



COGNITIVE
DECLINE
PARTNERSHIP
CENTRE

Diagnosis, treatment and care for people with dementia:

A CONSUMER COMPANION GUIDE TO THE CLINICAL PRACTICE GUIDELINES
AND PRINCIPLES OF CARE FOR PEOPLE WITH DEMENTIA

© NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People 2016

Published: September 2016

Suggested citation: Diagnosis, treatment and care for people with dementia: A consumer companion guide to the Clinical Practice Guidelines and Principles of Care for People with Dementia. NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People. Sydney. 2016.

Acknowledgement: Consumers from the Dementia Australia Consumer Network have contributed to the content of this Guide, in partnership with researchers from the NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People. The Partnership Centre receives support from the NHMRC and Funding Partners including Alzheimer's Australia, Brightwater Care Group, HammondCare and Helping Hand Aged Care.

Disclaimer: This document is a companion guide to the Australian Clinical Practice Guidelines and Principles of Care for People with Dementia, to be followed subject to the clinician's judgement and person's preference in each individual case. The Guidelines and the companion guide are designed to provide information to assist decision making and are based on the best evidence available at the time of development of this publication.

ISBN: 978-0-9945415-6-7



BACKGROUND

This is a consumer version of the Australian Clinical Practice Guidelines and Principles of Care for People with Dementia which can be downloaded from: www.sydney.edu.au/medicine/cdpc/resources/dementia-guidelines.php

WHAT IS DEMENTIA?

Dementia is a clinical syndrome (a set of medical signs and symptoms) that can be caused by a number of underlying diseases, including Alzheimer's disease. Dementia can affect memory, thinking, behaviour, communication and ability to perform activities of daily living.

WHAT ARE THE CLINICAL PRACTICE GUIDELINES?

The clinical practice guidelines describe a standard of care that should be available to all Australians with dementia as well as to people being investigated for the possibility of dementia.

The guidelines are based on the best research evidence; where there is inadequate evidence, they are based on the opinion of experts, including consumers. They let people with dementia and their carers know what kind of care and treatment to expect and they let doctors and health providers know what sort of care to provide. Having a version of the guidelines for consumers and a more detailed version for health workers means everyone knows what to expect.

This should make it easier to access, receive and provide care. Funding for the guidelines was provided by the NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People.



THE ROLE OF THIS GUIDE

People seeking or receiving care in Australia have rights relating to safety, respect, information and privacy as outlined in the Australian Charter of Healthcare Rights. This consumer version of the guidelines is designed to support consumers to be fully informed when being investigated or treated for possible or diagnosed dementia. It has been published to make the information in the guidelines accessible to anyone with an interest in dementia, such as someone who has dementia, someone who thinks they may have the signs and symptoms of dementia, someone who is concerned that a relative or friend may have dementia or someone who is caring for a person with dementia.

The guide is not intended to be a comprehensive summary of all aspects of dementia care. Dementia is a complex condition: people's needs vary depending on their age, gender, social and family support networks, type of dementia, residential address (urban or rural), other health conditions and their interests and roles. Clinical practice guidelines cannot take into account all of these factors. Therefore, while this document provides general advice, individuals will need to consider their own circumstances and act accordingly.

TO WHOM DOES THIS INFORMATION APPLY?

This information is relevant to anyone who has signs and symptoms of dementia, has been diagnosed with dementia or is close to someone who may or does have dementia.

Most people with dementia live at home with the support of partners, families and/or friends. People who live with/care for/provide support for a person who has or may have dementia are often referred to as 'carers'. Not everyone in this role likes to be referred to as a 'carer'. However, for simplicity the word 'carer' is used throughout this document to encompass all of these people who support a person with dementia in a non-professional capacity.

DIGNITY IN CARE

The Guidelines are underpinned by the principles developed by Dignity In Care program.

