

Dementia Care Guide

For Family Caregivers



Whiddon
Award-winning care



What Is this Guide?

Dementia can have a significant impact on the person diagnosed and their friends and family. This Dementia Care Guide has been developed by Whiddon to help family caregivers and people living with dementia (PLWD) gain a better understanding of these conditions and provide strategies for support and planning ahead. In this guide you will find:

- Information on what dementia is and how it can affect people.
- Practical tips and strategies for a family caregiver to assist people living with dementia.
- Additional resources where you can find support for living with dementia.

It is important to remember that everyone's experience with dementia is unique and we always recommend contacting a medical professional if you have any concerns. But that doesn't mean that you need to face this journey alone. We hope that by creating this guide, people impacted by this diagnosis can feel better prepared for what the future may hold.

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Dementia

Understanding Dementia

Dementia refers to a group of conditions that affect the brain's cognitive abilities and behaviour over time. This can have an impact on various functions such as memory, language, orientation, and awareness and can lead to changes in behaviour and personality. Although age can be a risk factor, it is not a normal part of the ageing process and can affect anybody.

In Australia, it is estimated that there are currently over 400,000 people living with dementia, with this number set to more than double by 2058. This means that the number of people caring for loved ones living with dementia is also set to increase exponentially. At the moment, whilst there is no cure for these conditions there are several strategies that can help mitigate the challenges that may arise. By implementing effective dementia support, you can help the people closest to you maintain their independence and quality of life. **Connection and relationships are most important and are not impacted by cognitive capacity.**

Dementia Diagnosis: Methods and Procedures

Dementia symptoms will vary depending on the type of condition present and each individual. However, in the early stages, people living with dementia can exhibit common symptoms including:

- Frequent forgetfulness
- Confusion about time and place
- Inability to recognise familiar people
- Difficulty finding the right words
- Repetitive behaviour
- Mood changes
- Restlessness
- Aggression

A diagnosis of dementia is confirmed when these symptoms persist over time and interfere with the person's ability to perform daily activities.

Types of Dementia



There are several types of dementia, but the most common forms are Alzheimer's disease and vascular dementia.

Alzheimer's Disease

Alzheimer's disease is the most well-known cause of dementia. This disease occurs when the brain's neural function is disrupted due to a build-up of proteins called 'plaques and tangles'. These protein structures affect normal brain functions, decreasing the amount of important chemicals that are needed for messages traveling through neurons. Common symptoms of Alzheimer's disease include:

- Short-term memory loss - difficulty recalling recent events and memories.
- Language and communication issues - such as repeating sentences or having difficulties finding the right word for something.
- Increasing confusion about time and place - losing track of time or getting lost in familiar places.

Vascular Dementia

Vascular Dementia is the second most common form of dementia and occurs when the brain does not receive enough oxygen. This is often the result of a stroke, or a constant lack of blood supplied to the brain over time. While it does share some similarities with Alzheimer's Disease, Vascular Dementia has its own set of unique symptoms including:

- Depression and apathy
- Difficulties with moving around
- Issues with decision-making and planning

There is also a wide range of less common causes of dementia including:

- **Lewy body disease** - caused by the buildup of tiny protein clumps in the brain known as Lewy bodies.
- **Frontotemporal dementia** - caused by protein buildup in the front and side parts of the brain, preventing them from working properly and affecting behaviour and speech comprehension.
- **Alcohol-related dementia** - related to the excessive consumption of alcohol which can affect mental functions.
- **Down syndrome & Alzheimer's disease** - a link has been suggested between the exponential production of certain proteins in people with Down syndrome and their abnormal breakdown which form the plaques that cause Alzheimer's.
- **HIV-associated dementia** - people who have HIV and AIDs may develop a complication that can lead to indirect damage to the brain's nerve cells.
- **Chronic Traumatic Encephalopathy (CTE) dementia** - linked to repeated head injuries which can affect a person's brain function over time.
- **Childhood dementia** - the result of progressive brain damage linked to over 70 rare genetic disorders including Batten disease and Sanfilippo syndrome.





Dementia's Evolution:

Stage and Degrees

Everyone living with dementia is unique and the rate at which these conditions progress will differ from person to person. While its progression can be slow and span over several years, there are also cases where it occurs rapidly within months. It can often be difficult for family members to witness this progression affect their loved ones and the increasing need for assistance with everyday tasks. However, understanding how dementia develops over time, will help you plan for any potential challenges that may appear in the future. While everyone experiences dementia at different rates, the progressive nature of these conditions means that it can usually be broken up into three stages.

Early-Stage (Mild)

In the early stages of dementia, the person may show symptoms that could be mistaken for other factors such as stress. Given its gradual

progression, it is often difficult to pinpoint the exact onset of dementia and people will usually require minimal support in their daily lives.

