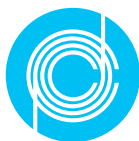


People with Dementia:

A CARE GUIDE FOR GENERAL PRACTICE



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PARTNERSHIP
CENTRE



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DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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Special Acknowledgement: the researchers thank the dementia care advocates who assisted through this research project. Especially Joan Jackman who kept us grounded in the real world of straightforward language and ideas; Danijela Hlis who was instrumental in reminding us about issues unique to culturally and linguistically diverse (CALD) peoples; and Kathy Henderson who kept us on track about the consumer perspective

Disclaimer: This document is a general guide, to be followed subject to the clinician's judgment and person's preference, choices and decisions in each individual case. The guideline is designed to provide information to assist decision making and is based on the best evidence available at the time of development of this publication.

NOTES:

*Full versions of sections of this document, including literature reviews can be found at: <https://cdpc.sydney.edu.au/research/care-service-pathways/primary-care-consensus-guide/>

*The Dementia in People with Intellectual Disability section of this publication is an abbreviated form of similar guidelines, which are updated regularly and can be accessed here: <http://unsw.to/iddementiaguidelines> and here <https://3dn.unsw.edu.au/content/health-mental-health-professionals>

Contents

| | |
|---|-----------|
| Overview..... | 3 |
| Communicating: Diagnoses and Consultations..... | 4 |
| Key Messages..... | 4 |
| Practice Points – What Can I Do?..... | 5 |
| Timely communication of the diagnosis..... | 5 |
| Communicating with the person..... | 10 |
| Communicating with the carer..... | 11 |
| Supporting carer communication with the person who has dementia..... | 12 |
| Caring for People with Dementia Experiencing Behavioural and Psychological Symptoms..... | 14 |
| Key Messages..... | 14 |
| Caring for Patients BPSD Flowchart..... | 18 |
| Practice Points – What Can I Do?..... | 20 |
| Underlying principles of care of people expressing BPSD..... | 20 |
| Assessing the person’s BPSD..... | 21 |
| Management of the person’s BPSD..... | 23 |
| First line management..... | 23 |
| Second line management..... | 26 |
| List of resources..... | 27 |
| Elder Abuse: Identification and Screening..... | 28 |
| Key Messages..... | 28 |
| Practice Points – What Can I Do?..... | 31 |
| Underlying principles of care where there is suspected elder abuse..... | 31 |
| Assessing for elder abuse risk and prevention strategies where the person has dementia..... | 33 |
| Assessing the person who has dementia for elder abuse..... | 34 |
| State and Territory Contact Information..... | 36 |
| Dementia In People with Intellectual Disability..... | 38 |
| Key Messages..... | 38 |
| Practice Points – What Can I Do?..... | 39 |

| | |
|--|-----------|
| Prevalence and incidence of dementia in Intellectual Disability (ID)..... | 39 |
| Risk factors for dementia in people with ID..... | 40 |
| Presentation of dementia in people with ID..... | 40 |
| Assessment of dementia in people with ID..... | 40 |
| Other investigations..... | 42 |
| Differential Diagnoses are as per the general population..... | 42 |
| Managing dementia in ID Coordination of services..... | 42 |
| Sharing the diagnosis..... | 43 |
| Risk assessment..... | 43 |
| Planning for declines..... | 43 |
| Managing medical complications..... | 44 |
| Review mental health and behaviour..... | 44 |
| Cholinesterase inhibitors and memantine..... | 44 |
| Caring for a family carer of a person with ID and dementia..... | 44 |
| List of Resources..... | 45 |
| Dementia Prevention..... | 46 |
| Key Messages..... | 46 |
| Practice Points – What Can I Do?..... | 48 |
| Supporting Carers of People with Dementia..... | 50 |
| Key Messages..... | 50 |
| Carer Support Flowchart..... | 52 |
| Practice Points – What Can I Do?..... | 53 |
| Assessment of the carer’s health needs..... | 53 |
| Provide carer support..... | 55 |
| Provide information and education..... | 57 |
| Facilitate carer access to resources and support services..... | 58 |
| Carer resources and support services..... | 59 |
| References – Communicating: Diagnoses and Consultations for People with Dementia..... | 62 |
| References – Caring for People with Dementia Experiencing Behavioural and Psychological Symptoms..... | 64 |
| References – Elder Abuse Identification and Screening..... | 65 |
| References – Dementia in People with Intellectual Disability..... | 66 |
| References – Dementia Prevention..... | 67 |
| References – Supporting Carers of People with Dementia..... | 68 |

Overview

Dementia is the second most common cause of death in Australia, and the leading cause of death for Australian women.¹ GPs and other primary carers will commonly be the first point of contact for people with dementia and their families and carers.

Between 2014 and 2019, Professor Dimity Pond and her research team at the University of Newcastle, along with Professor Kaarin Anstey and Dr Ruth Peters from NeuRA at UNSW and Dr Liz Evans and Professor Julian Trollor from the Department of Developmental Disability Neuropsychiatry (3DN) at UNSW, worked on developing this evidence-based Care Guide for General Practice.

The project was funded by the NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People (CDPC) at the University of Sydney (<https://cdpc.sydney.edu.au/>). This collaborative partnership centre funded research to improve the lives of people with dementia between 2013 and 2019.

The teams have brought evidence-based information and current best-practice together to create this booklet and they hope you find the information useful when caring for people with dementia in your practice. It is hoped you will keep a copy of this booklet handy.

The Literature Reviews that informed the Key Messages and Practice Points provided for you in this booklet, along with e-copies of the booklet, are available for download from the CDPC website

<https://cdpc.sydney.edu.au/research/care-service-pathways/primary-care-consensus-guide/>

Special Acknowledgement: the researchers thank the dementia care advocates who assisted through this research project. Especially Joan Jackman who kept us grounded in the real world of straightforward language and ideas; Danijela Hlis who was instrumental in reminding us about issues unique to culturally and linguistically diverse (CALD) peoples; and Kathy Henderson who kept us on track about the consumer perspective.

1 Australian Bureau of Statistics. 2019. 3303.0 – Causes of Death, Australia, 2018. <https://www.abs.gov.au/ausstats/abs@.nsf/mf/3303.0>

Communicating: Diagnoses and Consultations

Key Messages

Communicating the diagnosis

- A person-centred approach, considering language, culture, education and other factors, should be adopted.
- The diagnosis or the possibility of dementia should be communicated unless disclosure cannot be understood by the person or is against the person's expressed wishes. This respects the person's autonomy.
- Communication of the diagnosis or possibility of dementia should be timely. Timeliness is determined by assessing readiness and risk.
- Communication of the diagnosis or possibility of dementia should occur over time when appropriate.
- Whilst the autonomy of the person with dementia is a primary consideration, carers/family members should be present, whenever possible, during conversations about a dementia diagnosis.
- The person and their carer need support and information about the diagnosis. Implications of the condition and plans for subsequent consultations should be discussed with the person.

Communicating with the person and carer

- The desire to communicate is usually retained and should be optimised.
- Respectful and effective verbal and non-verbal communication is needed to enhance understanding of the person, their dementia, their preferences/choices, and to optimise involvement in decision-making.
- Communicate directly with the person with dementia and, if present, secondarily with their carer(s)/family members.

Practice Points – What Can I Do?

TIMELY COMMUNICATION OF THE DIAGNOSIS

Preparation

- Raise the possibility of dementia as a diagnosis and establish the person's consent for investigation and preferences for diagnosis disclosure.¹ Explain that knowledge of their condition will help the person to understand their health, seek appropriate assistance/further opinions and access dementia specific services.² Where the person's family request the diagnosis not be disclosed, this conflict should be resolved through discussion which addresses their disclosure concerns (e.g. evoking fear, distress or catastrophic reaction).³⁻⁵
- Use knowledge of the person with dementia and their family to plan a timely, individualised and appropriate approach to diagnostic investigation and diagnosis communication.¹ Consider the person's wishes, awareness, capacity to understand, psychological and social resources and safety, including the risk of negative psychological reactions.^{4, 6-8}

Assessing each person's capacity to understand the diagnosis

- Early in the investigative phase of the diagnosis, determine the person's and carer's understanding and attitudes about cognitive loss and dementia.^{1,4,9} Address any misconceptions or myths about the condition.⁹



After performing the cognitive function test say "I cannot exclude Alzheimer's disease or dementia from the results of this test, so we will need to do some more testing. Do you have any questions?"

(Suggestion from the GP Forum)



Communication

- Employ methods such as the ‘ask-tell-ask’ method ¹⁰ to explore the person’s knowledge and understanding of memory testing and dementia. Ask “Do you have any questions about the memory testing we have done/would like to do?” Followed by “I am concerned that you may have dementia. Have you heard of this condition?” and “Do you have any questions about what dementia is?”
- Recognise and respect that the person with dementia and their carer/ family may need time to comprehend and understand the implications of a diagnosis of dementia. Approaching the diagnosis over time can be helpful (e.g. by initially raising the condition as a possibility and later moving to more certainty).



I do think that there is sometimes an issue communicating with a person with early cognitive problems – especially if they are educated and articulate – where they respond with very plausible phrases to cover up their difficulties (GP Informant).



