Memory Support Guide

Information and
Services covering the
Central Highlands
Region Victoria

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



ACKNOWLEDGEMENTS

This document was developed as part of a Sector Support and Development initiative which brought together Dementia peak bodies, and Commonwealth Home Support Programme funded services working with people living with dementia across the Grampians region. This group known as Dementia Provision Forum identified a need to update resources and provide a comprehensive document of services available.

'Grey Matters' that was produced in November 2012 was a project that was funded by the Department of Health and Human Services. With the Transition to My Aged Care in 2016, Grey Matters was a valuable source of consumer information but did not reflect the many changes in the Service system and the impact on assessment and referral pathways. It was decided to cooperate to produce an updated version, known as The Memory Support Guide.

Specific regional information was provided by Wimmera Primary Care Partnership, Central Highlands Primary Care Partnership and Grampians Pyrenees Primary Care Partnership.

Wimmera Primary Partnership has edited and produced the new documentation in digital form and will be made accessible in PDF format on the three Primary Care Partnership (PCP) websites – http://www.wimmerapcp.org.au http://www.grampianspyreneespcp.org.au/

Further contributions to the development of this guide were made by the members of the Grampians Regional Dementia Provision Forum participants and Grampians Pyrenees Primary Care Partnership. Special thanks go to Dementia Australia for their assistance and access to resources and information throughout the development of this document.

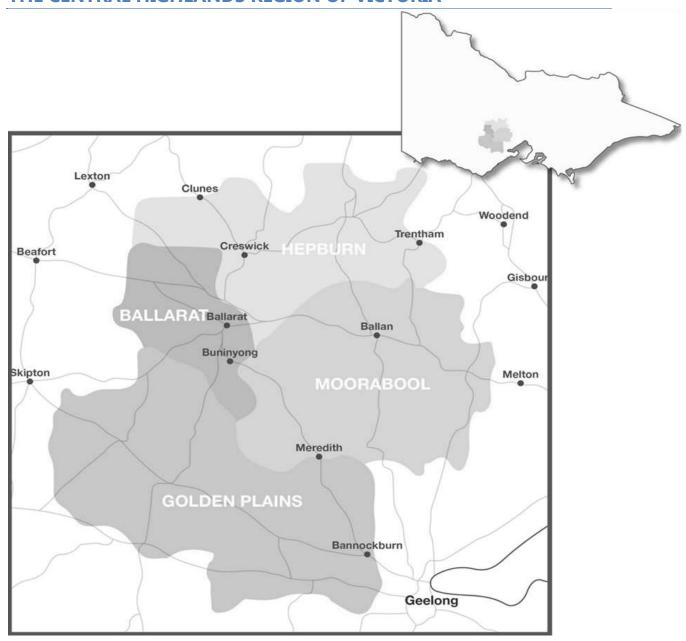
HOW TO USE THIS INFORMATION

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 Central Highlands 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 languages than English, Dementia Australia have a variety of help sheets, tip sheets and resources available to be downloaded from their website in other languages.

A copy can be obtained online (as detailed above) or by emailing cathyb@chpcp.org. If you have feedback about this document please email cathyb@chpcp.org

THE CENTRAL HIGHLANDS 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 midlife 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 - https://www.healthdirect.gov.au/ (click on find a health service) - https://westvicphn.com.au/health- https://westvicphn.com.au/health- https://westvicphn.com.au/health- https://westvicphn.com.au/health-directory#general-practitioner-lists

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 - https://mensshed.org/find-a-shed/#

Ballarat & District Aboriginal Cooperative (BDAC) –

(03) 5331 5344 - 5 Market Street Ballarat -

http://www.badac.net.au/services/health-community-care/

Ballarat Life Activities Club - 0466 275 416 -

http://life.org.au/the-clubs/ballarat/

Ballarat Regional Multicultural Council (BRMC) - (03) 5383

0613 - 145 Victoria Street Ballarat East -

http://www.brmc.org.au/

City of Ballarat - (03) 5320 5500 - 25 Armstrong Street South, Ballarat - http://www.ballarat.vic.gov.au/pc/community-directory.aspx

Golden Plains Shire - 1300 363 036 - 2 Pope Street Bannockburn -

https://www.goldenplains.vic.gov.au/residents/my-family

Hepburn Shire Council - (03) 5348 2306 - 76 Vincent Street

Daylesford - https://www.hepburn.vic.gov.au/social-

connectedness-2/My Community Directory - 1300 762 515 -

https://www.mycommunitydirectory.com.au/Victoria/Northern Grampia

Moorabool Shire Council - (03) 5366 7100 - 15 Stead Street Ballan - https://www.moorabool.vic.gov.au/social-support-and-community-connections

Neighbourhood Houses Victoria - (03) 9602 1228 -

https://www.nhvic.org.au

Probus - 1300 630 488 - https://www.probusvic.com.au/find-a-club/find-a-probus-club.html

Rotary Club Finder - <u>https://my.rotary.org/en/search/club-</u>finder

Senior Citizens Club Search - Victoria -

http://www.clubsofaustralia.com.au/Seniors-Citizen-andd-Retirees/Clubs-in-Victoria/50/0.html

U3A Network – University of the 3rd Age - (03) 9670 3659 - https://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



BainyApp - Website: https://brainyapp.com.au/

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 -

https://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 offices.



Ballan District Health Care - (03) 5366 7999 - 164 Inglis Street. Ballan - http://www.ballanhealth.com.au/allied-healthcare-wellbeing-services/

Ballarat Community Health - Phone: (03) 5338 4500 - https://bchc.org.au/services/exercise-fitness

City of Ballarat - (03) 5320 5500 - 25 Armstrong Street South, Ballarat - http://www.ballarat.vic.gov.au/pc/community-directory.aspx

Hepburn Shire Council - (03) 5348 2306 - Corner Duke and Albert Streets, Daylesford -

https://www.hepburn.vic.gov.au/facilities-services/community-development/

Golden Plains Shire Council - 1300 363 036 - 2 Pope Street, Bannockburn -

https://www.goldenplains.vic.gov.au/residents/my-family/health-and-wellbeing



Moorabool Shire Council - (03) 5366 7100 - 15 Stead Street, Ballan - https://www.moorabool.vic.gov.au/community-directory

Your Brain Matters risk reduction program

Your Brain Matters is Dementia Australia's dementia risk reduction program. 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. Your Brain Matters promotes a 'brain healthy' lifestyle, and also provides advice on how you can reduce your risk of developing dementia.



