Memory Loss

<http://at-aust.org/assets/HelpfulHandbookForMemoryLoss2017.pdf>

This publication is intended as a reference for people in the early stages of memory loss as well as their family / friends. It contains information on products and devices as well as tips and hints for managing the effects of memory loss.

The Dementia Guide – Dementia Australia

www.dementia.org.au - The Dementia Guide

For people with Dementia, their families and carers.

The University of Sydney – Brain and Mind Centre

<https://www.sydney.edu.au/brain-mind/our-research/healthy-ageing-and-neurodegeneration.html>

Our multidisciplinary research teams are leading the way in developing preventative and diagnostic tools and treatments for diseases such as Dementia, Parkinson's, Alzheimer's, Multiple Sclerosis, Motor Neurone Disease and Meniere's.

The University of Sydney – Cognitive Decline Partnership Centre

<http://sydney.edu.au/medicine/cdpc/documents/resources/Dementia-Guideline-Guide-2017-WEB.pdf>

Consumer Companion Guide – Diagnosis, Treatment and Care for People with Dementia

BOOKS



Dementia Australia Library

A comprehensive collection of resources about dementia

www dementialibrary.org.au
email library@dementia.org.au
phone 1800 100 500

These books are available from the library at Dementia Australia or check out your local library. In addition to print resources the library at Dementia Australia has an extensive eCollection that can be accessed at any time. Please get in touch if you would like to be signed up as a library borrower

Somebody I Used to Know / by Wendy Mitchell, Anna Wharton (2018)

When she was diagnosed with dementia at the age of fifty-eight, Wendy Mitchell was confronted with the most profound questions about life and identity. All at once, she had to say goodbye to the woman she used to be. Her demanding career in the NHS, her ability to drive, cook and run - the various shades of her independence - were suddenly gone. Philosophical, profoundly moving, insightful and ultimately full of hope, *Somebody I Used to Know* gets to the very heart of what it means to be human. A phenomenal memoir - it is both a heart-rending tribute to the woman Wendy once was, and a brave affirmation of the woman dementia has seen her become.

Loving someone who has dementia: how to find hope while coping with stress and grief / Pauline Boss (2011)

Boss outlines seven guidelines to stay resilient while caring for someone who has dementia. She discusses the meaning of relationships with individuals who are cognitively impaired and no longer as they used to be and offers approaches to understand and cope with the emotional strain of care-giving.

Boss's book builds on research and clinical experience, yet the material is presented as a conversation. She shows you a way to embrace rather than resist the ambiguity in your relationship with someone who has dementia

Caring for a loved one with dementia: a mindfulness-based guide for reducing stress and making the best of your journey together / Marguerite Manteau-Rao (2016)

A guide to help you reduce stress, stay balanced, and bring ease into your interactions with the person in your life living with dementia. In this book, you'll learn how to approach caring with calm, centred presence; respond to your loved one with compassion; and maintain authentic communication, even in the absence of words. Most importantly, you'll discover ways to manage the grief, anger, depression, and other emotions often associated with dementia care, so you can find strength and meaning in each moment you spend with your loved one.

A caregiver's guide to dementia: using activities and other strategies to prevent, reduce and manage behavioural symptoms / Laura N. Gitlin and Catherine Verrier Piersol (2014)

A Caregiver's Guide to Dementia explores the use of activities and other techniques to prevent, reduce and manage the behavioural symptoms of dementia. Separate sections cover daily activities, effective communication, home safety and difficult behaviours, with explicit strategies to handle agitation, repetitive questions, acting-out, wandering, restlessness, hoarding, resistance to care, incontinence, destructiveness, sexually and socially inappropriate acts at home and in public, aggressiveness, depression. Worksheets are provided to help caregivers customize the strategies that work best for them. The strategies featured in this guide have been used by the authors in their research and reflect approaches and techniques that families have found to be most helpful.

The 36-hour day: a family guide to caring for people who have Alzheimer disease, other dementias, and memory loss / Nancy L. Mace and Peter V. Rabins. (2017)

Through five editions, The 36-Hour Day has been an essential resource for families who love and care for people with Alzheimer disease.