- Plan person-specific diagnosis support and information before meeting with the person to disclose their diagnosis. Resources, including for people from culturally and linguistically diverse backgrounds, can be accessed from the national Dementia Australia website (<https://www.dementia.org.au/>).
- Should a person with dementia prefer not to be told the diagnosis, respect this preference.⁹ The diagnosis may also be withheld if the person is unable to comprehend the diagnosis.^{5,11} However, it is imperative that the person and carers understand there is a problem involving cognition/thinking that may need medical investigations and management.⁹

Communication

Communicating the diagnosis

- Plan sufficient time to communicate the diagnosis and for the person to ask questions. Some people ask many questions, others may not.⁹ A longer appointment is preferable, avoiding interruptions and distractions (e.g. phone calls).^{1,9,12}
- Ensure that the carer/family members are present when the diagnosis of dementia is communicated to the person.^{4,9,13} Each situation needs to be considered in the context of the patient, knowledge of their relationship with the carer/family and their expressed wishes. Where circumstances prevent a carer from being present, the GP needs to judge how and when to disclose the diagnosis.
- Signal to the person that you need to discuss some bad news.
- People with dementia should be addressed as partners in the conversation, as with any other person.¹²
- Tailor communication to the preferences, needs, and ideas of the person with dementia, and include information on prognosis as well as diagnosis.^{1,13} The ask-tell-ask method helps to tailor diagnosis disclosure.¹⁰ This method involves asking the person what they want to know and what they do know, telling them some limited information, then asking what they understand by what you just said. The diagnosis and prognosis may need to be revisited on many occasions, particularly if the GP or nurse has long term care of the patient.
- Use inclusive, appropriate and non-stigmatising language. When communicating with the person and carers/family members about BPSD use the terms 'changed behaviours' and 'expression of unmet needs' rather than BPSD, behaviours of concern, challenging or difficult behaviours, wanderer or wetter (see the Dementia Australia Language Guidelines <https://www.dementia.org.au/resources/dementia-language-guidelines>).¹⁴
- Communicate a specific diagnosis rather than a vague reference to memory or cognitive problems. The word 'dementia' should be used in the diagnosis, or/and more specific dementia terminology when known (e.g. Alzheimer's disease).⁹

Communication

- Explain dementia as a condition of the brain so the person with dementia understands the physical cause for cognitive problems and changes in behaviour.¹²
- Impart information needed to make initial sense of the diagnosis. Identify immediate practical implications of the diagnosis however delay non-urgent discussion and decisions until subsequent consultations – this allows the person with dementia and the carer time to absorb the information.^{1,4} Emphasise the often slow progression of the condition, the availability of symptomatic treatments and, although not successful at this time, ongoing research looking to find cures.³



You prepare people that this may be bad news. You set up the appointment. You make sure that their significant other is with you, and with them, and you give them the bad news. And you say, “and I want to see you tomorrow – or I want to see you next week”, “I want to see you in three days’ time – to talk about all the ways forward from here”, “Here’s some information – just take it away and look at it”. But I don’t expect them to take in anything more at that moment. That is not the moment.... they need to go away and cry. They need to go away and be with their family and they will come back with a thousand questions. But right then, it is not much point in giving them information.

(Suggestion from a GP Forum)



- Reassure the person that there will be opportunities to discuss the diagnosis again ^{1,4} during ongoing GP consultation throughout the course of their dementia.⁹ Agree on follow-up plans.

Communication

- If helpful at the time of diagnosis disclosure, refer to support services (e.g. Dementia Australia's "Living with Memory Loss" program).¹⁵
- The GP should ensure the patient is reviewed within 2 months of the specialist consultation at which the diagnosis is made, to further assist the person and carer in understanding the condition, the implications of the diagnosis, and care options.⁴

Responding to emotional reactions:

- Allow the person with dementia time to process receiving their diagnosis.⁶
- Acknowledge the person's emotional response and that of the carer as appropriate (e.g. anger, denial, shock, fear or relief).^{4,16}
- Respond to the person empathetically. Provide a balance of hope, by emphasising preserved abilities and skills, and realism in line with the person's individuality.¹³
- Explore coping strategies that may assist the person with dementia come to terms with the diagnosis.^{1,4,9}
- Encourage maintenance of social activities and other secondary prevention approaches, such as the Mediterranean diet, exercise and social activities (see Dementia Prevention section).¹⁷
- Plan for, assess and address potential negative psychological consequences of disclosure (e.g. minimisation, anger, denial, shock, grief, depression, suicidal ideation).⁴ Provide information, explanation and support for the person with dementia and their carer throughout the diagnostic process.^{3,4} Counselling may also be offered under a mental health care plan if the person is in the community and has depression, anxiety or other psychological condition as well as dementia, or otherwise referral to a psychogeriatrician.

Communication

Subsequent consultations

- Plan ongoing conversations with the person.⁴ Focus on abilities rather than disabilities and secondary prevention (see Dementia Prevention section). In the following 2-3 consultations cover:
 - dementia signs and symptoms;
 - course and prognosis of dementia;
 - treatments and strategies for health promotion/wellbeing;
 - resources for financial and legal advice, advocacy and support; and
 - medico-legal issues, including driving and planning for the future.³
- Provide written information on practical and emotional support; negotiate a GP management plan.¹ Reconsider the management of other chronic diseases that will be affected by dementia and may need renegotiating as part of the plan.
- Plan and/or utilise opportunistic conversations with carers/family to assess coping and communicate information and resource contact details (e.g. support groups, adult day care and respite care).⁹ Advise and encourage use of Dementia Australia associations and resources.¹⁴
- Consider providing a written summary of discussions for later reference.¹⁸

COMMUNICATING WITH THE PERSON

- Establish a person-centred relationship that optimises the person's ability to communicate, participate in decision-making and understand their condition.^{19, 20}
- Respond to the communication needs of CALD people by using a range of strategies to enhance communication, including professional interpreters.³
- Use a non-threatening, face-to-face position.²¹⁻²³
- Maintain comfortable eye contact.²¹⁻²³
- Keep introductions simple i.e. just one or two sentences. This will help the person with dementia focus on the conversation itself.^{12, 19, 21, 24}
- Focus on one question or idea at a time.^{12, 19, 21, 24}
- Speak in short simple sentences of four to six words with one verb per sentence and using the active voice.^{12, 19, 21, 24}

Communication

- Wait for a response, pause between ideas and/or signal topic changes to allow for slowed cognitive processing (e.g. Can we talk about your medications now?).^{12,19,21,24}
- Encourage responsiveness by displaying patience, speaking in a soft audible tone and using rephrasing, repetition and further explanation of ideas,²⁰ especially if English is the second language.
- Match intonation with message (e.g. if asking a question, make it sound like a question).^{12, 19, 21, 24}
- Use hand and facial gestures to reinforce verbal messages.²¹⁻²³
- Be aware of mood and emotion.²⁴
- Avoid confusing terms, such as 'positive' and 'negative' results. Focus on the main issues and regularly check that the information provided is being understood by the person with dementia.¹²
- Avoid metaphors, colloquialisms and pronouns. Poor working memory inhibits the ability to co-reference e.g. "Your husband told me... He said...".^{12,19,21,24}
- Search for specific information by asking who, where, when questions. Clarify information using questions requiring a yes/no response.²⁴ However remain aware that people with dementia frequently answer 'yes' when they are uncertain of the correct response.²⁴
- As appropriate, employ communication strategies used by the carer.²³
- When cognition is no longer able to support an answer, family members may need to act as primary informants.²⁴

COMMUNICATING WITH THE CARER

- Be aware that the carer may be stressed during consultations because of the need to observe and support the person they are caring for, as well as talking to the GP. Provide clarifications, reassurance and written summaries (if possible).
- Involve the patient in the decision-making processes during conversations with the carer. Ensure the patient is not ignored.¹⁹
- Ask the carer to describe how they communicate with the person in different contexts and for different functions.^{21,23}

SUPPORTING CARER COMMUNICATION WITH THE PERSON WHO HAS DEMENTIA

- Advise carers of resources to assist them with caring, including the Dementia Australia's 'Communication' Fact Sheet (<https://www.dementia.org.au/resources/help-sheets>).²⁵
- Suggest communications strategies that optimise communication, including:
 - attracting the person's attention (e.g. use the person's name, position yourself at the other person's eye level and keep eye contact);
 - avoiding distraction (e.g. turn off the radio or television, move to a quieter place);
 - having one person talk at a time;
 - being aware of their own expression and body language – show interest, try to appear relaxed and calm;
 - simplifying communication (e.g. short direct sentences using familiar words; avoid pronouns like 'she' or 'he' or 'it');
 - using visual aids (e.g. gestures, actions; show objects or pictures) while being aware that interpretation of visual information may also be impaired;
 - listening carefully, watching the person's non-verbal cues, expressions or direction of gaze to get their message;
 - encouraging communication using familiar and interesting topics (e.g. memorabilia, photos);
 - avoiding arguments if the person seems confused. Acknowledge the person's feelings and try to gently move on to another topic;
 - providing enough time to allow the person to respond – wait for 5 seconds after speaking before expecting a response;
 - helping the person find the right word by: suggesting a word; repeating an unfinished sentence with a suitable word; ask 'Do you mean...?';

Communication

- repeat, then rephrase if necessary (i.e. if he/she does not understand what was said try repeating your sentence and, if not successful, say the sentence in a different way);
- providing reminders of the topic of the conversation (e.g. clearly mention the topic of your conversation; repeat the topic throughout the conversation); and
- making it clear when you are changing the topics of the conversation by pausing between topics, or by mentioning the topic change.²⁰
- Identify ways to avoid conversational embarrassment for the person with dementia (e.g. suggesting it is better to repeat a small part of what a patient has just said, and add further information, than simply correcting the person).²⁶

Caring for People with Dementia Experiencing Behavioural and Psychological Symptoms

* Behavioural and Psychological Symptoms of Dementia (BPSD) remains an accepted term in clinical contexts, when communicating with patients, carers/family and community members the terms 'changed behaviours' and 'expression of unmet needs' are recommended by the Dementia Australia Language Guidelines (<https://www.dementia.org.au/resources/dementia-language-guidelines>). These alternative terms promote inclusive, respectful, appropriate and non-stigmatising language. Other terms for BPSD include responsive behaviours, behaviours of concern, challenging or difficult behaviours and non-cognitive or neuropsychiatric symptoms of dementia.

Key Messages

- Brain changes during dementia can lead to expression of behavioural and psychological symptoms of dementia (BPSD). These symptoms are an expression of the person's dementia rather than the person themselves and vary with dementia type and stage of the condition.
- BPSD affects most people with dementia at some time during their condition and can present in a multitude of ways. The severity and nature of BPSD varies.
- BPSD is independently associated with poor outcomes, including institutionalisation, reduction in patient and carer quality of life and carer burnout.