Your Brain Matters - https://yourbrainmatters.org.au

DEMENTIA AUSTRALIA

Dementia Australia represent the 425,416 Australians living with dementia and the estimated 1.2million 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 Memory Loss
- The National Younger Onset Dementia Key Worker program
- Dementia and Memory Community Centres
- Counselling
- Carer support groups
- Education for family carers
- Public awareness activities
- A national resources program

Through their work we 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/about-dementia/resources/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.

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.

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 simple words or substitute inappropriate words, making them difficult to understand. They might also have trouble understanding others.
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 - Someone
with dementia can 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:

- Ask for a longer appointment
- 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 further assessment by a specialist

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 ask 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 a see a geriatrician at the Cognitive Dementia and Memory Service (CDAMS). Geriatricians specialise 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 (CDAMS)

The aim of the CDAMS clinic is to assist people experiencing early changes to their memory and thinking by providing assessment and

diagnosis of the psychological, medical and social difficulties associated with these changes. An Assessment may include a visit to the person's own home.

A CDAMS Assessment will usually include an initial nursing assessment, medical assessment, neuropsychology assessment, feedback session and follow-up. 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.

If a person is unable to obtain a GP's referral they can self-refer if they are worried about memory loss or changes in their thinking.



CDAMS – Cognitive Dementia & Memory Service - (03) 5320 3704 - Queen Elizabeth Centre, 102 Ascott Street South, Ballarat https://www.bhs.org.au/node/187

THE COMPLEX CARE GERIATRIC CLINIC

Geriatric Assessments for people aged 65 and over are available through this service. The clinic will evaluate, discuss and prioritise with patients (and their families), their various health problems 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

Pathways to Diagnosis

improving the patient's health and life. This service is also available for patients in Residential Aged Care Facilities.

Home visits and Telehealth assessments

Home Visits are available for patients having difficulty attending the clinic, and includes some capacity to visit people living in regional areas. Telehealth assessments to regional and remote sites, via the Grampians Rural Health Alliance Network are available on short notice.

Home Visit Areas:

Greater Ballarat area, Creswick, Daylesford, Hepburn Springs & Trentham, Ballan & Bacchus Marsh, Beaufort & Skipton, Horsham, Stawell & Ararat



The Complex Care Geriatric Clinic - (03) 5320 3791 -

https://gp.bhs.org.au/node/188

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 (DBMAS) & SEVERE BEHAVIOUR RESPONSE TEAMS (SBRT)

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) https://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) - https://www.dementia.com.au/

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.



Djerriwarrh Health - (03) 5367 2000 - 35 Grant Street Bacchus Marsh - https://www.djhs.org.au/



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Assessments

MY AGED CARE

My Aged Care is an Australian Government website and phone line to help people over the age of 65 years or over 50 years for

Aboriginal & Torres Strait Islander people 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.

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. If they are calling for someone else, they will need to give their consent.

My Aged Care may then arrange for a trained assessor to come to the person's home. With their consent they will assess 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 costs. They will be told if you need a financial assessment.

The service finders on the My Aged Care website can help people locate and compare some services 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.



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. Referrals can be made by themselves or with their permission, by family, their doctor or other allied health professions.

Provided under the program, the Living at Home Assessment is a broad, strengths based assessment that seeks to identify peoples 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 (community connections).

The focus 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.

Note: HACC PYP funding is time limited and the future of this program is unknown. Please consult with your nearest service for more information.



Ballarat Health Services - (03) 5320 6690 - Queen Elizabeth Centre, 102 Ascot Street Sth, Ballarat -

http://www.bhs.org.au/node/186

Ballarat Regional Multicultural Council (BRMC) - (03) 5383 0613 - 145 Victoria Street, Ballarat East - http://www.brmc.org.au/



Golden Plains Shire - 1300 363 036 - 2 Pope Street, Bannockburn -

https://www.goldenplains.vic.gov.au/residents/my-family/seniors/aged-and-disability-services

Hepburn Shire Council - (03) 5348 2306 - Corner Duke and Albert Streets, Daylesford -

https://www.hepburn.vic.gov.au/community-care-home-based-services/

Integratedliving Australia - 1300 782 896 - 1818 Sturt Street, Alfredton - https://integratedliving.org.au/

Moorabool Shire Council - (03) 5366 7100 - 15 Stead Street, Ballan - https://www.moorabool.vic.gov.au/residents/family-services/active-ageing-and-community-access

Uniting Ballarat - (03) 5332 1286 - 105 Dana Street, Ballarat http://www.unitingcareballarat.com.au/services/aged-disability-services

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 NDIS The NDIS is a new way of providing 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, live in an NDIS rollout area and have a diagnosis of dementia. Visit the website to find providers of support under the NDIS.



National Disability Insurance Scheme (NDIS) - 1800 800 110

- https://www.ndis.gov.au/

AGED CARE ASSESSMENT SERVICES

The 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 Package (CHSP) (previously HACC - Home and Community Care) 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 for an ACAS 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 - Fax (03) 5320 3893

CenralIntakeTriage@bhs.org.au

My Aged Care - 1800 200 422 -

https://www.myagedcare.gov.au

Grampians Aged Care Assessment Service - (03) 5320 3740 https://www.bhs.org.au/node/184

DISTRICT NURSING SERVICE

District Nursing is a Commonwealth Home Support Programme (CHSP) funded 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 nurse provide 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 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 them find and link them with other community services if required and with their permission.