SOURCES OF FURTHER INFORMATION

Dignity in Care:
www.dignityincare.com.au

Federal Disability Discrimination Act: www.humanrights.gov.au/dda-guide-whats-it-all-about

Australian Charter of Healthcare Rights: www.safetyandquality.gov.au/national-priorities/charter-of-healthcare-rights/

Health and aged care professionals should provide person-centred care, by identifying and responding to the individual needs and preferences of the person with dementia, their carer(s) and family. The following 10 Principles of Dignity in Care should be used as the standard by which care is delivered and evaluated. If care is not being provided according to these principles it should be raised with the health care service provider. If you do not feel comfortable doing this directly, most services have procedures for addressing concerns. Alternatively, you may wish to contact an advocacy service. Such services can be found on the My Aged Care website.

10 PRINCIPLES OF DIGNITY IN CARE

- 1 Zero tolerance of all forms of abuse.
- 2 Support people with the same respect you would want for yourself or a member of your family.
- 3 Treat each person as an individual by offering a personalised service.
- 4 Enable people to maintain the maximum possible level of independence, choice and control.
- 5 Listen and support people to express their needs and wants.
- 6 Respect people's privacy.
- 7 Ensure people feel able to complain without fear of retribution.
- 8 Engage with family members and carers as care partners.
- 9 Assist people to maintain confidence and a positive self-esteem.
- 10 Act to alleviate people's loneliness and isolation.

ENSURING A TIMELY DIAGNOSIS

The earlier a diagnosis of dementia is obtained, the more time there is to make choices about what is important in the years ahead when living with this condition. A timely diagnosis means that people with dementia and their carers and families can make plans early, such as considering work commitments, financial planning and living situations. These plans should be put in place before the condition progresses.

SOURCES OF FURTHER INFORMATION

Dementia Australia:
www.detectearly.org.au

 1800 100 500

People commonly notice symptoms of dementia (such as memory loss) in themselves or others for a few months or more before seeking medical advice. Other common symptoms include apathy, reduced attention span, reduced initiative or changes in visuospatial abilities. Health professionals should respond to concerns promptly by conducting or arranging further investigation when symptoms are first reported. In older people, these symptoms should not be dismissed as 'part of ageing'.

SEEING A GP

When visiting a GP with concerns about memory loss, it would be helpful to take this guide to support the discussion.

When symptoms are first reported, a GP should:

- take concerns seriously, and not dismiss them as a normal part of ageing
- speak about the history of any symptoms with both the person with dementia and someone who knows that person well, if possible
- test memory and thinking skills (using a paper-based form)
- conduct a physical examination
- review medications
- consider whether symptoms may be due to another medical condition (including delirium or depression)
- order blood tests to exclude other reasons for symptoms
- offer access to counselling, if required.

Based on the findings, the GP may refer the person to a memory assessment clinic or specialist for further investigations. The general practitioner will also provide ongoing support and manage both the symptoms of dementia and other medical conditions.

SEEING A SPECIALIST

In Australia, medical specialists with expertise in dementia include geriatricians, neurologists, psychiatrists and psychogeriatricians. One of these specialists will conduct an assessment in a clinic and will usually be the person who makes and gives the diagnosis.

The specialist should be able to organise any necessary further tests or treatments. At some point a GP or specialist may order neuroimaging (either a CT scan or MRI scan) which they will use to help make a diagnosis. Medical science is constantly exploring new neuroimaging tests to help in the diagnosis of dementia. Although people may talk about tests such as PET or SPECT, the guidelines recommend that further research is conducted before these tests are used on all people with dementia.

Some services have nursing and allied health staff as part of their team who may offer further assessment and treatment after diagnosis. These include neuropsychologists, psychologists, social workers, speech pathologists, occupational therapists, dietitians, pharmacists, exercise physiologists or physiotherapists.

The memory assessment specialist should also link carers, family members or friends who would benefit from more support or information into services within the community.

TALKING ABOUT THE DIAGNOSIS

Receiving a diagnosis of dementia has an enormous impact on the person and their carer(s) and families. People often report feelings of loss, anger, uncertainty and frustration. Nonetheless, people often feel relieved to know what is wrong.

It is important that health professionals are honest and respectful when communicating the diagnosis to the person with dementia and those close to them. The diagnosis should be communicated in a way that is sensitive to the person with dementia's wishes, their relationship with the person providing the diagnosis and the context of the discussion. It needs to be understandable to the person with dementia with regard for their individual language and communication needs.