Behavioural and psychological symptoms

Assessing BPSD

- Multiple BPSD aetiologies commonly co-exist, leading to interrelated/mixed expressions of BPSD.
- Immediate and ongoing risks to the person, carer or others from BPSD should be assessed without delay, considering medical and psychosocial/environmental factors and the potential impact of abuse/neglect.
- To exclude clinical causes for BPSD the person should be initially assessed for clinical conditions, including history, physical examination and medications. Physical causes should also be excluded (e.g. hunger, thirst, fatigue).
- Changed behaviours, triggers, precipitating contexts and ensuing consequences should be identified. Analysis of behaviours informs the GP's understanding of the person's expression of BPSD and identifies target symptoms for management strategies.
- BPSD should be systematically re-assessed to inform ongoing symptom and impact management: for the person with dementia, carers/family and health care team.
- Specialist BPSD assessment/advice should be utilised when symptoms remain poorly managed/beyond the capacity of management strategies in primary care.

Behavioural and psychological symptoms

Managing BPSD

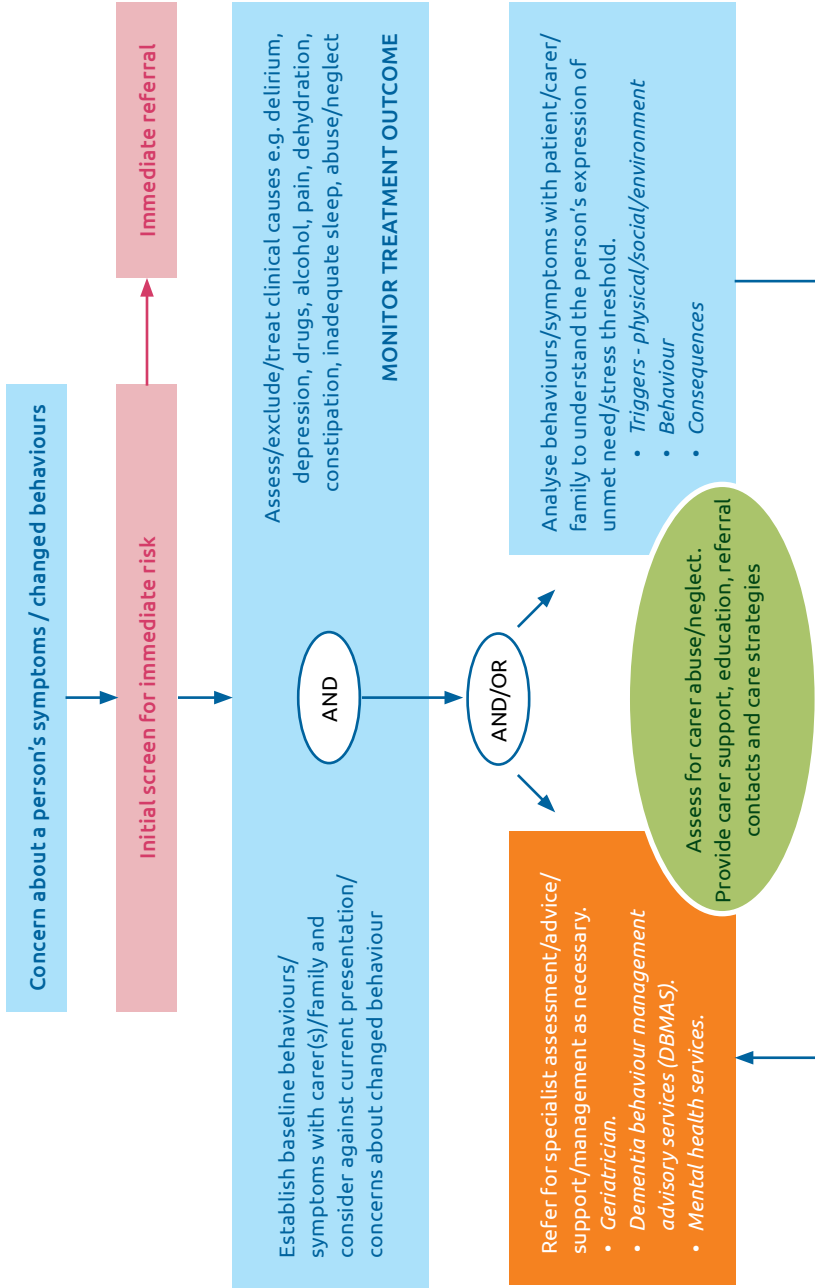
- The rights of the person with dementia should be recognised, respected and protected. Where the person with dementia is unable to engage in decision-making an appropriate alternative decision maker should be identified for decisions concerning BPSD management (see Advance Care Planning information available at <https://cdpc.sydney.edu.au/research/planning-decision-making-and-risk/>).
- Underlying causative clinical/physical conditions should be treated as a priority. Treatment outcomes should be monitored, and treatments revised as required.
- Urgent and/or ongoing mental health conditions should be managed or referred to appropriate mental health services.
- After addressing immediate risks, BPSD care strategies should be identified in collaboration with carers/health care team members. Initially, practical non-pharmacological strategies that respond to the needs expressed by the behaviour and complement the retained abilities of the person with dementia should be negotiated with care providers.
- Strategies should target identified behaviours/triggers and maximise the person's quality of life, balanced against risks and safety concerns. Environmental modification/simplification should be considered.
- Carer education in BPSD and care strategies/optimising the environment should be provided. Resources, referral and support should also be provided to match individual circumstances. Carer respite should be considered and offered as indicated.

Behavioural and psychological symptoms

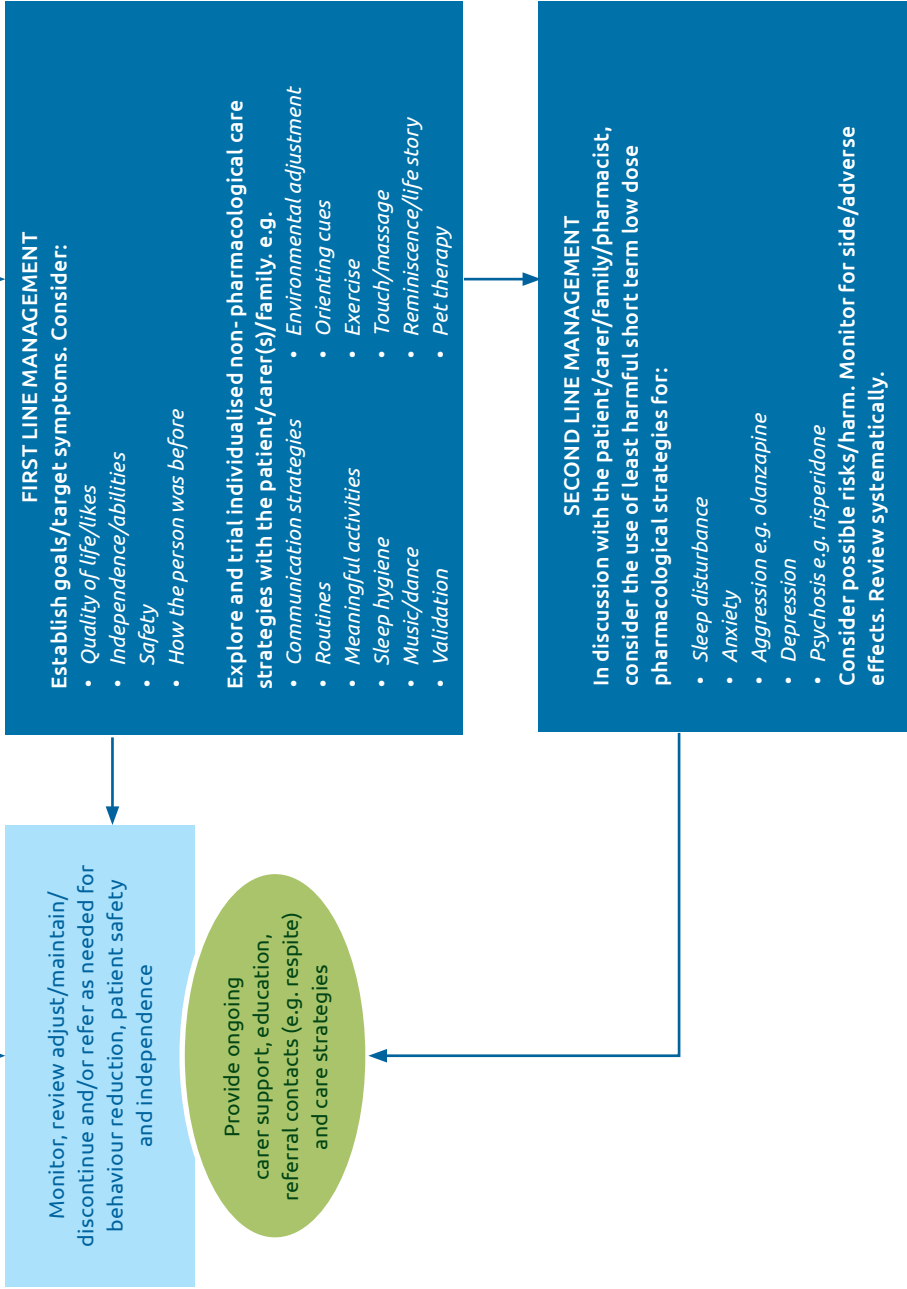
- Pharmacological strategies should be considered after unsuccessful trial/inappropriateness of non-pharmacological management. The use of medications for BPSD should be consistent with evidence-based guidelines and occur in consultation with the person and their carer. The least harmful medication and the lowest dose should be used for the shortest period of time. Medication use must be systematically and regularly reviewed. Where no efficacy is observed, medications must be discontinued.
- BPSD management should be systematically followed-up with the person, carers and care team members and adjusted as BPSD change. Care strategies may need to be tailored as any one strategy may work to different degrees in different circumstances. Carer distress and coping should also be monitored and addressed.

Behavioural and psychological symptoms

Caring for Patients with BPSD Flowchart



Behavioural and psychological symptoms



Behavioural and psychological symptoms

Practice Points – What Can I Do?