Ballan District Health & Care - (03) 5366 7999 - 164 Inglis Street Ballan - http://www.ballanhealth.com.au/district-nursing-3/



Djerriwarrh Health Service - (03) 5367 2000 - 35 Grant Street Bacchus Marsh - https://www.djhs.org.au/

Hepburn Health Services - (03) 5321 6570 - Hospital Street Daylesford - http://www.hhs.vic.gov.au/

Hesse Rural Health Services - (03) 5267 1200 - 9 High Street, Bannockburn - https://www.hesseruralhealth.net.au/

Integratedliving Australia - 1300 782 896 - 1818 Sturt Street, Alfredton - https://integratedliving.org.au/

St John of God Ballarat - (03) 9278 1775 - 1016 Mair Street Ballarat - https://www.sjog.org.au/our-services/home-nursing-and-care/health-choices/patients-and-clients



Support Options

COMMONWEALTH CARER RESPITE & SUPPORT SERVICES

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

Carer Respite Services provide:

- Short-term individual case management
- Assistance to access short-term, occasional and emergency respite
- Condition specific information
- Education sessions, support groups and programs
- Carer newsletter

Staff can assist the carer by:

- Reinforcing the value and significance of their role as a carer
- Link carers with local support services, groups and other carers
- Provide information about opportunities for respite
- Assist the carer to plan and access respite services
- Encourage and support carers to focus on their personal health and well-being and opportunities which may benefit their caring role and relationship



Ballarat Health Services - (03) 5333 7104 - 106 Market Street Ballarat - https://www.bhs.org.au/node/188

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.

Support Options

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
 peson'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 day centre 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.
- Overnight or weekend respite may be provided under 'cottage style' respite in the community or in the home of a host family.
- **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 a free assessment with a Regional Assessment Service (RAS) to work out if they are eligible for planned respite care under the Commonwealth Home Support Programme.



Ballarat & District Aboriginal Cooperative (BADAC) - (03)

5331 5344 - 5 Market Street, Ballarat -

http://www.badac.net.au/services/health-community-care/

Ballarat Health Services Carer Respite & Support - (03) 5333

7104 - 106 Market Street Ballarat -

https://www.bhs.org.au/node/188

City of Ballarat - (03) 5320 5636 - 25 Armstrong Street South,

Ballarat - http://www.ballarat.vic.gov.au/pc/seniors.aspx

Golden Plains Shire - 1300 363 036 - 2 Pope Street,

Bannockburn -

https://www.goldenplains.vic.gov.au/residents/my-

family/seniors/aged-and-disability-services

Hepburn Shire Council - (03) 5348 2306 - Corner Duke and Albert Streets, Daylesford -

https://www.hepburn.vic.gov.au/community-care-home-based-services/

Moorabool Shire Council - (03) 5366 7100 - 15 Stead Street,

Ballan - https://www.moorabool.vic.gov.au/residents/family-services/active-ageing-and-community-access

My Aged Care - 1800 200 422 -

https://www.myagedcare.gov.au/

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

Tipping Foundation (Vista Community Support) - (03) 5320 0300 - 42 Eastwood Street. Ballarat -

https://www.tipping.org.au/contact/locations/grampians/

Uniting Ballarat - (03) 5332 1286 - 105 Dana Street, Ballarat http://www.unitingcareballarat.com.au/services/aged-disability-services

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 on a planned or emergency basis. They may use this type of respite service if their carer will be away to attend an event, or 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. Eligible people can access residential respite for up to 63 days each financial year. This time can be extended in lots of 21 days if an assessment finds that a person needs this extra time.



Ballan District Health & Care - (03) 5368 1100 - 164 Inglis Street. Ballan - http://www.ballanhealth.com.au/respite/ Ballarat Health Services - (03) 5320 3740 - George Skerritt West Wing, Queen Elizabeth Centre, 102 Ascot St South Ballarat https://www.bhs.org.au/node/184

Hesse Rural Health Services - (03) 5267 1200 - 9 High Street, Bannockburn -

https://www.hesseruralhealth.net.au/?page_id=379

My Aged Care - 1800 200 422 -

https://www.myagedcare.gov.au/

National Disability Insurane Scheme (NDIS) - 1800 800 110 https://www.ndis.gov.au/

SOCIAL SUPPORT GROUPS (FORMERLY DAY CENTRE OR 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.

Throughout 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 a person will need a minimal level of independence with 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 HACC assessment service but a person can also self-refer.



Ballarat & District Aboriginal Cooperative (BADAC) - (03) 5331 5344 - 5 Market Street, Ballarat -

http://www.badac.net.au/services/health-community-care/ **Ballarat Health Services -** (03) 5320 3740 - George Skerritt

West Wing, Queen Elizabeth Centre, 102 Ascot St South Ballarat

https://www.bhs.org.au/node/184

Ballarat Regional Multicultural Council (BRMC) - (03) 5383 0613 - 145 Victoria Street, Ballarat East - http://www.brmc.org.au/

City of Ballarat - (03) 5320 5636 - 25 Armstrong Street South, Ballarat - http://www.ballarat.vic.gov.au/pc/seniors.aspx Golden Plains Shire - 1300 363 036 - 2 Pope Street,

Bannockburn -

Support Options



https://www.goldenplains.vic.gov.au/residents/my-family/seniors/aged-and-disability-services

Hepburn Shire Council - (03) 5348 2306 - Corner Duke and Albert Streets, Daylesford -

https://www.hepburn.vic.gov.au/community-care-home-based-services/

Hepburn Health Service - (03) 5321 6596 - Hospital Street, Daylesford - http://hhs.vic.gov.au/general.php?pageID=114 **Hesse Rural Health Services -** (03) 5267 1200 - 9 High Street, Bannockburn -

https://www.hesseruralhealth.net.au/?page_id=61

Moorabool Shire Council - (03) 5366 7100 - 15 Stead Street, Ballan - https://www.moorabool.vic.gov.au/residents/family-services/active-ageing-and-community-access

Uniting Ballarat - (03) 5332 1286 - 105 Dana Street, Ballarat http://www.unitingcareballarat.com.au/services/aged-disability-services

Tipping Foundation (Vista Community Support) - (03) 5320 0300 - 42 Eastwood Street Ballarat -

https://www.tipping.org.au/contact/locations/grampians/

Vision Australia - (03) 5337 4555 - 1300 Howitt Street,

Wendouree - https://www.visionaustralia.org

COTTAGE RESPITE HOUSES

Cottage respite is an option that seeks to take the stress out of organising respite as it does not require an ACAS assessment. The flexibility of the program is appreciated by carers as it provides a short break, day and night, without having to access residential respite care or an ACAS assessment.