Whether a person has Alzheimer disease or another form of dementia, he or she will face a host of changes. The 36-Hour Day will help family members and caregivers address these challenges and simultaneously cope with their own emotions and needs.

What if it's not Alzheimer's: a caregiver's guide to dementia / edited by Lisa Radin & Gary Radin (2008)

This book is a comprehensive guide dealing with frontotemporal degeneration (FTD), one of the largest groups of non-Alzheimer's dementias. The contributors are either specialists in their fields or have exceptional hands-on experience with FTD. Beginning with a focus on the medical facts, the first part defines and explores FTD as an illness distinct from Alzheimer's disease. Also considered are clinical and medical care issues and practices, as well as such topics as finding a medical team and rehabilitation interventions.

A caregiver's guide to Lewy Body dementia / Helen Buell Whitworth, James Whitworth (2010)

Although Lewy Body dementia is the second leading cause of degenerative dementia in the elderly, it is not well known or understood and is often confused with Alzheimer's Disease or Parkinson's. The Caregivers Guide to Lewy Body dementia is the first book to present a thorough picture of what Lewy Body dementia really is.

The book is written in everyday language, and is filled with personal examples that connect to the readers' own experiences. It includes quick fact and caregiving tips for easy reference, a comprehensive resource guide, and a glossary of terms and acronyms.

This is the ideal resource for caregivers, family members, and friends of individuals seeking to understand Lewy Body dementia.

My book about brains, change and dementia: what dementia is and what does it do? / Lynda Moore; illustrated by George Haddon. (2018)

'Sometimes, a person's brain gets sick with a disease called dementia.' What does dementia do to the brain? And how can we help if someone we know, like a parent or a grandparent, has the disease?

This book breaks down misconceptions about dementia and speaks directly to children aged under 5 about the realities of the disease, using age appropriate language in an engaging and informative way. It reassures parents of the value of open and honest conversation about the challenges raised by dementia and offers advice and support in the opening 'Guide for grown ups'. It includes a diverse audience of characters, to emphasise that ANY child can be impacted by dementia in their loved ones.

Can I tell you about dementia? A guide for family, friends and carers / Jude Welton; Jane Telford (2012)

Meet Jack - an older man with dementia. Jack invites readers to learn about dementia from his perspective, helping them to understand the challenges faced by someone with dementia and the changes it causes to memory, communication and behaviour. He also gives advice on how to help someone with dementia stay as mentally and physically active as possible, keep safe and continue to feel cared for and valued.

With illustrations throughout, this useful book will be an ideal introduction to dementia for anyone from child to adult. It will also guide family, friends and carers in understanding and explaining the condition and could serve as an excellent starting point for family and classroom discussions.

Keeping love alive as memories fade: the 5 love languages and the Alzheimer's journey / Gary Chapman, Deborah Barr and Edward G. Shaw (2016)

Across America and around the world, the five love languages have revitalized relationships and saved marriages from the brink of disaster. Can they also help individuals, couples, and families cope with the devastating diagnosis of Alzheimer's disease (AD)? The authors give a resounding yes. Their application of the five love languages creates a

new way to touch the lives of those living with dementia as well as their caregivers. At its heart, this book is about how love gently lifts a corner of dementia's dark curtain to cultivate an emotional connection amid memory loss. This collaborative work between a healthcare professional, caregiver, and relationship expert will correlate the love languages with the developments of the stages of AD and discuss how both the caregiver and care receiver can apply the love languages.

Before I Forget: How I Survived a Diagnosis of Younger-Onset Dementia at 46 / Christine Bryden (2015)

Some days all I want to do is give up the constant, exhausting struggle and stop trying to be normal. But I can't. It's not in me to walk away from a fight. I'll keep fighting and telling my story. Before I forget.'