UNDERLYING PRINCIPLES OF CARE OF PEOPLE EXPRESSING BPSD

- Recognise and protect the rights of people with dementia expressing BPSD.
- Aim to maximise the quality of life and safety of the person with dementia within the least restrictive environment.
- Recognise that behavioural symptoms may be a form of communication and due to a range of perceptual and cognitive issues.
- Recognise the impact of BPSD on the person with dementia and their carer(s).
- Collaborate with those affected by the expression of BPSD to manage BPSD, using a person centred approach.³
- Communicate with the person, carers/family and community members about BPSD using the terms ‘changed behaviours’ and ‘expression of unmet needs’ (see the Dementia Australia Language Guidelines at <https://www.dementia.org.au/resources/dementia-language-guidelines>). Use of these terms promotes inclusive, respectful, appropriate and non-stigmatising language.⁴
- Systematically follow-up BPSD management with the person, carers and care team members and adjust as symptoms change. Carer distress and coping should be monitored.
- Minimise the emergence of BPSD by providing assistance to identify the contributing factors to the behaviours that impact on the quality of life for the person with dementia, and their care (for example, referral to Dementia Support Australia (DBMAS) <https://dementia.com.au/services/overview>, Dementia Australia <https://www.dementia.org.au>, local specialist services and/or Allied Health Professionals). Assistance should include:
 - delivering tailored behavioural therapies and regimes which involve events the person with dementia finds pleasant;
 - problem-solving BPSD; and
 - optimising the environment of the person with dementia.⁵

Behavioural and psychological symptoms

ASSESSING THE PERSON'S BPSD

Assess for immediate and potential risks posed by BPSD

- Assess degree of risk considering biological and psychosocial/environmental factors, such as:
 - acute health/medical deterioration (see Assess the person clinically section);
 - physical changes (e.g. self-injury as a result of physical aggression);
 - risks to carer and others (psychological/physical); or ³.
 - mental health issues (e.g. depression, suicidal ideation, anxiety, psychotic symptoms).
- Consider pharmacological management if a high physical risk situation is evident. See recommendations 77-90 in the *Clinical practice guidelines and principles of care for people with dementia* for guidance in the required process. Ensure your own/carer safety and that of others around. Avoid arguing or attempting to reason with the person expressing BPSD.³
<https://cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/>
- Urgently refer to a psychogeriatrician/psychiatric emergency/crisis team or hospital emergency department when the person with dementia is placed at risk due to suicidal thoughts, severe depression or is acting on delusions/hallucinations.
- Refer immediately to local geriatric services or the emergency department where management of symptoms is inappropriate/unmanageable in primary care.

Assess the person clinically

- Assess the person for clinical changes that may cause BPSD, particularly when the onset of symptoms has been abrupt or uncharacteristic for the person. Include:
 - physical health problems (e.g. infection, dehydration, constipation, delirium, pain, inadequate sleep, abuse/neglect);
 - medical comorbidities; and
 - medication review.

Behavioural and psychological symptoms

Assess the person's changed behaviours

- Assess BPSD symptoms and triggers. BPSD often includes disturbances or changes in mood or emotion, thinking, perception, motor movement and personality.^{3,5} Examples are listed below.

| Symptoms | Triggers | |
|----------------------|-----------------------------|---------------------------------|
| Psychological | Delirium | Hot or cold |
| Anxiety | Physical illness | Anxiety |
| Depression | Trauma | Cultural or social issues |
| Psychosis | Excessive noise/stimulation | Loneliness |
| | Constipation | Grief |
| Behavioural | Medication | Lack of structure/daily routine |
| Aggression | Lighting (too light/bright) | Boredom |
| Apathy | Dehydration | Pain |
| Agitation | Depression | Distressing behaviour of others |
| Disinhibition* | Confusion | Fatigue |
| Wandering | Hunger or thirst | Behavioural response of others |
| Nocturnal disruption | Fear | |
| Vocal disruption | Excessive demands | |

Adapted from ^{3,5,6}

*Note: disinhibition may be due to a range of cognitive problems, for example poor memory and not remembering where the toilet is, apraxia and not being able to mobilise motor planning to get to the toilet, or agnosia and not recognising the toilet even when it is there.

- Assess for psychosocial factors impacting on the person and their expression of BPSD, including:
 - the characteristics of the person with dementia (e.g. personal and psychological history, cultural background, migration and language);
 - the characteristics of the carer(s) and care relationship (e.g. how the relationship was prior to the diagnosis of dementia, roles, attitude to caring for the person with dementia, ability to provide care, including the risk of abuse); and
 - the care environment (e.g. physical, social, cultural).
- Identify target behaviours, the precipitating context/triggers and ensuing consequences to enable management strategies to be based on this analysis and care priorities.⁶

Behavioural and psychological symptoms

MANAGEMENT OF THE PERSON'S BPSD

- Based on assessment and analysis of BPSD, the Antecedents-Behaviour-Consequences (A-B-C) approach suggests that it is helpful to identify and implement strategies that address target behaviours, the precipitating context/triggers and ensuing consequences.^{3, 5, 7, 8} Strategies should be developed with the person and their carer/health care team and focus on the retained abilities of the person with dementia and quality of life.³



The resident with dementia was wanting to attract the attention of the visiting guitar player, behaviour that was disruptive and prevented other residents from enjoying a guitar player's performance. To address the behaviour and meet the resident's needs, the RAC staff took the resident out into the garden, which she loved, about 15 minutes before the guitar player arrived. She was given a cup of tea and a biscuit and brought back in just in time for lunch, by which time the guitar player had finished for the day.

(BPSD analysis & strategy example from a GP consultation group member).



FIRST LINE MANAGEMENT

Trial non-pharmacological strategies initially

- Non-pharmacological approaches are favoured for sub-acute and long-term care of the BPSD. Where possible offer multicomponent interventions and individualised support for the person with dementia, preferably involving activities they enjoy.⁹ Interventions that appear most beneficial include:
 - for depression and/or anxiety - music therapy, reminiscence therapy, support and psychotherapy;

Behavioural and psychological symptoms



A pre-recorded playlist of a person's favourite music can be offered to the person when a carer, from experience, knows that the person becomes increasingly anxious/agitated or they identify that the person's mood has lowered. Listening to personally meaningful music has a positive impact on wellbeing.¹

(Strategy Example – Personalised Playlist).



- for people experiencing agitation – therapies including massage, dancing, music or reminiscence, behavioural management intervention programs.⁹



A Life Story book can be on hand and shared with the person when showing initial signs of agitation. Sharing the life story with the person helps them to reminisce and connect with who they are and the person reminiscing with them. A person who is becoming agitated from increased stimulation in their environment can be guided to a quiet place and asking them to tell you about an aspect of themselves from the book. The conversation follows the person's lead and focuses on them.

Life stories are a collection of images and brief information about the person with dementia. It often starts with pictures of the person and a brief positive history of the person – one which avoids topics or images known to be distressing.

(Strategy Example – Life Story Book and Reminiscence).



- While exercise may not directly reduce expression of BPSD, a relationship has been shown between exercise and higher levels of independence in activities of daily living (see <https://cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/>). A regular simple exercise regime such as a 20-30-minute walk, five or more days a week, appears to benefit both the carer and the person living with dementia.¹⁰

Behavioural and psychological symptoms

Provide carer/family support - practical strategies and referral

- Provide the carer with practical strategies that will assist them in caring for a person expressing BPSD. For example:
 - Should the person with dementia begin to get agitated or upset, acknowledge their view rather than arguing a point. Walk away for a few minutes if safe to do so or divert attention to an enjoyed activity (e.g. having a cup of tea or walking in the garden together). However, always ensure personal safety and have a safety plan in place.
 - Use communication strategies (see Communication section) such as making one point at a time.
 - Provide visual and other cues to assist the person with their daily routine.
 - Keep the environment quiet, reducing background noise and avoid overstimulation.
 - Provide care in a relaxed manner, while allowing the person to do simple things for themselves.
 - Encourage the person to be involved in an activity that is meaningful and of interest to them, in terms of premorbid interests.
 - Notice sudden changes in behaviour and look for a reason (e.g. pain, dehydration, constipation or infection).
 - Consider utilising carer respite.
- Refer the carer to resources about BPSD and management strategies. Options include:
 - Dementia Support Australia (now incorporating the Dementia Behaviour Management Advisory Service (DBMAS)) provides clinical support to professionals and family carers of someone showing BPSD, including at home. Details about this support service and eligibility can be found at <https://dementia.com.au/services/overview> or by contacting the 24-hour helpline (1800 699 799).
 - A Guide for Family Carers: Dealing with Behaviours in People with Dementia (<http://www.dementiaresearch.org.au/bpsdguide.html>).¹¹

Behavioural and psychological symptoms

- Reassess the person's BPSD and management strategies with the person and carer/health care team regularly and adjust as BPSD changes. In residential care, GP contribution to the care plan for the person may be beneficial (e.g. by suggesting urinalysis if behaviour is unusual).

SECOND LINE MANAGEMENT

Pharmacological strategies

- Pharmacological strategies should be provided after unsuccessful trial/ inappropriateness of non-pharmacological management.
- The introduction of medications for BPSD should occur in consultation with the person and their carer/health care team.⁹
- The least harmful medication should be used for the shortest period of time. Ensure that the lowest dose is used.^{5, 12}(Refer to Clinical Practice Guidelines and Principles of Care for People with Dementia for evidence-based guidance). <https://cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/>
- People with dementia experiencing agitation should have a trial of specific serotonin reuptake inhibitors (SSRIs) with the strongest evidence being for citalopram.⁹
- Because of increased risk of cerebrovascular events, antipsychotic medications should be used with caution and monitored for adverse effects. In addition, the antipsychotic use risks severe untoward reactions in people who have Dementia with Lewy Bodies.⁹
- Medication use must be systematically and regularly reviewed. Where no efficacy is observed, medications should be discontinued, and a new management plan developed and monitored in collaboration with the person and the carer/health care team.