It is available to primary carers of people with dementia and offers them an overnight or weekend stay in a home environment.

The Cottage Respite Program aims to provide person-centred care appropriate to the individual needs of the person. In order to

accurately meet their needs an assessment is completed by an experienced coordinator prior to booking the respite stay to ensure appropriate care needs, and a safe and stimulating environment.

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 which is why the information below is not colour coded to a specific area.



Ballarat Health Services – Eyres House - (03) 5332 4720 - 810 Ligar Street Ballarat - https://www.bhs.org.au/node/195

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, our thoughts, whether they are positive or negative.

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 change to form new friendships with people who understand the pressure of caring.

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



Bacchus Marsh Carer Support Group - (03) 5333 7104 http://www.bhs.org.au

Ballarat Health Services – Carer Support - (03) 5332 4270 106 Market Street Ballarat - http://www.bhs.org.au
Community Visitors Scheme - (03) 9845 2729 https://agedcare.health.gov.au/older-people-their-families-and-carers/community-visitors-scheme

Carer Respite & Support Services - (03) 5333 7104
106 Market Street Ballarat - https://www.bhs.org.au/node/188
Hepburn Health Service - (03) 5321 6596 - Hospital Street,
Daylesford - http://hhs.vic.gov.au/general.php?pageID=28
Switchboard - A free service reducing social isolation in the

LGBTI+ community throughout Victoria - 1800 184 527 http://www.switchboard.org.au/out-about/

Uniting Ballarat - (03) 5335 3501 - 105 Dana Street, Ballarat http://www.unitingcareballarat.com.au/34-services/30-support-for-carers-program

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.

Cardholders are also entitled to free travel on public transport on a Sunday plus two return off-peak travel vouchers each year.



Victorian Government Carer Card Program - 1800 901 958 - http://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 profession educators with 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. Download a flyer for more information, or book in online. Sessions currently being offered include:

- Introduction to Dementia and Services: A Good Place to Start
- What is Dementia?
- <u>Effective Communication</u>
- Coping with Changes in Behaviour
- Mild Cognitive Impairment What this Diagnosis Means for You
- Blokes in the Caring Role
- The Caring Role A Compassionate Approach
- <u>Dementia: managing the changes</u>
- Coping with Carer Stress
- How Dementia Friendly is your Home?
- <u>Considering Residential Care</u>

Support Options

- Grief, Loss and Dementia
- Younger Onset Dementia: National Disability Insurance Scheme (NDIS)
- <u>Centrelink Benefits and Services for People with Dementia and their Carers</u>
- Family Information and Support Session Flyers

Dementia Helpline - 1800 100 500 -

https://www.dementia.org.au/support/support-in-your-region/victoria/regional-sessions-and-group-programs

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.



Gateway Counsellor - (03) 9815 7800 -

https://www.dementia.org.au/support/services-and-programs/vic/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 over six sessions and aims to provide additional knowledge, skills and resources for carers, family and friends that is supportive of their caring role.



Ballarat Health Services - (03) 5333 7104 - 106 Market Street Ballarat - https://www.bhs.org.au/node/188

MEMORY LANE CAFÉ, MEMORY STRATEGY GROUPS & COFFEE & CONVERSATIONS

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

The Australian governments, under the Commonwealth Home Support Program (CHSP), have provided funding for Café Style Support Programs that are offered throughout Victoria.

These cafés 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.



Ballarat Health Services – Memory Mingle - (03) 5333 7104

http://www.bhs.org.au/node/435

Djerriwarrh Health Services – Coffee & Conversation - (03) 5367 9857 - https://djerriwarrh.org.au/

SOCIAL SUPPORT & 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 brain function and physical abilities.

Participating in outings and activities or receiving a weekly visit 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 Region that provides social support and visiting programs. The programs encourage positive social contact that can help to defeat loneliness and isolation.

Transport is available to most events on request and a small fee may be charged to cover the costs of transport & activities.

Some Social Support Programs may also provide volunteer support to appointments for medical and related services.



Bacchus Marsh Senior Citizens - (03) 5367 3239 - 10 Bennett Street Bacchus Marsh

Ballan Senior Citizens - (03) 5368 1598 - 78 Steiglitz Street Ballan

Ballarat & District Aboriginal Cooperative (BADAC) - (03)

5331 5344 - 5 Market Street, Ballarat -

http://www.badac.net.au/services/health-community-care/

Ballarat Regional Multicultural Council (BRMC) - (03) 5383 0613 - 145 Victoria Street, Ballarat East -



http://www.brmc.org.au/index.php/our-services/aged-support-services

Blackwood Senior Citizens - (03) 5368 6613 - Martin Street Blackwood

Bungaree Senior Citizens - (03) 5334 0454 - Old Melbourne Road Bungaree

City of Ballarat - (03) 5320 5500 - 25 Armstrong Street South, Ballarat - http://www.ballarat.vic.gov.au/pc/community-directory.aspx

Community Visitors Scheme - (03) 9845 2729

https://agedcare.health.gov.au/older-people-their-familiesand-carers/community-visitors-scheme