Middle-Stage (Moderate)


During the middle stage, dementia symptoms become more apparent and can have a bigger impact on the person's daily life. They may have a poor memory of recent events or not recognise friends and family. Some extra support may be required to perform certain tasks.

Late-Stage (Severe)

Late-stage symptoms of dementia are severe and will require much more support. The person is likely to find it more challenging to perform daily routines such as eating, drinking and walking.



What Can We Expect?



Stage	Symptoms and Challenges	Helpful Strategies
Early	<ul style="list-style-type: none"> ● Forgetfulness ● Difficulty learning and following conversations ● Limited attention span ● Problems with orientation and directions ● Communication difficulties ● Work-related issues ● Mood shifts and depression ● Passiveness and withdrawal ● Mild coordination problems ● Difficulty with challenging cognitive tasks 	<ul style="list-style-type: none"> ● Provide written reminders ● Use clear and simple language ● Break tasks into smaller steps ● Create a structured routine ● Offer emotional support ● Encourage social engagement ● Maintain a healthy lifestyle ● Encourage physical activities ● Simplify daily tasks and responsibilities
Middle	<ul style="list-style-type: none"> ● Pronounced memory loss ● Declining concentration ● Mood shifts ● Sense of loss and insecurity ● Withdrawal or passiveness ● Repetitive actions and questions ● Delusions and hallucinations ● Need for assistance with daily activities ● Changes in sleep and appetite patterns 	<ul style="list-style-type: none"> ● Use memory aids (notes, photos) ● Maintain familiar routines ● Redirect during repetitive behaviour ● Validate emotions and experiences ● Create a safe and calm environment ● Provide assistance with personal care ● Offer comforting activities ● Monitor sleep and manage routines ● Adapt diet to changing preferences
Late	<ul style="list-style-type: none"> ● Severe memory impairment ● Need for assistance with eating ● Loss of speech capacity ● Require walking assistance ● Incontinence of urine and stool 	<ul style="list-style-type: none"> ● Offer soft and easily manageable foods ● Communicate through touch and nonverbal cues ● Focus on comfort and sensory stimulation ● Use mobility aids safely ● Provide assistance with toileting needs ● Maintain a soothing and consistent environment

How To Support Someone Living With Dementia

Being a family caregiver for a loved one with dementia can be challenging, but with the right strategies and understanding, you can create a more supportive environment for their well-being. Here are some essential tips and techniques to support someone living with dementia:

Communication Strategies

Effective communication is the cornerstone of caregiving for individuals with dementia. As their cognitive abilities change, finding the right ways to connect becomes essential.

1

Reminiscence

Encouraging reminiscence can be a powerful tool to evoke cherished memories and foster emotional connections. Engaging in shared reminiscing can bring joy and comfort to both you and your loved one.

2

Validation

Instead of correcting or challenging their beliefs or memories, validation allows you to acknowledge and respect their feelings and experiences, maintaining their dignity and minimising potential distress.

3

Reality Orientation

Balancing validation with reality orientation can be beneficial in certain situations. By gently guiding them to the present reality using clear and simple language, you can help reduce confusion and anxiety.

4

Be Kind and Empathetic

Compassion and empathy are essential when communicating with someone living with dementia. By approaching them with kindness and understanding, you can establish trust and a positive rapport.

5

Be Inclusive

Inclusivity involves actively involving your loved one in conversations and decisions, acknowledging their thoughts and preferences, even if their verbal expressions are limited.

6

Be Mindful of Body Language

Non-verbal communication, such as body language and facial expressions, plays a significant role in conveying emotions and intentions. Being mindful of your own body language can foster a more comfortable environment for your loved one.

7

Use Reminders and Notes

Utilising visual aids, such as written reminders or sticky notes, can help your loved one remember important events or daily routines, reducing anxiety and confusion.

Understanding Their Behavioural Changes

Observing and understanding the behavioural changes in someone with dementia is crucial for providing appropriate care and support.

Behaviours are now being considered ‘unmet needs’. The greatest unmet need for the PlwD is the slow loss of intimate connection with family and friends.

1

Aggression

Aggressive behaviours, stemming from fear, untreated pain, frustration or confusion, can be distressing for both the individual and the caregiver. Identifying triggers and employing calming techniques can help manage and prevent such behaviours.



2

Apathy

Apathy, characterised by a lack of interest or motivation, can be addressed by finding activities that align with their interests and abilities. Depression is common in Dementia, and a GP or Geriatrician assessment is worthwhile. Gentle encouragement, intimate connection that makes them feel valued and worthwhile will help support them to re-engage with the world around them.