Behavioural and psychological symptoms

List of Resources

- Utilise dementia and BPSD resources to enhance GP understanding, assessment and management of BPSD. Options include:
 - Behaviour Management: A Guide to Good Practice – available through the Dementia Centre for Research Collaboration (DCRC)³ (<http://www.dementia.unsw.edu.au/researchers.html?view=dcrc&layout=project&pid=258>).
 - A Clinician's Field Guide to Good Practice: Managing BPSD¹³ (<http://dementiakt.com.au/resource/bpsd-guide-clinician/>).
 - The Australian Government's Better Access to Mental Health Care initiative is available to patients with dementia living in the community who have an additional clinically diagnosable mental disorder, such as depression, anxiety disorder, panic disorder or alcohol use disorder. This initiative is NOT available to people with dementia or delirium alone, and no other mental disorder. The full list of disorders covered by this initiative can be found at this site <https://www.psychology.org.au/for-the-public/Medicare-rebates-psychological-services/Medicare-FAQs-for-the-public>. Services covered by this program include assessment and therapy provided by eligible psychologists, social workers and occupational therapists.¹⁴
 - Credentialed mental health nurses can provide services, under a chronic disease management plan.
 - From 2019, mental health services can be provided in residential aged care. The Residential Aged Care initiative is accessed through Primary Health Networks (PHNs). Further information is available from local PHNs and from [https://www.health.gov.au/internet/main/publishing.nsf/Content/2126B045A8DA90FDCA257F6500018260/\\$File/11PHN%20Guidance%20-%20Psychological%20treatment%20services%20in%20Residential%20Aged%20Care.pdf](https://www.health.gov.au/internet/main/publishing.nsf/Content/2126B045A8DA90FDCA257F6500018260/$File/11PHN%20Guidance%20-%20Psychological%20treatment%20services%20in%20Residential%20Aged%20Care.pdf)
 - Severe Behaviour Response Teams <https://dementia.com.au/services/overview> GPs can make referrals to this service which is for people living in residential care, where there is evidence of risk, and behaviours are defined as severe.

Elder Abuse: Identification and Screening

Key Messages

- Elder abuse refers to any intentional or unintentional behaviour pattern (action or inaction) that results in psychological, financial, physical or social harm to a person aged over 65 years, or 45 years for Aboriginal and Torres Strait Islander peoples. In Aboriginal and Torres Strait Islander people the term “elder abuse “ may need to be replaced with “abuse of older persons”.
- Elder abuse leads to poor health outcomes, including distress, morbidity and mortality.
- There are several types of elder abuse including neglect and emotional/psychological, physical, social, sexual and financial abuse. Abuse types may occur in isolation or co-exist. Psychological abuse is the most common type of abuse in older people with dementia.
- Older person risk factors for abuse include cognitive impairment (e.g. dementia), behavioural problems (e.g. BPSD), functional dependency and poor health/frailty. These risk factors are common in older people with dementia living at home or in residential aged care (RAC).
- Abuser risk factors for elder abuse include caregiver burden and stress, negative care-giving motivation factors and psychiatric/psychological problems. A trusted person who is close to and relied upon by the older person is typically the abuser (e.g. the older person’s own children).
- Relationship risk factors for elder abuse include family disharmony, conflicted relationships and family violence history.
- Environment risk factors include living in a rural or remote community and low social support.

Elder abuse

- GPs and practice nurses have a key role in reducing the risk of elder abuse, monitoring for signs of abuse and responding when suspected or identified. Safe, respectful and inclusive care of older people with dementia includes sensitive assessment of and person-centred response to suspected abuse and elder abuse.
- There is no gold standard method for identifying elder abuse and little validation of screening questionnaires for use with older people who have dementia. However, screening methods, including signs and symptoms and common risk factors for abuse, can assist GPs/ practice nurses to broach the topic of personal safety and assess for abuse risks and harm. Importantly, as dementia impacts on cognitive function and many methods rely on the older person's ability to recount experiences, more reliance may be needed on identifying signs of abuse and risks factors.
- Older person factors may make identification of abuse more problematic. For example, through denial or sense of shame/ embarrassment, concerns about punishment by the abuser for disclosure, fears about losing their carer or concerns about repercussions from breaking family solidarity.
- Risks for elder abuse should be managed proactively with the older person and carer as part of a comprehensive care plan. Information about options should be provided. Care and prevention should be tailored to the specific needs and circumstances of the older person and carers, including the older persons stage of dementia. Evidence based guidance for dementia care and carer support should be followed and revised as circumstances and needs change over time.
- GPs and practice nurses should thoroughly and clearly document assessed risks, and signs/symptoms of elder abuse.

Elder abuse

- As the reporting of elder abuse is not mandatory in Australia, except in relation to specific offences occurring within Commonwealth-funded aged care facilities (physical and sexual assault), the decision to voluntarily report abuse and intervene should prioritise, where possible, the expressed wishes of the older person. Alternatively, an uninvolved substitute decision maker.
- Australian laws provide the legal framework for reporting crimes that occur as elder abuse (e.g. physical and sexual abuse). With the consent of the person or substitute decision maker, the police should also be notified where there is an immediate risk of physical harm or serious risk of damage to property. State and territory policies detail voluntary reporting frameworks and agencies for other types of elder abuse.

Practice Points – What Can I Do?

UNDERLYING PRINCIPLES OF CARE WHERE THERE IS SUSPECTED ELDER ABUSE

- Recognise the impact of dementia on the older person, their carer, family relationships, living and economic circumstances.
- Recognise and respect the decision-making and privacy rights of the person with dementia.
- Aim to maximise the older person's quality of life and safety over the duration of their condition and across care environments. Regularly communicate with the older person and their carers about the demands of caring, the older person's needs and the problems/stressors they both encounter. Assess coping. Encourage timely use of support services and respite.
- Minimise the potential for elder abuse by knowing and assessing for risk factors and signs/symptoms of abuse.
- Recognise that older people and health care professionals may have difficulty raising, discussing and responding to elder abuse.
- Recognise that elder abuse is a serious circumstance for the older person and that different types of abuse (see table below) may occur and change over time – in isolation or combination.
- Recognise the important role of GPs and practice nurses in preventing, recognising and responding to elder abuse risks, suspected elder abuse and abuse, including in RACs.

Elder abuse

| Type and definition | Examples |
|--|---|
| Emotional (or psychological or social) abuse Using threats, humiliation or intimidation which causes mental anguish, fear, shame or isolation. | <ul style="list-style-type: none">• Verbal abuse, harassment or bullying• Threats of physical harm or institutionalisation• Withdrawing emotional support.• Preventing contact with family and friends |
| Physical abuse Causing physical pain or injury | <ul style="list-style-type: none">• Pushing, shoving, slapping, kicking or burning.• Restraining with rope or ties or locking in a room.• Using chemical restraints such as alcohol, medications or poisons. |
| Sexual abuse Any unwanted sexual contact or activity | <ul style="list-style-type: none">• Inappropriate touching• Sexual harassment• Sexual assault |
| Financial or material abuse Using someone's assets illegally or improperly. | <ul style="list-style-type: none">• Using credit cards without the person's permission.• Moving into the older person's home, but not for the benefit of the older person.• Stealing goods, whether expensive items or basic necessities. |
| Neglect Failing to provide the basic necessities of life. | <ul style="list-style-type: none">• Not giving the person adequate food, clothing, shelter, medical or dental care.• Receiving the Carers' Allowance and not providing the care required |

Adapted from Kurrel and Naughtin ¹, Australian Law Reform Commission (ALRC) ²

Elder abuse

ASSESSING FOR ELDER ABUSE RISK AND PREVENTION STRATEGIES WHERE THE PERSON HAS DEMENTIA

- Assess degree of abuse risk considering older person, abuser, relationship and environmental factors detailed in the following table.

Risk factors for elder abuse

| | |
|------------------------------|---|
| Elder person factors | <ul style="list-style-type: none">• Cognitive impairment• Behavioural problems• Psychiatric illness or psychological problems• Functional dependency• Poor physical health or frailty• Low income or wealth• Trauma or past abuse• Ethnicity• Low literacy levels or a lack of awareness of rights. |
| Perpetrator factors | <ul style="list-style-type: none">• Caregiver burden or stress• If carers have a negative motivation for providing care (e.g. there are no other carers available or suitable)• Psychiatric illness or psychological problems (including anxiety, depression and anger).• Having a strong sense of entitlement towards the older person's property |
| Relationship factors | <ul style="list-style-type: none">• Family disharmony• History of family violence• Poor or conflictual relationships |
| Environmental factors | <ul style="list-style-type: none">• Low social support• Living with others (except for financial abuse)• Living with adult dependents with a disability or health issue• Living in a rural or remote community |

Adapted from Johannesen and LoGiudice ³, Bagshaw, Wendt ⁴, Camden, Livingston ⁵, Cooper, Selwood ⁶, Macneil, Kosberg ⁷, Seniors Rights Victoria ⁸

Elder abuse

- The mitigation of risk factors (e.g. carer burden) should be included as prevention strategies in care plans for people with dementia and their carers. Information about options should be provided. Enhance support for the older person and their carer by referral to community support services. These services are also important for monitoring and support older people at risk of abuse; for example, implement, maintain or enhanced home services where possible. Refer carers to support and respite services, including Dementia Support Australia (<https://www.dementia.com.au/>) where there are problems in coping with behavioural and psychological symptoms of dementia (BPSD). Substance abuse or a gambling addiction in the carer may also be a factor contributing to the abusive behaviour, in which case organising the appropriate support services for the abuser may be warranted.^{8,9}
- Prevention strategies require systematic review and adjustment as the older person's circumstances change and their dementia progresses over time. Many people at risk of abuse, are actually abused.

ASSESSING THE PERSON WHO HAS DEMENTIA FOR ELDER ABUSE

- The use of screening tools to identify abuse in people living with dementia can be difficult in the case of dementia. The EASI © has been validated in early dementia.¹⁰ GPs should therefore assess for the signs of abuse, and evaluate risk factors (see above) to identify suspected abuse and abuse in the case of dementia.
- While the signs of abuse might not be visible or conclusive¹¹ the GP should assess the older person for the presence of possible signs and symptoms of elder abuse (see table below). Where the possibility of abuse is suspected the GP should utilise time during consultation with the older person and carer to observe the emotional reactions and body language of the older person and the suspected abuser. A detailed picture may not be possible during one consultation, but rather built over a sequence of planned visits with the older person. Time alone with the older person may be needed in order to assess for some signs and symptoms of abuse and risk factors.