When she was just 46, Christine Bryden – Science advisor to the prime minister and single mother of three daughters – was diagnosed with younger-onset dementia. Doctors told her to get her affairs in order as she would soon be incapable of doing so. Twenty years later she is still thriving, still working hard to rewire her brain even as it loses its function. She shares what it's like to start grasping for words that used to come easily. To be exhausted from visiting a new place. To suddenly realise you don't remember how to drive. To challenge, every day, the stereotype of the 'empty shell'. Brave and inspiring, this is Christine's legacy for people with dementia and those who care about them.

Green vanilla tea / Marie Williams (2013)

When Marie Williams' husband Dominic started buying banana Paddle Pops by the boxful it was out of character for a man who was fit and health conscious. Dominic, Marie and their two sons had migrated to Australia to have a life where they shared more family time - when gradually Dominic's behaviour became more and more unpredictable. It took nearly four years before there was a diagnosis of early onset dementia coupled with motor neurone disease. Marie began to write, as she says, as a refuge from the chaos and as a way to make sense of her changing world.

Making tough decisions about end-of-life care in dementia / Anne Kenny. (2018)

In *Making Tough Decisions about End-of-Life Care in Dementia*, Dr. Anne Kenny, a skilled palliative care physician, describes how to navigate the difficult journey of late-stage dementia with sensitivity, compassion, and common sense. Combining her personal experience caring for a mother with dementia with her medical expertise in both dementia and end-of-life care, Dr. Kenny helps the reader prepare for a family member's death while managing their own emotional health.

Drawing on stories of families that Dr. Kenny has worked with to illustrate common issues, concerns, and situations that occurs in late-stage dementia, this book includes practical advice about making life-altering decisions while preparing for a loved one's inevitable death, medical care, pain, insomnia, medication, and eating, caring for the caregiver, and having conversations about difficult topics with other family members and with health care, legal, and financial professionals.

Creating moments of joy along the Alzheimer's journey / Jolene Brackey (2017)

When people have short-term memory loss, their lives are made up of moments. We are not able to create perfectly wonderful days for people with dementia or Alzheimer's, but we can create perfectly wonderful moments, moments that put a smile on their faces and a twinkle in their eyes. Five minutes later, they will not remember what we did or said, but the feeling that we left them with will linger. The new edition of *Creating Moments of Joy* is filled with more practical advice sprinkled with hope, encouragement, new stories, and generous helpings of humour. In this volume, Brackey reveals that our greatest teacher is having cared for and loved someone with Alzheimer's and that often what we have most to learn about is ourselves.

Live and laugh with dementia: the essential guide to maximizing quality of life / Lee-Fay Low. (2018)

For every person with dementia, their family and carers face the decision of how best to care for them. This book is all about how to make life with dementia as positive as possible - to maximize quality of life for all concerned. Just as we need to exercise our body's muscles to keep them strong, flexible and working well, so too do we need to exercise our mental muscles (our brain) to strengthen and maintain our neural capabilities. By tailoring activities to suit the needs and abilities of dementia patients, we can help them to: maintain their relationships with others; maintain their self-identity; slow the decline of mental function by providing physical and mental stimulation; stave off boredom; and, experience happiness and pleasure.



Appendix

COMMON DEFINITIONS FOR THE AGED & AGEING

Advance care planning	A process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known so they can guide decision-making at a future time when that person cannot make or communicate his or her decisions.
Advance care directive	A written plan completed and signed by a competent adult. An advance care directive can record the person's preferences for future care and appoint a substitute decision maker to make decisions about health care and life management when the person is unable to express their preferences because of illness or injury.
Advocate	An advocate is a person who can support or represent you in your dealings with others.
Advocate	The process of speaking out on behalf of an individual or group to protect and promote their rights and interests
Aged Care Assessment Service (ACAS)	ACAS are teams of health professionals who conduct comprehensive face-to-face assessments of older people who have complex aged care needs. ACAS can approve older people to access residential care, Home Care Packages and transitional care. An ACAS assessor may include a nurse, social worker and/or other health professionals.
Aged care	This is the personal and/or nursing care to support you to stay as independent and healthy as you can be. Aged care can also help you if you're caring for someone older by giving you a helping hand to look after the person you care for. It is delivered through two main ways in an aged care home and home care.
Allied health support	Allied health support services assist you with minor health conditions and work with other assistance available to you through the health system. These services can include physiotherapy (exercise, mobility, strength and balance), speech pathology (helps with difficulties in communicating, swallowing and eating), occupational therapy (help to recover or maintain your physical ability), podiatry (foot care), dietitian (nutrition assessment, food and nutrition advice, dietary changes), exercise physiologists (physical activity and education to assist with managing chronic conditions such as diabetes and heart disease).
Assistance with Care and Housing	Assistance with Care and Housing services links a person aged 50 years and older and prematurely aged, or on a low income, or is 45 years or older (for Aboriginal or Torres Strait Islander people) and is homeless or at risk of becoming homeless with a provider to find better, more stable accommodation. Once this is organised, a person might then be linked to other services to receive help at home or in the community.