Djerriwarrh Health Services – Friendly Visiting Program - (03) 5367 9673 - Bacchus Marsh Community Health Centre, Cnr Grant & Turner Street Bacchus Marsh -

https://www.djhs.org.au/allied-community-health/friendly-visiting-program

Golden Plains Shire - 1300 363 036 - 2 Pope Street, Bannockburn -

https://www.goldenplains.vic.gov.au/residents/my-family

Hepburn Health Services - (03) 5321 6596 - Hospital Street, Daylesford - http://hhs.vic.gov.au/general.php?pageID=28

Hepburn Shire Council - (03) 5348 2306 - Corner Duke and Albert Streets, Daylesford -

https://www.hepburn.vic.gov.au/social-connectedness-2/

Pentland Hills Uniting Church - (03) 5368 7233

Uniting Ballarat - (03) 5332 1286 - 105 Dana Street, Ballarat http://www.unitingcareballarat.com.au/services/aged-disability-services

Switchboard – A free service reducing social isolation in the LGBTI+ community throughout Victoria - 1800 184 527

http://www.switchboard.org.au/out-about/

Uniting Church Bacchus Marsh - (03) 5367 2543

Moorabool Shire Council - (03) 5366 7100 - 15 Stead Street, Ballan - https://www.moorabool.vic.gov.au/social-support-and-

community-connections

MEMORY WELLNESS PROGRAMS

Integratedliving offer a range of innovative programs and supports for those who are concerned about the wellness of their mind, living with or supporting someone with Dementia.

Some of these programs and supports include:

- Pop Up Memory Clinics
- Memory Wellness Programs
- Dementia & End of Life Respite
- Mental Health Respite Carer Support

Through their respite programs they enable carers to have a break and participate in social, family or community life. They also provide a number of social solutions for older people, including transport in many areas.

Integratedliving is conducting memory wellness programs in communities across their organisation. The fun, free program introduces a range of strategies for self-management of general wellbeing and brain health.



Integratedliving - 1300 782 896 - 1818 Sturt Street, Alfredton https://integratedliving.org.au/our-services/our-services/dementia-programs-mental-health/

COUNSELLING AND SUPPORT

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

Counselling is provided throughout Victoria by telephone, in the family home, at one of our metropolitan or regional offices and via email or video conference by visiting (link is external).

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

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.

Eligibility

The CHSP is designed to provide small amounts of support services in a timely manner to frail older people who have difficulty performing activities of daily living without help due to functional limitations. Services funded under the CHSP include domestic assistance, transport, meals personal care, home maintenance and modifications, social support, nursing and allied health. People need to be 65 years or older (50 years or older and identify as an Aboriginal or Torres Strait Islander person) 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.

If a person has been injured or hospitalised they may be eligible for extra services through the program for a short time to help them get back on their feet after they return home.

Assessment

For an assessment and eligibility call My Aged Care on 1800 200 422. The My Aged Care staff will ask the person questions about their current needs and circumstances so they can refer them to appropriate aged care services. They will need to have a home support assessment with a Regional Assessment Service (RAS) before they can be approved for care.

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 by their contributions to the cost of these services.

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.

Read more about the <u>cost of help at home</u>.



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.



Ballarat Health Service - (03) 5320 3740 -

https://www.bhs.org.au/node/184

My Aged Care - 1800 200 422 -

https://www.myagedcare.gov.au

CONSUMER DIRECTED CARE (CDC)

Home care packages are delivered on a Consumer Directed Care (CDC) basis. This means a person (and their carer) have more choice and control over what services are delivered and where and when they are delivered.

CDC means the eligible person:

- get more say in the care and services they access, how they are delivered and who delivers them to them
- has conversations about your needs and goals
- works with their service provider to develop their individual care plan
- agrees how much involvement they have in managing their care package

Support Options

- knows how their package is funded and how their individual budget is spent through monthly income and expense statements
- the service provider will ensure that their package continues to meet your needs with ongoing monitoring and formal reviews.

If the person's circumstances change they and their home care provider can change the care plan to suit their needs.



Ballarat Health Service - (03) 5320 3740 -

https://www.bhs.org.au/node/184

My Aged Care - 1800 200 422 -

https://www.myagedcare.gov.au

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 the aim 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. The aim is to strengthen the abilities of the person and restore them to a level of health and functioning that will make it easier for them to return home and achieve their goals.

Transition care can be provided in either a home-like residential setting or in the community. The program usually lasts for 7 weeks, but depending on the person's circumstances a maximum of 12 weeks may be needed. A further 6 week extension may be required depending on their situation.

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 their needs. Considering long term accommodation and care can be stressful so exploring their options early can ensure that the person knows what they can and can't expect as well as giving them a good understanding of the process involved to access residential care.

Some residential aged care services are built or have certain areas built specifically 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.



Aged Care Guide - https://www.agedcareguide.com.au
Ballarat Health Service - (03) 5320 3740 -

https://www.bhs.org.au/node/184

My Aged Care - 1800 200 422 -

https://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.

Support Options

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 capability to undertake daily activities.



Ballan District Health & Care - (03) 5366 7999 - 164 Inglis Street Ballan - http://www.ballanhealth.com.au/

Hepburn Health Services - (03) 5321 6570 **-** Hospital Street Daylesford - http://www.hhs.vic.gov.au/

Ballarat Health Services - (03) 5333 7104 **-** 106 Market Street Ballarat - https://www.bhs.org.au/node/188

Hepburn Shire Council - (03) 5348 2306 - Corner Duke and Albert Streets, Daylesford - https://www.hepburn.vic.gov.au/ **Vision Australia -** (03) 5337 4555 - 1300 Howitt Street

Wendouree - https://www.visionaustralia.org/

Djerriwarrh Health Service - (03) 5367 2000 - 35 Grant Street Bacchus Marsh - https://www.djhs.org.au/

Hesse Rural Health Services - (03) 5267 1200 - 9 High Street, Bannockburn - https://www.hesseruralhealth.net.au/

City of Ballarat - (03) 5320 5636 - 25 Armstrong Street South Ballarat - http://www.ballarat.vic.gov.au/

Moorabool Shire Council - (03) 5366 7100 - 15 Stead Street Ballan - https://www.moorabool.vic.gov.au/

FINANCIAL SUPPORT FOR AIDS & EQUIPMENT

Aids and equipment can be essential and may make life easier and safer for carers. However, equipment is often expensive. Various government schemes and not-for-profit organisations loan or provide free or subsidised equipment to people with illnesses or disability.