The person giving the diagnosis should provide information about dementia in a clear manner and emphasise that progression is often slow, treatments for specific symptoms are available and that research is striving to find cures, though so far without success.

People with a history of depression and/or self-harm may be at particular risk of depression, self-harm or suicide following a diagnosis of dementia, particularly in the first few months after diagnosis. While self-harm or suicide is uncommon, counselling should be offered as an additional way to support at-risk people during this time.

QUESTIONS TO ASK ABOUT THE DIAGNOSIS

- What type of dementia do I have?
- What are the symptoms and how might they develop over time?
- What further tests or investigations should I have?
- How long will I have to wait until I have these tests?
- How long will it take to get the results of these tests?
- What will happen after I get the results?
- What are the implications for work/driving? (where appropriate)
- _____
- _____
- _____

SOURCES OF FURTHER INFORMATION

Dementia Australia:
www.dementia.org.au/about-dementia/i-have-younger-onset-dementia

☎ 1800 100 500

National Disability Insurance Scheme:
www.myplace.ndis.gov.au/ndisstorefront/index.html

☎ 1800 800 110

Dementia Alliance International:
www.dementiaallianceinternational.org

The Lovell Foundation:
www.lovellfoundation.com.au

☎ 0418 586 079



YOUNGER ONSET DEMENTIA

The term younger onset dementia refers to dementia where symptoms begin when the person is under the age of 65. Dementia in younger people is less common and can be difficult to diagnose. While all people with dementia have unique needs, younger people with dementia are more likely to be in paid work, caring and financially supporting children and be physically active. Some programs for people with dementia are predominantly designed with older, less active people in mind and so might be less relevant or enjoyable for younger people. Health professionals should be conscious of this and ensure that services are age and interest appropriate. Dementia Australia have established services designed specifically to support people with younger onset dementia in the form of a key worker program. People with younger onset dementia may also be more inclined to join online support groups that enable them to connect with people both within Australia and worldwide.

While there are research studies describing the needs of people with younger onset dementia, there are fewer studies evaluating the effectiveness of programs specifically designed for this group of people. Thus, while the guidelines recommend that services should be tailored, there are no other variations in recommendations. The lack of research into younger onset dementia is acknowledged and is being addressed.

ADVANCE CARE PLANNING

SOURCES OF FURTHER INFORMATION

Advance care planning Australia
www.advancecareplanning.org.au

☎ 1300 208 582

Start2Talk:
www.start2talk.org.au

☎ 1800 100 500

As dementia progresses, a person will gradually become more reliant on family or friends to make decisions about their finances, health care and living arrangements. At first, the person with dementia may need some support and guidance from someone that they trust to make decisions (supported decision making), but eventually they may need someone to make decisions on their behalf. It is important for people living with dementia to discuss their wishes for future care with their families and/or friends while they are able to express themselves clearly – these wishes should be formalised in an advance care plan. This is also important for carers, so that they are confident that they are following the wishes of the person with dementia.

Advance care planning is the process of planning for future health and care to ensure that the person with dementia's values, beliefs and preferences are known so that they can be used to guide future decision making. Laws around advance care planning and substitute decision making are different in each state and territory, so it is important to find out about local requirements.

Advance care plans should be revisited with the person with dementia and their carer(s) and family on a regular basis and following any significant change in health condition or circumstance.

QUESTIONS TO ASK ABOUT ADVANCE CARE PLANNING

- How is dementia likely to affect the things I can and cannot do?
- Where can I find financial and legal advice to help me plan for the future?
- Where can I find out more about making written instructions about my care and recording my preferred place of care?

- _____
- _____
- _____
- _____
- _____
- _____

ACCESSING SERVICES IN THE COMMUNITY

People with dementia, whatever their age, should not be excluded from any health care services because of their diagnosis. In the community, the general practitioner is usually the person's most consistent health care provider.