Care plan	In consultation with you, the health professionals who provide your care may develop a care plan for you. If you like, your family or a friend can also be involved in this process. The care plan outlines your care needs and instructions about how these needs will be met.
Carer allowance	If you are a carer providing daily care and attention for an adult with a disability, a severe medical condition or who is frail aged at home, then you may be eligible for a carer allowance. This is a fortnightly payment administered by Services Australia which may be paid in addition to other payments.
Carer payment	If you are a carer who is unable to participate in paid employment because of the demands of your caring role, then you may be eligible for income support in the form of a carer payment. This payment is administered by Services Australia.
Commonwealth Home Support Programme (CHSP)	If you are an older person and need help to stay at home and to be more independent in the community, then you may benefit from the Commonwealth Home Support Programme. The Commonwealth Home Support Programme provides a comprehensive, coordinated and integrated range of basic maintenance, support and care services for older people and their carers.
Community and District nursing	If you are frail aged, then you may need nursing care from an enrolled or registered nurse at a community and/or district nursing to improve or maintain your health and wellbeing.
Comprehensive Assessment	The Aged Care Assessment Service (ACAS) will conduct a holistic, face-to-face assessment for medium to high level care needs. These outcomes may include referrals to services within CHSP, also residential care, respite care, home care packages and flexible care.
Domestic Assistance	Domestic Assistance services include home related tasks such as, cleaning, dishwashing, clothes washing, ironing, and unaccompanied shopping.
Flexible care	There are flexible aged care places provided through a number of different programs which can provide you with an alternative to more traditional community and residential care. These include Multipurpose Services, the Transition Care Program, Short Term Restorative Care and the Aged Care Innovative Pool.

Home & Community Care (HACC) for Younger People	<p>The Home and Community Care Program for Younger People (HACC PYP) provides services to support younger people with disabilities, and their carers. These services help people live as independently as possible in the community.</p> <p>If you think that you (or a family member or a person you care for) might find these services helpful, contact your local council or community health centre. They will meet with you to discuss the sort of services you need and how often you might need them. This meeting will usually be in your home. You may want a family member, friend, interpreter or advocate with you.</p>
Home Care Packages	<p>The types of services provided under a home care package will depend on your needs.</p> <p>There are four levels of home care packages designed to give the care needed: Level 1 supports people with basic-care needs; Level 2 supports people with low-level care needs; Level 3 supports people with intermediate-care needs; Level 4 supports people with high-level care needs.</p>
Home maintenance	<p>Home maintenance services support you to stay in your own home by making your home safer and more secure. Services can include changing light bulbs, maintaining an emergency alarm, minor repairs such as replacing tap washers, major repairs such as carpentry, painting and roof repairs, garden maintenance such as lawn mowing and removing rubbish.</p>
Home modification	<p>Home modification services can include installing grab and shower rails, easy-to-use tap sets, hand rails, ramps and other mobility aids, installing an emergency alarm and other safety aids, and other minor renovations. Home modifications must be installed by a licensed tradesperson and organised through the service provider.</p>
Medical Treatment Decision Maker	<p>Medical Treatment Decision Maker lets a person choose someone to make decisions about their medical treatment.</p>
My Aged Care	<p>My Aged Care assists older people, their families and carers to access aged care information and services via the My Aged Care website and My Aged Care contact centre (1800 200 422).</p>
National Screening Assessment Form [NSAF]	<p>To ensure a nationally consistent and holistic screening and assessment process, the NSAF is used by My Aged Care contact centre staff and local assessment services.</p>
Personal care	<p>Personal care services include everyday tasks such as bathing and getting dressed, assistance with eating, going to the toilet, grooming, getting in and out of bed, and moving about the house.</p>