3

Repetition

Repetitive behaviours, such as asking the same questions repeatedly, are common in dementia. Responding with patience and understanding, along with redirection techniques, can alleviate frustration for both parties.

4

Identifying Triggers/Underlying Needs

Be attentive to things that may cause behavioural changes, such as environmental factors or routine changes or most commonly UNTREATED PAIN. This enables you to take proactive steps to minimise agitation and stress. If you SEE a behavioural CHANGE, THINK first about PAIN.



5

Personalised Coping Strategies

Discovering individualised coping strategies, such as deep breathing exercises or favourite activities, can empower your loved one to manage stress and maintain emotional wellbeing.



6

Maintain Consistency

A stable and familiar environment can help individuals with dementia feel more secure and reduce fear and confusion. Establishing and maintaining consistent daily routines can contribute to their overall comfort.

Activities to Engage Them

Engaging in meaningful activities provides cognitive stimulation and emotional connection, enriching the lives of those with dementia.

1

Safe Assistance during Meal Prep

Involving your loved one in meal preparation tasks, adapted to their abilities, allows them to contribute to daily routines and maintain a sense of independence.



2

Reminiscing

Reminiscing involves talking about past activities, events and experiences that evoke happy memories, usually with the use of prompts such as photographs, and other familiar items from the past, including music, smells and anything which stimulates the senses.



3

Flower Arrangement

Engaging in flower arrangement provides a creative outlet and sensory experience. This activity can evoke positive emotions and serve as a delightful decorative element.

4

Engaging Everyday Tasks

Encouraging participation in simple, everyday tasks, such as folding laundry or organising items can instil a sense of purpose and routine.

5

Encourage Physical Activity

Regular exercise can enhance mood and reduce anxiety. Finding appropriate activities, such as walks or gentle exercises, can positively impact their physical and emotional health.



6

Social Engagement

Arranging gatherings or outings with family and friends fosters social interaction and a sense of belonging, reducing feelings of isolation.

Start Planning Ahead

Thinking about the future changes that you will have to make because of the progression of dementia can be a challenging prospect. That's why it's always important to involve the person you're supporting when planning ahead. Doing so gives the PLwD a chance at deciding what they want for the future and choosing the person they want to make certain decisions when the time comes.



Arrange Financial, Legal, and Care Matters

When it comes to dementia care, it's crucial to address financial, legal, and care matters sooner rather than later. Begin by ensuring that all necessary legal documents are in place, such as wills, power of attorney, and advanced care directives. These documents will provide clear guidance on how to manage their affairs as the disease progresses. Engage in open discussions with your loved one about their preferences and decisions regarding finances and healthcare. This not only empowers them to make choices aligned with their wishes but also offers you valuable insights to better support them.



Care Provider or Long-Term Care at Home

Deciding whether to provide care at home or seek assistance from a care provider is a significant decision that requires careful consideration. In Australia, there are options available that cater specifically to dementia care. If you opt for care at home, creating a safe and comfortable environment becomes paramount.

Make adjustments to the home to reduce hazards, provide memory aids, and establish daily routines that offer familiarity. Should the need arise for long-term care outside the home, research reputable care facilities that specialise in dementia care. Visit them, ask questions, and ensure they align with your loved one's needs and preferences.



Programs & Support

Australia offers a range of programs and support services tailored to dementia care. Look into local resources such as Dementia Australia, which provides invaluable information, education, and support for both caregivers and PLwDs. These organisations can help you connect with support groups, workshops, and educational sessions that address the unique challenges you may face. Additionally, inquire about government-funded programs that offer financial assistance and respite care to ease the caregiving journey.

Throughout this process, remember that it's normal to experience a mix of emotions as you navigate this path, so be sure to prioritise your own well-being too. Seek support from friends, family, and support groups who understand the challenges you're facing. By embracing a collaborative and empathetic approach, you're creating an environment where your loved one's wishes are honoured, and their comfort and dignity remain at the forefront.



Reducing The Risk Of Dementia

It is important to acknowledge that there is currently no surefire way to prevent dementia. As people reach middle age, changes can start to occur in the brain, with a number of factors that can increase the risk of developing dementia-related symptoms. These risk factors can include:

- Age
- Social isolation
- Smoking
- Lack of exercise
- Drinking alcohol
- Genetics & Family History

Whether it's growing older, our genetics or our family history, there are certain factors that are unavoidable. However, scientific research has suggested that keeping the brain healthy can significantly reduce or delay the risk of developing dementia. This can be achieved by modifying parts of your life such as:

Prioritising Your Physical Health

Eating a balanced diet and participating in regular exercise can have a significant impact on reducing the risk of dementia. Regulate your meal portions and ensure that your diet is rich in nutrients, minerals and healthy fats. For general tips on healthy eating, we recommend visiting the Australian Dietary Guidelines.