SOURCES OF FURTHER INFORMATION

My Aged Care website:
www.myagedcare.gov.au

☎ 1800 200 422

National Disability Insurance Scheme: www.myplace.ndis.gov.au/ndisstorefront/index.html

☎ 1800 800 110

Advocacy services:
www.myagedcare.gov.au/how-make-complaint/advocacy-services

☎ 1800 200 422

Dementia Australia:
www.dementia.org.au

☎ 1800 100 500

Carer's Australia:
www.carersaustralia.com.au

☎ 1800 242 636

Allied Health professionals:
www.dementia.org.au/about-dementia/resources/allied-health-professionals

☎ 1800 100 500

Information provided by health professionals should be provided in a way that is understandable. People from culturally and linguistically diverse backgrounds should be provided with information in the language with which they are most familiar.

As the condition progresses, people with dementia and their carers tend to require more help to manage daily activities as the symptoms of dementia worsen. This may include help with self-care (e.g. showering), home duties (e.g. cleaning) or travel (e.g. attending medical appointments).

Care coordinators (also known as key workers or case managers) can help, by interviewing the person and family, helping them access services that match their needs, and reviewing and making changes to services when needed.

The My Aged Care phone line 1800 200 422 may be helpful as a starting point in looking for a case coordinator; usually care coordination services are linked to people on a home care package.

QUESTIONS TO ASK ABOUT COMMUNITY SERVICES

- Are there any support organisations in my local area?
- How can I make sure that I receive the right services?
- Can you provide any information for my family/carers?
- _____
- _____
- _____
- _____
- _____
- _____
- _____

LIVING WELL WITH DEMENTIA AND REHABILITATION SERVICES

People with dementia will benefit from maintaining a healthy and active lifestyle to contribute to overall health and wellbeing.

This includes:

- *doing regular exercise*
- *maintaining a healthy diet*
- *regularly monitoring weight and seeking help if there are changes in weight*
- *maintaining good oral health through regular dental appointments*
- *keeping engaged in activities that are meaningful and enjoyable*
- *maintaining a regular routine*
- *Remaining socially engaged and connected*
- *managing other health conditions (comorbidities).*

A multidisciplinary care team which specialises in providing services for people with dementia (involving a medical practitioner, nurse and allied health staff) is best placed to provide a comprehensive assessment and treatment plan.

Many treatments have been trialled to reduce the symptoms of dementia. However, while some may be heavily marketed, the scientific evidence does not necessarily support recommending their use:

- Brain training programs aim to reduce decline in memory and thinking skills. Overall, the current research evidence does not show that regular use of these programs leads to better cognitive skills or levels of independence.
- Nutritional drinks are currently being investigated to reduce the symptoms of mild cognitive impairment and dementia, of which one, at the time of publication (Souvenaid®) is marketed in Australia. There is currently insufficient evidence to recommend the routine use of Souvenaid® in people with mild Alzheimer's disease. Souvenaid® should not be recommended for people with moderate or severe Alzheimer's disease.

QUESTIONS TO ASK ABOUT A HEALTHY LIFESTYLE

- What can I do to remain as active and independent as possible?
- How can I create a safe home environment?
- What activities will help me maintain fitness, strength, balance and flexibility?
- What should I do if I have put on weight or lost weight?
- How do I maintain good oral health?
- _____
- _____
- _____
- _____
- _____
- _____
- _____

SUPPORTING CARERS

Providing care and support for any person with a long-term illness or disability can be hard – carers often report poor physical and mental health.

SOURCES OF FURTHER INFORMATION

Carer’s Australia:
www.carersaustralia.com.au

☎ 1800 242 636

My Aged Care:
www.myagedcare.gov.au/caring-someone/respice-care

☎ 1800 200 422

Carers Gateway:
www.carergateway.gov.au

☎ 1800 422 737

Carers require support to maintain their own health and wellbeing as well as to support the person for whom they care. Carers of a person with dementia are no exception.

Carers of people with dementia should be supported to develop strategies and skills to overcome specific problems that they may have in providing care. They should also be provided with advice on how to better cope. Carers have access to many services and can do a number of things to get support in this role:

- Speak with their general practitioner about their health and needs regularly. This continues to be important if the person with dementia moves into residential care as well as after their death.
- Seek respite in a format that is helpful (i.e. in-home respite, day respite, planned activity groups and residential respite).
- Access programs that provide education about dementia and local services.
- Ask for information regarding how to join a mutual support group.
- Ask about access to counselling, if required.