Powers of attorney	<p>The powers of attorney cover different areas of decision making:</p> <ul style="list-style-type: none"> • Enduring Power of Attorney (financial) allows a person to choose someone to make financial and legal decisions for them. e.g. paying bills • Enduring Power of Attorney (personal) allows a person to choose someone to make personal decisions for them. e.g. where they live. • Supportive Power of Attorney allows a person to choose someone to help them make decisions. This is not enduring and does not give decision making powers. • General Power of Attorney allows a person to choose someone who will make specified financial and legal decisions for them. This power ceases if they lose the capacity to make their own decisions.
Prematurely aged people	<p>People aged 50 years and over (or 45 years and over for Aboriginal and Torres Strait Islander people) whose life course such as active military service, homelessness or substance abuse, has seen them age prematurely.</p>
Reablement	<p>The use of timely assessment and short term, targeted interventions to assist people to maximise their independence, choice, health outcomes and quality of life and minimise support required. The provision of reablement services is part of the wellness philosophy.</p>
Regional Assessment Service (RAS)	<p>The Regional Assessment Service (RAS) will be responsible for conducting holistic face-to-face assessments of older people seeking entry-level support at home, provided under the Commonwealth Home Support programme (CHSP), as well as linking in to other services that are outside of the aged care system.</p>
Residential aged care	<p>If you receive personal and/or nursing care in a residential facility, as well as accommodation, you are in residential aged care. This type of care also includes appropriate staffing to meet your nursing and personal care needs; meals and cleaning services; furnishings, furniture and equipment.</p>
Respite	<p>Respite care (also known as short-term care) is a form of support for carers or care recipients. It gives the carer the opportunity to attend to everyday activities and have a break from their caring role. It also gives the care recipient a break from their usual care arrangements. Respite care may be given informally by friends, family or neighbours, or by formal respite services.</p>

Restorative care	Restorative care involves evidence based interventions that allow a person to make a functional gain or improvement in health after a setback, or in order to avoid a preventable injury. Interventions are provided or are led by allied health workers based on clinical assessment of the individual. These interventions may be one to one or group services that are delivered on a short-term basis.
Service provider	A service provider is an organisation funded to provide aged care services to a person.
Social support	Social support services can help you maintain an active social life to prevent loneliness and isolation. Social support services can include visits to your home, help with shopping and other related activities, help to access support groups and recreational activities in the community.
Special needs group	Under the CHSP, Special Needs groups include people from Aboriginal and Torres Strait Islander communities, people from culturally and linguistically diverse backgrounds, people who live in rural and remote areas; people who are financially or socially disadvantaged, veterans, people who are homeless, or at risk of becoming homeless, people who are lesbian, gay men, bisexual, transgender and intersex, people who are care leavers and parents separated from children by forced adoption or removal.
Support Plan	Following an assessment by RAS or ACAS, a support plan is created that includes a summary of the assessment and all the agreed upon referrals and actions. This support plan will be shared with the appropriate service providers, with the client's consent. The client will also receive a copy.
Transport services	Transport services can help get you to and from your appointments and around your community. You can get picked up by a transport service or receive vouchers or subsidies, for taxi services.
Wellness	A philosophy that focuses on whole of system support to maximise clients' independence and autonomy. It is based on the premise that even with frailty, chronic illness or disability; people generally have the desire and capacity to make gains in their physical, social and emotional wellbeing and to live autonomously and independently. It emphasises prevention, optimising physical function and active participation. It focuses on finding the service solutions to best support each individual's aspirations to maintain and strengthen their capacity to continue with their activities of daily living, social and community connections.