Elder abuse

Possible signs and symptoms of elder abuse

| | |
|---|--|
| Emotional (or psychological or social) abuse | Unexplained passivity or withdrawal. Reduced social contact. Anger, depression or unexplained weight loss. A carer who answers for the person with dementia or obstructs a private consultation with the person. Regular requests for sedatives. |
| Physical abuse | Unexplained bruises, welts, lacerations, sprains or fractures. Unexplained changes in behaviour possibly due to overmedication or undermedication. Unexplained physical pain. Withdrawal, anxiety or depressed mood. |
| Sexual abuse | Bruising, inflammation, tenderness or abrasions to the genital area. |
| Financial or material abuse | Unexplained anxiety, avoidance, social withdrawal or depression. Lack of money to purchase food or medication. Improperly attired for the weather. Reluctance or guilt about identifying their abuser. |
| Neglect | Poor mobility Decubitus ulcers or pressure sores Poor hygiene or body odour Frequent infections or unexplained medical conditions. Unexplained weight loss, anxiety or depressed mood. |

Adapted from Yaffe and Tazkarji ¹²

- Consider the influence of barriers to the older person disclosing abuse e.g. fear, shame or concerns about discovery. People living with dementia who depend on a caregiver might be particularly reluctant to disclose abuse for fear of the loss of support.¹³ People with dementia may have difficulties discussing their feelings or remembering instances of abuse.
- Consider who may be a potential abuser. In an RAC, “the abuser may be another resident (sometimes with dementia), a staff member (including volunteers), visitors or family members”.^{14(p76)}

Elder abuse

- Where abuse is suspected the GP should collect a detailed medical history which includes psychosocial and cultural information, document relevant findings from physical examinations (including photos of injuries where relevant), document observations of the person's behaviour including body language and interactions with carers/family/RAC staff members, order laboratory and imaging tests as appropriate, devise plans with the patient to enable support, education, and follow-up, implement patient safety plans and monitor ongoing abuse.^{15, 16}
- The reporting of elder abuse is not mandatory in Australia, except in relation to specific offences occurring within Commonwealth-funded aged care facilities.^{1, 17} The decision to voluntarily report abuse and intervene should therefore prioritise the expressed wishes of the older person.⁸ Taking this stance also respects the older person's privacy. However, if the person with dementia does not have the capacity to make decisions/engage in supported decision-making, the GP should consult the older person's substitute decision maker (SDM). If the SDM is the suspected abuser or if there is no clear indication of the existence of an SDM, the GP should contact the public guardian, public advocate or appropriate body in their own state or territory if it is considered necessary or desirable to safeguard the person with dementia's wellbeing. Further information can be obtained by contacting the relevant state and territory helplines below.

STATE AND TERRITORY CONTACT INFORMATION

| Possible signs and symptoms of elder abuse | | |
|--|--|--|
| Australian Capital Territory | Older Persons Abuse Prevention Referral and Information Line (APRIL) | (02) 6205 3535 |
| New South Wales | NSW Elder Abuse Helpline | 1800 628 221 |
| Northern Territory | Elder Abuse Information Line | 1800 037 072 |
| Queensland | Elder Abuse Prevention Unit | 1300 651 192 |
| South Australia | SA Elder Abuse Prevention Phone Line | 1800 372 310 |
| Tasmania | Tasmanian Elder Abuse Helpline | 1800 441 169 |
| Victoria | Seniors Rights Victoria | 1300 368 821 |
| Western Australia | Advocare Inc | 1300 724 679 (Perth) 1800 655 566 (Rural) |

Elder abuse

Different reporting mechanisms should be used depending upon each older person's specific circumstances (e.g. abuse type, location and abuser).

- **Cases of a criminal nature** (e.g. physical or sexual assault) - If there is an immediate risk of physical harm, or there is suspicion that the abuse is of a criminal nature, the GP should notify the police. Extra care to document injuries should be taken in case of criminal abuse cases.⁸
- **Cases relating to professional malpractice** - suspicions of abuse by providers of health services, such as GPs, nurses and allied health professionals should be notified to the Australian Health Practitioners Regulation Agency (AHPRA), including professional malpractice cases relating to RACs (www.ahpra.gov.au).
- **Cases requiring guardianship intervention** - if the case relates to an older adult who has lost capacity to make decisions (for example, due to dementia) the matter should be referred to the Guardianship authority (or your state equivalent) for investigation or advocacy (refer to Table 19 in Chapter 13 of the RACGP White Book <https://www.racgp.org.au/clinical-resources/clinical-guidelines/key-racgp-guidelines/view-all-racgp-guidelines/white-book>)
- **Making a complaint about aged care services** - anyone can make a complaint about aged care in Australia by discussing issues directly with a service provider or by contacting the Aged Care Quality and Safety Commission. Most complaints can be addressed quickly by discussing the issue(s) with the aged care service provider, in person or over the phone. If this is not possible, you can contact the Commission via <https://www.agedcarequality.gov.au/>

Dementia in People with Intellectual Disability

*This is an abbreviated form of similar guidelines, which are updated regularly and can be accessed here: <http://unsw.to/iddementiaguidelines> and here <https://3dn.unsw.edu.au/content/health-mental-health-professionals>

Key Messages

- GPs need to be aware that people with intellectual disability (ID) are at increased risk of dementia.
- Alzheimer's disease, in particular, is very common in Down syndrome, is often of early onset, and typically begins with changes in personality and executive function. People with Down syndrome should receive a comprehensive baseline 'healthy' assessment at around 30 years of age, and again at 40. From 30 onwards, questions regarding signs of decline should be incorporated into annual health checks.
- In people with other forms of intellectual disability (ID), average dementia onset is approximately 10 years prior to that experienced by the general population. A practical approach would be to screen for evidence of decline at around the age of 40, by asking questions about decline and using a carer-report checklist. This checklist should be repeated at the age of 50 and each year thereafter. Those with signs of potential decline should receive a comprehensive assessment.
- After performing a standard dementia work-up, refer a person with suspected cognitive declines to an experienced psychologist or psychiatrist for a full cognitive assessment.
- Diagnosing dementia in people with ID requires establishing longitudinal declines in function, ideally across at least 3 sequential assessments. Standard tests used with the general population are unsuitable for this group.¹¹

Intellectual disabilities

- A number of screening checklists are available. The US National Task Group Early Detection Screen for Dementia (NTG-EDSD) is free to download from <http://aadmd.org/ntg/screening> and can be used qualitatively to examine declines.
- Important principles for managing dementia in patients with ID include:
 - Be equipped to manage mental disorders in people with ID. Recommended adjustments to practice can be found here <https://3dn.unsw.edu.au/the-guide>.
 - Screen and examine for other potential causes of cognitive decline
 - Use principles of dementia care applicable to people without ID, including communicating the diagnosis to the patient as early as possible in a manner they understand; seeking their preferences for care; coordinating services across relevant sectors (which may include the disability sector); and, where applicable, encouraging family carers to access emotional support and to make use of respite services
- There is general information about supported decision-making with people with dementia available here: <https://cdpc.sydney.edu.au/research/planning-decision-making-and-risk/supported-decision-making/>
- The Down Syndrome Association of Australia website has information on supported decision-making here: https://www.downsyndrome.org.au/news/supported_decision_making.html

Practice Points – What Can I Do?

PREVALENCE AND INCIDENCE OF DEMENTIA IN INTELLECTUAL DISABILITY (ID)

- People with intellectual disability (ID) are at higher risk of dementia than the general population.
- Down syndrome carries a higher risk of dementia, and specifically Alzheimer's disease, with younger onset. (see 1 for review)
- Dementia in people with ID from other causes is less researched. Prevalence studies show conflicting results. However, research indicates that the onset of dementia in people with non-DS ID is on average 10 years earlier than in the general population. ²

Intellectual disabilities

RISK FACTORS FOR DEMENTIA IN PEOPLE WITH ID

- Specific risk factors for dementia in people with ID include Down syndrome, poor physical and mental health, including undiagnosed health problems, and sensory impairments.
- Risk factors for dementia in the general population are also relevant to people with ID: poor diet and exercise, cardiovascular risk factors, poor engagement in education, social activities, and employment, head injury, and genetic factors such as APOE genotype.

PRESENTATION OF DEMENTIA IN PEOPLE WITH ID

- The full range of dementias may appear in people with ID, including mixed presentations.³ A sizeable group of people with ID with suspected declines meet some, but not all, criteria for dementia.
- At least in people with Down syndrome, behavioural and personality changes and declines in executive function may appear before memory deficits.⁴⁻⁸

ASSESSMENT OF DEMENTIA IN PEOPLE WITH ID

- There is no gold-standard diagnostic test for dementia in people with ID. Assessment tools useful for the general population are not appropriate for this group. Diagnosing dementia in people with ID requires demonstrating a decline from baseline in cognition and functioning⁹, across at least three longitudinal assessments.¹⁰
- The earliest signs of dementia can be easily overlooked or misattributed by carers.
- Primary care providers should screen for dementia in people with ID. When this should occur depends on whether the person has Down syndrome.
- Comprehensive cognitive assessments should be conducted for those at high risk of dementia. This includes people with Down syndrome, and those with non-Down syndrome ID who show signs of slowing or declines.

Intellectual disabilities

For People with Down Syndrome

- provide education for the person with Down syndrome and their carers about the risk of dementia and the warning signs, at around 30 years of age
- include questions about functional declines, cognitive slowing, or changes in personality or executive function in annual health checks from the age of 30 onwards. This could include a carer-report checklist to facilitate discussion (see below)
- arrange a comprehensive baseline cognitive assessment at around age 30 to establish a 'healthy baseline'. Repeat the baseline cognitive assessment at the age of 40 for those who appear to have no signs of functional decline and/or no concerns
- arrange regular (e.g. annual) repeat assessments where concerns or changes are noted (whether before the age of 40 or afterwards).

For People with non-Down Syndrome Intellectual Disability

- ask questions regarding decline in function, changes in personality or behaviour, and cognitive slowing at the age of 40 and again at 50, and each year thereafter. A carer-report checklist could also be used at these points (see below).
- arrange regular (e.g. annual) comprehensive assessments once a concern or change in cognition or function is noted.
- A carer-report screening checklist is available in several languages downloadable from <http://aadmd.org/ntg/screening>. This is currently recommended as a qualitative tool only. It can facilitate a discussion with the person and their carer/s regarding potential declines. Where declines are noted, a person should be referred to a psychologist or psychiatrist for a comprehensive assessment.
- A comprehensive assessment should cover memory; executive function; praxis; visual spatial skills; language including a sample of their writing and/or utterances; attention and processing speed ¹¹; and adaptive behaviour (or Instrumental Activities of Daily Living).