A lack of exercise is one of the largest risk factors for dementia. Engaging in physical activities has a positive impact on the brain, increasing blood and oxygen flow as well as supplying the necessary nutrients for new cells to grow. Exercising can also reduce the risk of other health conditions such as high blood pressure, heart disease and diabetes.

Limit Alcohol Intake And Avoid Smoking

If you choose to drink alcohol, do so in moderation. This typically means following the recommended Australian guidelines of a

maximum of four standard drinks per day, with at least two days per week being alcohol-free.

Smoking should be avoided at all costs as it can restrict blood vessels and decrease oxygen delivery to the brain. This can increase the risk of heart disease, stroke and cancer as well as symptoms related to dementia. Always remember that it's never too late to quit. Start off with resources such as nicotine gum or patches and by speaking to your doctor.

Maintaining Your Social Life

Social interaction is an important part of keeping your mind engaged and reducing potential feelings of loneliness or depression. Engaging in regular conversations and participating in social activities with your friends and family will help to maintain emotional well-being. In addition, we recommend considering joining a community club or organisation based on your interests. This provides the perfect opportunity to meet new people and establish new connections with groups that can foster a sense of belonging.

Keeping Mentally Stimulated

Mental stimulation is essential for keeping your brain healthy and is linked to a reduced risk of dementia. Research has shown that engaging in brain exercises can strengthen its ability to continue working even if cells are damaged and help to establish new neural connections that enhance mental sharpness. Examples of brain exercises and activities that you can do include:

- Reading
- Taking up a hobby
- Brain-training exercises or puzzles
- Enrolling in a course to learn something new
- Painting
- Using technology

Organisations & services that can assist you

As you embark on this caregiving journey, remember that you're not alone. There are numerous organisations and services in Australia that can offer support to you and your loved ones.

Dementia Australia

Dementia Australia is a leading national organisation that is dedicated to supporting the needs of people living with dementia and their families. They currently represent nearly 2 million Australians and provide a wealth of resources, including educational materials, support services and workshop sessions. Whether you have some concerns about potential symptoms or require practical assistance in caring for your loved ones, Dementia Australia is committed to helping anyone who has been impacted by dementia.

For more info, visit www.dementia.org.au

My Aged Care

My Aged Care is a website set up by the Australian government to help people navigate the aged care system. They can provide information about accessing government-funded services, residential care options, and financial considerations. This can be particularly valuable as your loved one's care needs evolve over time.

Visit www.myagedcare.gov.au for more.

Cognitive Dementia and Memory Service

The Cognitive Dementia and Memory Service specialises in the diagnosis and management of dementia and memory-related conditions. They provide comprehensive assessments and tailored care plans to help families better understand their loved one's condition. If you or someone you know has concerns about changes to memory and thinking, you can ask a local health professional to refer you or contact the service yourself.

Clinics are located across Australia and can be found at

www.australiandementianetwork.org.au/ or www.dementia.org.au/helpline

National Dementia Helpline

The National Dementia Helpline is a free telephone service that is staffed by a team of professionals who can assist with all aspects related to dementia. The helpline can provide confidential counselling, updated resources, information about Dementia Australia and referrals to support services.

The service runs 24 hours a day, seven days a week, 365 days a year.

Call **1800 100 500** or visit www.dementia.org.au/helpline

Whiddon's Aged Care Services

Community Care and Support at Home

Community Care is a range of flexible and personalised home care services to support you to live safely and independently. At Whiddon, we're dedicated to making sure that you spend less time worrying about daily routines and more time enjoying life to the fullest. This includes helping with tasks such as cooking and cleaning, offering companionship and social interactions and in-home nursing and medical assistance.

Residential Aged Care

Whiddon is committed to ensuring that all of our residents receive the best possible care while living in our residential aged care homes. All of our staff are specially trained to employ our award-winning model of care known as MyLife. Centred around building and maintaining relationships, it seeks to create an environment that enriches the lives of residents and ensures that they feel a sense of dignity and purpose.

Several of our homes also have dedicated dementia wings and related care services that ensure the safety of your loved ones.

In addition, we also run an exclusive healthy ageing program for people living with dementia known as Chat, Stories & Tea. This is based on an existing program known as Cognitive Stimulation Therapy which involves running a variety of activities in a structured social group. By incorporating our relationship-based care model, our program ensures that the needs of our residents are met through social therapy, all while improving their cognitive function and general well-being.

Get In Touch With Whiddon

Whiddon's Aged Care Services are available across New South Wales & Southern Queensland. For more information get in touch with our customer service team who can help you find the right services for you or your loved one's needs.

Call Us

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