What equipment and aids are available?

There are many types of equipment available. A person might need equipment and aids for daily tasks like moving, showering or feeding the person they care for.

Advice on finding the right equipment

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 <u>home support and home care</u> <u>packages</u>
- <u>Rehabilitation Appliances Program</u> (Department of Veterans Affairs)
- Australian Hearing Services
- A person may also be able to get assistance with the cost of running <u>essential medical equipment</u>, such as oxygen equipment or a home dialysis machine.

State and territory equipment schemes

Each state and territory has its own equipment schemes, although what is available varies. 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: <u>Aids and Equipment Program</u>

Equipment assistance from non-government organisations

Some non-government organisations also provide and loan equipment.

Support Options



Aztec Equipment - (03) 5336 3900 - 612 Skipton Street, Redan https://astecservices.net.au/

Independent Living Centres Australia - 1300 885 886 - Display locations: Shop C1 Central West Shopping Centre 67 Ashley Street Braybrook & 54 Railway Road, Blackburn https://ilcaustralia.org.au/search_category_paths
Omni Healthcare - (03) 5333 4006 - 206 Creswick Road Ballarat - http://www.omnihealthcare.com.au/
State-wide Equipment Program - 1300 747 937 - PO Box 1993 Bakery Hill - https://swep.bhs.org.au/applying-for-aids-and-equipment.php

HOME MEDICINES REVIEW

Home Medicines Reviews have been designed to enhance the quality use of medicines and reduce the number of adverse medicine events, by assisting consumers to better manage and understand their medicines through a medication review conducted by an accredited pharmacist in the patient's home.

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

The service involves cooperation between the GP, pharmacist, other health professionals and their patient (and, where appropriate, their carer). A HMR service improves the patient's and 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 patient and other health care providers involved in the patient's care.

ABORIGINAL HEALTH SERVICES

The local Aboriginal Health Service will deliver health and wellbeing services to the Aboriginal community and will be dedicated to building cultural pride and ensuring their services respect Aboriginal culture, history and experience.

Ballarat & District Aboriginal Cooperative - Phone: (03) 5331 5344 - reception@badac.net.au - 5 Market Street Ballarat http://www.badac.net.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 every day activities such as meal times, 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 interest in past interests and past times. Importantly, reminiscence allows them to take on a teaching role through the sharing of your stories.

Reminiscence involves exchanging memories between them and the young, 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 history '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.

Therapies & Activities

It is best to begin the putting together of 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 by 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 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.

People can obtain a copy of the <u>'Information about me'</u> booklet from any of the services listed in this guide, or by clicking on the link above or below.

A completed <u>'Information about me'</u> booklet is a great place to start but people may wish to make their own unique book. It is entirely up to them. 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.

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 advanced care directive (medical).

PAYMENTS FOR OLDER AUSTRALIANS

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

When they receive Age Pension, they may also be eligible to receive help with living and household costs.

Pension Loans Scheme - people can apply for a non-taxable loan if they need extra income or help for a short time or an indefinite period. There is no lump sum.

If they are granted a loan, the loan will be paid to them fortnightly. They can choose the amount of the fortnightly loan, up to the maximum rate of pension. If they already get the maximum rate of pension then loan payments cannot be paid.

Commonwealth Seniors Health Card – are available to people who have reached age pension age and don't qualify for a payment from Centrelink or the Department of Veterans' Affairs. They also need to meet an income test, and are an Australian resident currently living in Australia

Planning for the Future

Widow Allowance – to be eligible for this payment a person must be a woman born on or before 1 July 1955 and not be part of a couple. They need to have become widowed, divorced or separated since turning 40 and haven't had a job in the 12 months just before they claim, which was 20 hours a week or more, and for a total of 13 weeks or more. They will also need to meet income and assets tests and meet residence rules.

Carer Payment – a carer may receive a carer payment, but only if the person they are caring for scores high enough on the ADAT or DCLAD. The person be cared for will have had these needs for at least 6 months or will have them for the rest of their life. The carer will also need to be under the pension income and assets test limits.

A carer may also be eligible for a **Carer's Allowance**. If they give extra care to someone who has a disability or severe illness or is frail aged and their care needs score high enough on the ADAT or DCLAD. The person they care for will have these needs for at least 12 months or the rest of their life.



Australian Government – Department of Human Services

132 717 – Carers - 132 300 – Older Australians - Visit any Centrelink Office -

https://www.humanservices.gov.au/individuals/subjects/payments-older-australians

LEGAL DOCUMENTS AND 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.
- Medical Treatment Decision Maker (MTDM) lets a person choose someone to make decisions about their medical treatment.
- Enduring Power of Guardianship lets a person choose someone who can make lifestyle decisions for them.
- 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

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 they feel are important, and can provide peace of mind for themselves and their loved ones.

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



Central Highlands Community Legal Centre - (03) 5331 5999

15 Dawson Street North, Ballarat - http://www.chclc.org.au/

Office of Public Advocate - 1300 309 337 -

http://www.publicadvocate.vic.gov.au/

Victoria Legal Aid - 1300 792 387 -

https://www.legalaid.vic.gov.au/

Seniors Rights Victoria - 1300 368 821 -

https://seniorsrights.org.au/

Seniors Information Victoria - COTA - 1300 135 090 -

https://cotavic.org.au/info/siv/

ADVANCE CARE DIRECTIVE

An advance care plan (or sometimes called an Advanced 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.

Advance Care planning gives a person the opportunity to think about their beliefs, values and their goals for 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 can 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.

This program is supported by the Victorian Department of Health. It explains how and why to do advance care planning and provides a step by step process.