Intellectual disabilities

OTHER INVESTIGATIONS

- Medical examination including biochemical, haematological and thyroid function tests, should be performed as per recommendations for the general population.¹²
- Testing for the APOE ε4 allele can help determine dementia risk
- Assess vision and hearing problems. This may require referral to a specialist optometrist or audiologist in the case of illiterate or non-verbal people.
- Neuroimaging can cause a high degree of anxiety for people with ID, and can require sedation for people with moderate to profound ID.
- Review medications and doses, particularly drugs with anticholinergic effects, even if the person has been on them for some time.¹¹

DIFFERENTIAL DIAGNOSES ARE AS PER THE GENERAL POPULATION

- Note the increased risk of undiagnosed medical or mental health problems, many of which are treatable.
- Also note the potential for grief and abuse to present as declines.¹²

MANAGING DEMENTIA IN ID COORDINATION OF SERVICES

- Adults with ID frequently fall through the gaps between services. When making referrals, first check service eligibility criteria.
- A person with ID who develops dementia remains eligible for disability-related supports but should also be eligible for specific dementia care services.
- The National Younger Onset Dementia Keyworker Program can be accessed even before a formal diagnosis is made.
- A range of allied health professionals may be involved in the care of someone with ID and dementia to promote their wellbeing.

Intellectual disabilities

SHARING THE DIAGNOSIS

- Wherever possible, communicate the diagnosis to the person with ID in a manner they can understand.
- Establish ahead of time if they want a support person to be present, if they require communication aids, and assemble resources such as easy-to-read fact sheets about dementia. An example is available for download from the Alzheimer's Society ((United Kingdom (UK)) website at <https://www.alzheimers.org.uk/get-support/publications-and-factsheets/easy-read-factsheet-what-dementia>
- Communicate both the diagnosis and the supports available to them and any options regarding future care. Ascertain their preferences for care options.
- The diagnosis should also be communicated to the person's support network, once consent to their involvement is given. Provide education regarding dementia and what to expect.

RISK ASSESSMENT

- Do a standard risk assessment but repeat it more often as decline may be faster.
- Wandering, getting lost, or choking may present earlier. The risk of abuse may be higher.

PLANNING FOR DECLINES

- As dementia progresses, the care goal needs to shift from supporting independence towards providing care and eventually palliative care.^{13, 14}
- In many cases, the person with ID, their family and service providers want them to remain ageing in place. However, if and when their care requirements can no longer be met in their current place, options include transfer to an aged-care facility or to another disability service.
- Long-term planning for such transitions is important.

Intellectual disabilities

MANAGING MEDICAL COMPLICATIONS

- People with ID are more likely to have pre-existing physical health problems than the general population.
- Late-onset seizures are particularly common in people with Down syndrome and AD.

REVIEW MENTAL HEALTH AND BEHAVIOUR

- People with ID (without dementia) experience a high rate of behaviours of concern, and so there is risk of new or escalating behaviours being overlooked or misattributed.
- Review existing medications before prescribing new ones to manage behaviours.¹⁵
- Commence medication at a lower dose with attentive follow-up.¹⁵
- Be aware that extrapyramidal side effects may be difficult to recognise in people with ID.^{16, 17}

CHOLINESTERASE INHIBITORS AND MEMANTINE

- Further research is needed to establish the efficacy of these medications in people with ID.
- Be aware of the increased potential for side effects, especially in people with Down syndrome who can often have cardiac problems and small stature.
- Commence at a lower dose, with slow titration and frequent review, particularly for those with Down syndrome.

CARING FOR A FAMILY CARER OF A PERSON WITH ID AND DEMENTIA

- Family carers of people with ID who develop dementia are a unique group of carers. Where needed, arrange access to mental health professionals and encourage carers to access respite services.
- Educational resources on caring for a person with ID and dementia are available from the Down's Syndrome (UK) website (https://dsagsl.org/wp-content/uploads/2012/11/ds_and_alzheimers1.pdf) and the BILD (UK) website (<http://www.bild.org.uk/resources/ageingwell/dementia/>)

Intellectual disabilities

List of Resources

| | |
|--|--|
| The US National Task Group | Early Detection Screen for Dementia (NTG-EDSD) – http://aadmd.org/ntg/screening |
| The British Psychological Society | “Dementia and People with Intellectual Disabilities: Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia” http://www.bild.org.uk/resources/ageingwell/dementia/ |
| Bild (UK) | “Dementia Support” http://www.bild.org.uk/resources/ageingwell/dementia/ |
| Alzheimer’s Society (UK) | “Factsheet: What is dementia?” https://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1092 |
| Down’s Syndrome Association (UK) | “Down’s Syndrome and Alzheimer’s Disease: A Guide for Parents and Carers” https://dsagsl.org/wp-content/uploads/2012/11/ds_and_alzheimers1.pdf |
| IDMH | Intellectual Disability mental health e-learning resources for Professionals http://www.idhealtheducation.edu.au/ |
| Dementia Australia | “Living with intellectual disability and dementia” https://www.dementia.org.au/about-dementia/resources/videos/collections?playlist=Intellectual%20Disability |
| The University of Queensland | Comprehensive Health Assessment Program (CHAP) https://qcidd.centre.uq.edu.au/resources/chap |

Dementia Prevention

Key Messages

- No disease modifying treatments are currently available for Alzheimer's Disease (AD).¹
- Brain damage caused by transient ischaemic attacks (TIAs) and stroke is irreversible and increases the risk of subsequent dementia in late-life.
- Collectively modifiable risk factors account for more cases of dementia than genetic risk factors.
- Many of the risk factors for dementia are also risk factors for other diseases such as cancer, heart disease, diabetes and stroke. There is therefore an economy in approaching prevention across these multiple outcomes, particularly in the management of vascular risk factors.
- Middle-age appears to be a critical period when risk factors emerge that increase late-life risk of dementia.²
- Many risk factors for dementia are modifiable by lifestyle change, medication and avoidance of environmental hazards. Based on each person's individual risk profile mid- and later life modifications for risks include:
 - smoking cessation;
 - physical activity according to Australia's Physical Activity and Sedentary Behaviour Guidelines ³,
 - healthy eating taking into account medical conditions, including 2+ fish meals per week and the Mediterranean diet;
 - reducing problem alcohol consumption;
 - increasing social participation and cognitively engaging activities;

Prevention

- optimising sleep hygiene and promoting healthy sleep patterns;
- maintaining normal BMI;
- reducing high total serum cholesterol in middle-aged adults;
- for people with diabetes, maintain usual lifestyle and pharmaceutical management;
- for patients with depression, treating according to depression guidelines;
- managing vascular risk factors (hypertension, atrial fibrillation etc.) according to guidelines;
- de-prescribing benzodiazepines and anticholinergics where possible; and
- not prescribing hormone replacement therapy (HRT) for cognitive symptoms.

Note: Throughout this chapter, Alzheimer's disease is abbreviated as AD and Vascular dementia, VaD.

Practice Points – What Can I Do?

| Risk Factor | Present in Mid-life | Present in Late-life | Recommendation |
|----------------------------------|--------------------------|----------------------|---|
| Smoking | Increases risk | Increases risk | Support cessation (even in later life). Refer to programs |
| Physical activity | Reduces risk | Reduces risk | Prescribe according to Australia's Physical Activity and Sedentary Behaviour Guidelines. https://www1.health.gov.au/internet/main/publishing.nsf/content/health-pubhlth-strateg-phys-act-guidelines ³ |
| Diet | Presumably reduces risk* | Reduces risk | Healthy eating taking into account medical conditions (e.g. diabetes). Recommend eating 2+ fish meals per week, support diet with nutrient pattern similar to Mediterranean diet. |
| Alcohol | Hazardous increases risk | | Assess alcohol consumption, refer problem drinking for treatment. Recommend NHMRC guidelines. Methodological difficulties in assessing exposure to alcohol. No evidence to recommend consumption of alcohol. |
| Low social engagement | - | Increases risk | Advise increase in social participation. |
| High cognitive engagement | May reduce risk | Reduces risk | Advise increase in cognitively engaging activities |
| Sleep disorders | May increase risk | Increase risk | Advise on sleep hygiene, refer to sleep clinic |
| Overweight/obesity | Increases risk | No association | Advise maintaining weight in normal BMI range. Reduce overweight/obesity in middle age. |
| High Cholesterol | Increases risk | No association | Advise reduction of high total serum cholesterol in middle-aged adults |
| Diabetes | Increases risk | Increases risk | Usual lifestyle and pharmaceutical management. Include cognitive impairment as potential complication in education and assessment. |

Prevention

| Risk Factor | Present in Mid-life | Present in Late-life | Recommendation |
|----------------------------|------------------------|------------------------|---|
| Hypertension | Increases risk | May increase risk | Treat according to Heart Foundation guidelines |
| Atrial Fibrillation | Increases risk | Increases risk | Treat in accordance with guidelines e.g. Heart Foundation Guidelines |
| Stroke | Increases risk | Increases risk | Manage vascular risk factors to reduce risk of future stroke |
| Depression | Increases risk | Increases risk | Treat as per guidelines e.g. RANZCP Guidelines |
| Statins | - | May Reduce risk | Usual practice. Note no RCT evidence of benefit. |
| Anti-hypertensives | May Reduce risk | May Reduce risk | Treat according to Heart Foundation guidelines |
| Benzodiazepines | - | Increases risk | De-prescribe where possible |
| Anti-inflammatory | NSAIDs may reduce risk | NSAIDs may reduce risk | No RCT evidence of benefit. Usual practice for other conditions, not indicated for cognition. |
| HRT | No association | No association | Do not prescribe for cognitive symptoms |
| Anticholinergics | - | Increases risk | De-prescribe where possible |