QUESTIONS TO ASK ABOUT CARING FOR A PERSON WITH DEMENTIA

- How can I help and support the person with dementia?
- What additional help are carers entitled to?
- How much regular respite care am I entitled to?
- What financial benefits may be available?
- _____
- _____
- _____
- _____
- _____
- _____
- _____

STRATEGIES TO MANAGE THE SYMPTOMS

MEDICATIONS FOR COGNITIVE SYMPTOMS

The guidelines recommend a number of medications as possible treatments for people with certain conditions causing dementia. These include medications known as acetylcholinesterase inhibitors (donepezil, rivastigmine, galantamine) or other medications such as memantine.

These medications do not provide a cure; however, they do reduce symptoms in some people. These medications are covered by the Pharmaceutical Benefits Scheme in some cases but are not in other cases. Because decisions are made on a case-by-case basis, it is important for a person with dementia to ask their doctor specific questions about medications, such as:

- Would a trial of an acetylcholinesterase inhibitor or memantine be beneficial in my circumstances?
- What are the possible side effects?
- What should I do if I experience side effects?
- How much will the medications cost me?

Any prescription for one of these medications should be reviewed within the first month, to see if it has any benefit. It should then be reviewed at regular intervals to determine whether the drug remains beneficial. Pharmacists can provide extra information about these drugs.





CHANGED BEHAVIOURS

People with dementia need to be listened to and understood; however, they may experience a gradual decline in their ability to communicate clearly with others. If a person with dementia feels they are not being understood and cannot express their needs and frustrations, this may cause anxiety, agitation, apathy and/or depression. These are known as 'changed behaviours' and may be distressing to both the person with dementia and their carer(s) and families. Providing care that is consistent with the 10 Principles of Dignity in Care can help minimise these symptoms. Understanding the person's usual personality and interests is also beneficial. For example, someone that has always been a very active person who preferred to be outdoors may become agitated if their accommodation does not allow for activity or time outside.

People who know the person with dementia well can play a key part in managing changed behaviours. Carer(s) should be supported to develop skills in managing the symptoms and communicating effectively with the person with dementia.

Changed behaviours can be managed with or without medications or by using a combination of both approaches. Before trying medications, the person with dementia and/or the carer should speak with a doctor and ask for an assessment from someone who has experience in working with people with changed behaviours and their carers. The assessment may help determine particular reasons for the changed behaviours (e.g. pain, hunger, illness, boredom, frustration, difficulty communicating) that might be able to be addressed.

Many strategies have been shown to be beneficial:

- Engaging in meaningful and enjoyable activities (that can be done without much assistance) may address issues of boredom.
- Listening to music, and receiving support and counselling may reduce symptoms of depression and/or anxiety.
- Listening to music, receiving a massage and participating in programs that involve conversation and reminiscing.

SOURCES OF FURTHER INFORMATION

The Dementia Behaviour Management Advisory Service:

www.dbmas.org.au

☎ 1800 699 799

MEDICATIONS TO MANAGE CHANGED BEHAVIOURS

It is recommended that medications are avoided, where possible. However, sometimes medication is required to manage changed behaviour if the person with dementia is severely distressed or at risk of hurting themselves or someone else:

- Analgesia may be recommended if the person is thought to be in pain.
- Antipsychotics should not usually be prescribed for people with mild to moderate symptoms of dementia but may be required for people with severe symptoms which are distressing to themselves or others. They should be avoided in people with Dementia with Lewy Bodies.
- SSRI antidepressants may be trialled in people with dementia who are agitated.

It is uncertain whether antidepressants are helpful in the treatment of depression in people with dementia. However, if the person with dementia has a history of major depression (before their dementia diagnosis), antidepressants should be considered in the usual way.