Advance Care Planning - 1300 208 582 -

https://www.advancecareplanning.org.au/

Office of Public Advocate - 1300 309 337 -

http://www.publicadvocate.vic.gov.au/



Other Useful

Contacts



Alliance for Forgotten Australians - 0488 460 646, 0419 854 980 - PO Box 212 Camberwell VIC 3124 - 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'. http://www.forgottenaustralians.org.au/

Australian Government Department of Human Services

132 717 – Carers, 132 300 – Older Australians – Visit any
Centrelink Office - Payments and services for older Australians

who are retired, planning for retirement or considering working

who are retired, planning for retirement or considering working past age pension age.

https://www.humanservices.gov.au/individuals/subjects/payments-older-australians

Australian Hearing - 1300 412 512 - The nation's leading hearing specialist and largest provider of Government funded hearing services. https://www.hearing.com.au/

GLHV – Gay Lesbian Health Victoria - (03) 9479 8760 - Promoting the health and wellbeing of LGBTI Victorians. http://www.glhv.org.au/

National Relay Service - 1300 60 60 24 - A phone solution for people who are deaf or have hearing or speech impairment. Transgender Victoria - (03) 9020 4642 (voicemail) - 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.

http://www.transgendervictoria.com

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.

Medicare - 132 011 - Information about payments and services for Medicare.



Additional Resources

ONLINE RESOURCES

At Home with Dementia

http://at-aust.org/assets/HelpfulHandbookForMemoryLoss2017.pdf A manual for people with Dementia and their Carers.

Carer Gateway

https://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

https://www.dementia.org.au/

Alzheimer's and Dementia Resources

Dementia Australia - Helpsheets

https://www.dementia.org.au/about-dementia/resources/help-sheets

Advice on the issues most commonly raised about dementia.

Dementia Australia - Resources

https://www.dementia.org.au/resources

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

Dementia Daily

https://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

https://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

https://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

https://www.dementiatrainingaustralia.com.au/tag/resources/

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 https://www.dta.com.au/resources/environmental-design-resources-introduction/

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. Topics covered in the book include: preparing for the future, around the home, communication and conversing, money management, remembering things, cooking, cleaning, shopping, safety, security, taking tablets, getting places and product lists.

The Dementia Guide - Dementia Australia

https://www.dementia.org.au/resources/the-dementia-guide

Description: For people with Dementia, their families and carers.

The University of Sydney - Brain and Mind Centre

https://www.dta.com.au/resources/environmental-design-resources-introduction/

We are dedicated to finding better ways to diagnose and treat frontotemporal dementia, alongside working to discover the cause of the condition.

Additional Resources

The University of Sydney – Cognitive Decline Partnership Centre http://sydney.edu.au/medicine/cdpc/documents/resources/Dementia-Guidline-Guide-2017-WEB.pdf

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

BOOKS

For Persons with Dementia

Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease / Joanne Koenig Coste (2004)

Revolutionizing the way we perceive and live with Alzheimer's, Joanne Koenig Coste offers a practical approach to the emotional well-being of both patients and caregivers that emphasizes relating to patients in their own reality.

First Person Accounts

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

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.

What the Hell Happened to My Brain? : Living with dementia / Kate Swaffer (2016)

Kate Swaffer was just 49 years old when she was diagnosed with a form of younger onset dementia. In this book, she offers an all-too-rare first-hand insight into that experience, sounding a clarion call for change in how we ensure a better quality of life for people with dementia. Kate describes vividly her experiences of living with dementia, exploring the effects of memory difficulties, loss of independence, leaving long-term employment, the impact on her teenage sons, and the enormous impact of the dementia diagnosis on her sense of self.

Alzheimer's from the inside out / Richard Taylor 2007

Diagnosed with Alzheimer's disease at age 61, the former psychologist courageously shares an account of his slow transformation and deterioration and the growing division between his world and the world of others.

Dancing with Dementia: my story of living positively with dementia / Christine Bryden 2005

This book is a vivid account of the author's experiences of living with dementia, exploring the effects of memory problems, loss of independence, difficulties in communication and the exhaustion of coping with simple tasks. She describes how, with the support of her husband Paul, she continues to lead an active life nevertheless, and explains how professionals and carers can help.

Somebody I used to know / Wendy Mitchell (2018)

Mitchell was 58 when she was diagnosed with early-onset Alzheimers. She began to write about the experience of losing herself, and the result is this remarkable memoir.

Fiction

Still Alice/ Lisa Genova (2009)

Alice Howland is proud of the life she worked so hard to build. A Harvard professor, she has a successful husband and three grown children. When she begins to grow forgetful, she dismisses it for as long as she can, but when she gets lost in her own neighbourhood she knows that something has gone terribly wrong.

Resources for Caring

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)

This book outlines an approach to caring with calm, centred presence; responding with compassion; and maintaining authentic communication, even in the absence of words. Most importantly, discover ways to manage the grief, anger, depression, and other emotions often associated with dementia care.

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

Information on diagnostic evaluation; resources for families who care for people with dementia; legal and financial information; information on nursing homes and other communal living arrangements; research, medications, and the biological causes and effects of dementia.

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

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.

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

This book 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.

Family/Carer Accounts of Dementia

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.

Fraying: mum, memory loss, the medical maze and me / Michele Gierck (2015)

Fraying chronicles a mother's and a daughter's journey through memory loss and the medical maze. The relationship between the spirited, determined 88-year-old protagonist - who refuses to passively accept medical pronouncements - and her daughter is at times difficult, yet always respectful and loving, warm and upbeat.

Alzheimer's: a love story / Vivienne Ulman (2009)

In Alzheimer's: a love story, Vivienne records with tender lyricism and searing honesty the progress of her mother's Alzheimer's, her own grief over the gradual loss of her beloved mother, and the way in which her parents' enduring love for each other sustains them.

Hazel's journey: a personal experience of Alzheimer's / Sue Pieters-Hawke and Hazel Flynn 2004

In November 2003 Hazel Hawke went public with the news that she had Alzheimer's Disease. Now Hazel's daughter Sue tells the full story of her mother's life in the past 10 years: stepping out as her own woman after her split from Bob, the early signs of what would prove to be Alzheimer's, and the gentle happiness in her life now.

Losing Clive to younger onset dementia: One family's story / Helen Beaumont 2009

Clive Beaumont was diagnosed with Younger Onset Dementia at age 45, when his children were aged just 3 and 4. He had become less and less able to do his job properly and had been made redundant from the Army the year before.

Clive's wife, Helen, tells of how she and the rest of the family made it through the next six years until Clive died: the challenge of continually adapting to his progressive deterioration; having to address the legal implications of the illness; applying for benefit payments; finding nursing homes; and juggling her responsibilities as a wife, a mother and an employee. She also describes the successful founding and development of The Clive Project, a registered charity set up by Helen and others in a bid to establish support services for people with Younger Onset Dementia. Younger Onset Dementia is comparatively rare, but not that rare. This story is for the family and friends of people with the condition, for the people themselves, and for the professionals working with

Remember me, Mrs V? / Tom Valenta 2007

them.

A moving memoir of a husband caring for his wife, Marie, who was diagnosed with Alzheimer's disease at age 54. Tom describes his struggle of looking after his wife, arranging professional and voluntary in-home support and continuing to work. Ultimately he is forced to seek permanent residential care for Marie. There are thirteen cameos of other carers and how they dealt with a family member who was stricken with Alzheimer's or other form of dementia. This book will be of great assistance to all men and women caring for a loved one.

Books on Activities

We can, we can: purpose and pleasure for people living with dementia / Paula Bain and Marina Cavill 2012

This collection of activities respects the diversity, as well as the need for a person-centred approach to activities.

Chocolate rain: 100 ideas for a creative approach to activities in dementia care / Sarah Zoutewelle-Morris 2011

For those seeking creative solutions to improving the well-being of people living with dementia.

Montessori based activities for persons with dementia: Volume 1 & 2 / Cameron J. Camp 1999-2006



Appendix

AGENCY/SERVICE LIST

The agencies and services mentioned throughout this guide are listed here in alphabetical order with the page number they are located on so you can find their details easily.

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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.
Advanced 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. 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 transition 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 for the Aged	The former ACHA Program supported older people who were older or prematurely aged people on a low income who were homeless (at the time) or may have been at risk of becoming homeless as a result of experiencing housing stress, or not having secure accommodation.

Care plan Carer allowance	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. 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 the Department of Human Services 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 the Department of Human Services.
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. The CHSP builds on the strengths of home support programmes which came before it and from 1 July 2015 consolidates the following programmes: • The Commonwealth Home and Community Care (HACC) Program • Planned respite services under the National Respite for Carers Program (NRCP) • The Day Therapy Centres (DTC) Program • The Assistance with Care and Housing for the Aged (ACHA) Program.
Community nursing and health centres	If you are frail aged, then you may need nursing care from an enrolled or registered nurse at a community nursing and health centre to improve or maintain your health and wellbeing.
Comprehensive	The Aged Care Assessment Service (ACAS) will conduct a holistic,
Assessment	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 Assistant services include home related tasks such as, cleaning, dishwashing, clothes washing, ironing, and unaccompanied shopping.

Enduring power of attorney Flexible care	An enduring power of attorney allows a person to delegate the management of their affairs, even if they're no longer able to understand the implications. A person can only give an enduring power of attorney while they're able to understand the nature and effect of the document. An enduring power of attorney comes into effect once a person loses mental capacity. 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	The Home and Community Care (HACC) program provides services to support younger people with disabilities, and their carers. These services help people live as independently as possible in the community. If you think that you (or a family member or a person you care for) might find HACC 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.
Home Care Packages	The types of services provided under a home care package will depend on your needs. 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.
Home maintenance	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.
Home modification	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, other minor renovations. Home modifications must be installed by a licensed tradesperson and organised through the aged care provider.
My Aged Care	My Aged Care was introduced on 1 July 2013 and 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).

National Screening Assessment	To ensure a nationally consistent and holistic screening and assessment process, the NSAF will be used by My Aged Care contact centre staff, the RAS and existing ACATs.
Form [NSAF]	contact control stant, the 10 to and existing restrict
Personal care	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.
Respite	Planned respite is about receiving services on a short term or time limited bases and planned in advance. Planned respite can be provided in a client's home or temporarily in another setting such as a day centre or in the community
Prematurely aged people	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.
Reablement	The use of timely assessment and short term, targeted interventions to: assist people to maximise their independence, choice, health outcomes and quality of life; appropriately minimise support required and reliance on future and or alternate support; maximise the cost effectiveness of programs; support people to continue to participate and remain engaged in their local communities as they wish. The provision of reablement services is part of the wellness philosophy.
Reassessment	Reassessment is undertaken by the My Aged Care RAS and focuses on the strengths and needs of the individual client. RAS assessors are appropriately skilled, and trained to undertake assessments (and reassessments) and identify services appropriate for a diverse range of clients.
Regional Assessment Service (RAS)	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.
Residential aged care	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.

Respite care	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 and 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.
Restorative care	For a smaller sub-set of older people, restorative care may be appropriate, where assessment indicates that the client has potential to make a functional gain. 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 which are delivered by, or under guidance of an allied health professional.
Service plan	A service plan recognises client abilities and need to regain/retain; Recognises that service support needs to enable the person and provide opportunities to build capacity – focus is on achieving outcomes; Service support provided for those activities that the individual cannot do without assistance; Supports ' to do' or 'do with'; and Regular review is built into the care plan.
Service provider	A service provider is an organisation funded to provide aged care services to older people.
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 are: 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; parents separated from children by forced adoption or removal.
Support Plan	Following an assessment by RAS or ACAS, a support plan will be created that will include 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 for their own future reference.

Transport services can help get you to and from your **Transport** services appointments and around your community. You can get picked up by a transport service or receive vouchers or subsidies, for taxi services. Your state and territory Department of Health may also have services to assist. 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.