QUESTIONS TO ASK ABOUT TREATMENT OR THERAPY

- Why have I been offered this particular type of treatment?
- What are the pros and cons of having this treatment?
- What will the treatment involve?
- How will the treatment help me?
- What effect will it have on my symptoms and everyday life?
- What sort of improvements might I expect?
- What are the options for having other treatments instead?
- Is there some written material (like a leaflet) about the treatment that I can have?
- Are there any long-term effects or side effects of taking this medicine?
- What should I do if I get any side effects?
- _____
- _____
- _____

END-OF-LIFE CARE

Dementia is the second leading cause of death in Australia. As such, as dementia progresses, there is an increasing focus on palliative (or end-of-life) care.

SOURCES OF FURTHER INFORMATION

Palliative Care Australia:
www.palliativecare.org.au

☎ (02) 6232 0700

Planning and preparing for this stage will help a person with dementia have a dignified end of life consistent with their expressed wishes, as documented in their 'planning ahead' and 'advance care plan' documents. It is critical that these documents are prepared soon after diagnosis and reviewed regularly so that the wishes of the person with dementia can be followed. It may also be helpful to find an advocate who knows what the person with dementia wants. Palliative care can be provided in residential aged care facilities or in the person's own home if this is preferred.

In general, people with advanced dementia should continue to be offered food and drink by mouth. Providing food and fluids by artificial means (e.g. using a feeding tube) should not generally be used in people with severe dementia as one of the signs that end of life is approaching is a disinclination to eat. Decisions about eating and drinking should consider the potential benefits weighed against potential side effects and should be made in conjunction with the carer(s) and family after providing them with up-to-date information.

Some people with dementia and their families have reported that they felt overwhelmed when asked about brain donation for research purposes. Dementia Australia have an information sheet about brain donation which may be helpful for people who are considering this.



CONSUMER QUICK REFERENCE GUIDE - IMPROVING THE CARE FOR PEOPLE WITH DEMENTIA

WHAT IS DEMENTIA?	EARLY DIAGNOSIS	ASSESSMENT OF DEMENTIA	CARING FOR YOU AND YOUR CARERS	TREATMENTS
<p>Symptoms include:</p> <ul style="list-style-type: none"> ➤ Memory loss ➤ Difficulty thinking, understanding and concentrating ➤ Impairment of perception ➤ Changed behaviours such as agitation and depression ➤ Communication difficulties affecting reading, writing and speech ➤ Reduced ability to perform activities of daily living. 	<ul style="list-style-type: none"> ➤ Talk to your doctor if you are concerned about your memory or thinking or changed behaviours. ➤ Seek investigation of your symptoms the first time you notice them. 	<p>Your doctor will arrange a variety of tests to make the diagnosis of dementia, which may include:</p> <ul style="list-style-type: none"> ➤ Memory Assessment ➤ CT or MRI (Neuroimaging of your brain) ➤ Blood tests ➤ Review of other health conditions. 	<p>Talk to your Doctor about your care needs.</p> <p>There are legal considerations to consider such as:</p> <ul style="list-style-type: none"> ➤ Advanced Care Directive ➤ Enduring Power of Attorney ➤ Ask for information about local services to support you to remain in your preferred place and to be active and independent as long possible. ➤ Health care services should be trained in dementia care and treat you with dignity and have respect for your individuality, cultural background and preferences. ➤ Carers need support too, ask about carer support groups and respite services. 	<p>There are many different treatments for dementia:</p> <ul style="list-style-type: none"> ➤ Healthy life style including: ➤ Good nutrition ➤ Regular exercise ➤ Maintaining independence ➤ Maintaining social engagement and connection ➤ Massage and Relaxation. ➤ Medications to manage cognitive decline symptoms and changed behaviours.
WANT MORE INFORMATION?				

<p>READ GUIDELINES</p> <p>http://sydney.edu.au/medicine/cdpc/resources/dementia-guidelines.php</p>	<p>CONTACT YOUR DOCTOR</p>	<p>DEMMENTIA AUSTRALIA</p> <p>☎ 1800 100 500</p> <p>www.dementia.org.au</p>	<p>MYAGEDCARE</p> <p>www.myagedcare.gov.au</p>
--	-----------------------------------	---	--





Flinders
UNIVERSITY

[www.sydney.edu.au/medicine/cdpc/
resources/dementia-guidelines.php](http://www.sydney.edu.au/medicine/cdpc/resources/dementia-guidelines.php)