* Note that some for many risk factors, there is no or insufficient information available on whether they increase risk of dementia in mid-life or late-life. Inferences can be made about some (e.g. smoking, diet) based on the wider literature and their impact on heart disease or stroke. For some risk factors, RCT evidence is not consistent with cohort studies (e.g. statins)

Supporting Carers of People with Dementia

Key Messages

- Carers play a key role in supporting people with dementia to live in the community and residential aged care services.
- Though caring offers rewards, carers often experience carer burden/strain and are at risk of poor health. Addressing carer well-being enables the carer to better provide for the well-being of the person with dementia and potentially enables longer care in the community. GPs should regularly assess, manage and review the carer's relationship with the person with dementia and their emotional and physical health, or encourage the carer to seek regular health assessment and advice from their treating GP.
- GP assessment, management and review of carer health should be person centred. Care should include screening and preventative health strategies. The health effects of the caring role should be monitored until after the death of the person with dementia.
- Carer experiences of caring should be elicited, listened to, respected and included when assessing, managing and reviewing care of the person with dementia and making decisions. Consideration should be given to the potential considerable short and long-term impact of BPSD on carer well-being (See BPSD Chapter).
- Carer access and involvement with dementia support programs optimises care for the person with dementia and carer well-being. Referral to support programs/resources should be based on assessed needs and tailored to the carer and person with dementia and should include:
 - information on dementia as a disease process and consequences, tailored to stage of the person's disease and the carer's situation;
 - practical strategies and skills to support the carer in communication with and meeting the care needs of the person with dementia, including engaging with the person through use of pleasant and meaningful activities and problem-solving changed behaviour;

Supporting carers

- accessing support organisations specific to dementia and caring (e.g. Carers Australia);
 - accessing volunteer organisations which provide unpaid assistance or support. People with a culturally and linguistically diverse (CALD) background may benefit from contacting CALD specific organisations (e.g. CALD Clubs and Migrant Resource Centres); and
 - maintaining physical and emotional carer well-being and fitness. As depression, stress-related psychiatric disorders, and a reduced quality of life are often experienced by carers, specialist psychological support may be appropriate.
- Respite can enhance carer well-being and assist carers to continue caring in the community. Respite appropriate to the needs/situation of the carer and person with dementia should be offered and encouraged where available (e.g. culturally specific services, activity groups and in-home, day or residential respite services).

Supporting carers

Carer Support Flowchart



Supporting carers

Practice Points – What Can I Do?

ASSESSMENT OF THE CARER'S HEALTH NEEDS

- Recognise the potential for changes in carer well-being and that the carer may have difficulty in addressing on their own well-being.
- Aim to regularly assess the health needs of the carer. Regular consultation intervals and ensuring adequate consultation time can assist in assessing carer health over time and as the demands of caring change. Alternatively encourage/facilitate regular health assessment and advice by the carer's treating GP.

“

The GP really has two patients – the person with dementia and the carer

(Quote from carer forum).

”

- Use a person-centred approach to assess and review the carer's relationship with the person with dementia and the carer's emotional and physical health. Regularly check-in with the carer by asking general health questions to ascertain how they are coping e.g. ask about their sleep and appetite.¹ Elicit, respect and consider carer experiences of caring as part of this assessment.

“

Validate the carers view (of caring) without alienating the person with dementia. Listen to carer information about activities of daily living and ensure that carer confidentiality isn't broken in conversations with the person with dementia.

(Quotes from carer forum).

”

Supporting carers

- A carer burden self-report measure (e.g. Zarit Burden Interview²) can be used to inform interviews directed at identifying high levels of carer burden.
- To assess carer emotional well-being consider/explore:
 - feelings of being trapped by the carer role and/or lacking in time for themselves;
 - feelings of being under a lot of stress or feeling overwhelmed;
 - carer perceptions of coping (e.g. How does the carer perceive they are managing? What helps them to cope/coping skills used? How do they relieve stress? How do they perceive their own health?)³;
 - the adequacy of existing social support (e.g. What are the carer's commitments? What help does the carer have? Do they keep in touch with friends and family?)³;
 - whether the carer feels able to manage changed behaviours exhibited by the person with dementia³;
 - carer ability to maintain religious/spiritual activities³;
 - symptoms of depression and anxiety (e.g. loss of interest or enjoyment in usual activities, feelings of hopelessness, feeling irritable or feeling edgy; sleep disturbance);
 - possible fears about the future and what it will entail for the carer/person with dementia; and
 - presence of financial strain/hardship.
- To assess carer physical well-being consider:
 - how the carer perceives their own health and whether caring is impacting on their physical health³;
 - the effects of fatigue, sleep disruption and physical demands of caring activities,
 - presence and change in chronic health conditions;
 - maintenance of routine screening (e.g. cardiac risk; cervical/breast screening) and preventative health programs (e.g. flu vaccination);
 - engagement in routine physical health maintenance activities (e.g. medication use, physical activity, weight management, healthy diet); and

Supporting carers

- impacts of caring during home based care, residential care and after the person with dementia has died.
- When assessing the carer's relationship with the person with dementia consider:
 - the impact of caregiving on their relationship with the person with dementia ³;
 - impacts of loss and grief whilst caring, during residential care and after the person with dementia has died; and
- whether decision-making processes for health and financial affairs are in place and functioning.³

PROVIDE CARER SUPPORT

- Schedule regular appointments with the person with dementia and their carer following diagnosis. This can assist in alleviating carer stress by facilitating discussion of care issues and planning for future challenges.⁴
- Involve carers in planning, decision making and care/management of the person with dementia.
- Encourage a positive attitude toward caring and self-management.
Suggest carers:
 - be proactive, and learn about dementia;
 - use problem-based coping approaches – seek information, name and confront and problem solve issues;
 - keep up leisure activities and self-care;
 - seek assistance from others including family and friends and those in the broader community;
 - accept that they and family members cannot be perfect carers;
 - be open in their communication with health professionals;
 - anticipate that as dementia progresses, they will have to adjust expectations; and
 - ask for respite if required.³

Supporting carers

- Acknowledge the carer's experience of caring, competence and contribution by caring for the person with dementia. Help the carer feel valued (e.g. "You are doing a great job").⁴
- Explain that the well-being of the carer is necessary and important to the well-being of the person with dementia.⁴ Where carers are reluctant to seek or accept support, GPs could indicate to the carer that they are "under doctor's orders" to utilise the help that is available.¹
- Help to normalise carer feelings/reactions to caring and ease their sense of isolation by encouraging access to resources such as Dementia Australia and associated local support groups ^{1,3} (see Facilitate access to carer resources and support services).
- Optimise care for the person with dementia and carer well-being by encouraging carer access and involvement with dementia support programs. Refer to support programs/resources based on assessed needs and individual circumstance/preferences of the carer and person with dementia, including resources/services which provide:
 - information on dementia as a disease process and consequences, tailored to stage of the person's disease;
 - practical strategies and skills to support the carer in communicating with and meeting the care needs of the person with dementia, including engaging with the person through use of pleasant and meaningful activities, environmental adjustment and problem-solving changed behaviours;
 - interaction with other carers, particularly those caring for a person with dementia (e.g. Carers Australia); and
- unpaid volunteer assistance or support. People with a culturally and linguistically diverse (CALD) background may benefit from contacting CALD specific organisations (e.g. CALD Clubs and Migrant Resource Centres).
- Offer and encourage respite to enhance carer well-being and assist carers to continue caring in the community. Respite should be appropriate to the needs/situation of the carer and person with dementia (e.g. culturally specific services, activity groups and in-home, day or residential respite services).⁵

Supporting carers

- Refer to professional support services as appropriate for the carer. As depression, stress-related psychiatric disorders, and a reduced quality of life are often experienced by carers, specialist psychological support may be appropriate. Psychological group interventions for carers of people with dementia may improve carers' mental health conditions.⁶ Strategies that blend support, education, practical counselling about common carer stresses and community resources appear to mitigate carer burden and depression.^{3,7}
- Provide GP recommendations, support and guidance to assist in reducing carer remorse and indecision over inevitable decisions. Recommendations, support and guidance should be in the context of an understanding of the person with dementia and carer's beliefs, preferences, family tensions, racial and ethnic differences.³

PROVIDE INFORMATION AND EDUCATION

Providing carers with information and education is critical for carers to provide optimal care.³



Sometimes GPs won't talk to the carer because of a problem with privacy for the person living with dementia.

(Quotes from carer forum).



GPs should first ascertain what experience and understanding the carer has about dementia, and then provide education and information (written information, brochures and websites) on:

- dementia and its consequences, appropriate to the stage of the disease;
- realistic expectations for treatment ¹ (see Clinical Practice Guidelines and Principles of Care for People with Dementia ⁸);
- advance care planning (see Advance Care Planning chapter for further information) ³;
- available dementia specific and support services, including encouragement in their use;

Supporting carers

- the importance of carer well-being - attending to their own emotional and other health needs ¹;
- being a carer, how their role will change as the dementia progresses, and the strategies they could use to cope. Support groups can offer a safe environment for carers to discuss issues with others experiencing similar challenges and life-changing events;
- managing changed behaviours and providing coping strategies, because the carer's knowledge of dementia-related behaviour directly correlates to quality of care ³; and
- common issues (e.g. safety concerns) and how to address these proactively.

FACILITATE CARER ACCESS TO RESOURCES AND SUPPORT SERVICES

- Explicit recommendation of support services by the GP may provide additional motivation for carers to seek out the educational, emotional and social support they need. Following is a range of support services that may assist carers.

Carer Resources and Support Services

| Service | Contact Information | Services Offered |
|------------------------------|--|---|
| Dementia Australia | <p>https://www.dementia.org.au/ National Dementia Helpline 1800 100 500 during business hours 13 36 77 for those with a hearing or speech impairment.</p> | <ul style="list-style-type: none"> Free specialist counselling service for people with dementia, their families and friends. Carer support groups. Family carer education and help sheets on a range of topics. Living with Dementia Series (LWDS). National Younger Onset Dementia Key Worker Program. State and territory specific information. |
| At home with dementia | <p>A manual for people with dementia and their carers © Copyright - Agency for Clinical Innovation 2019 https://www.aci.health.nsw.gov.au/resources/aged-health/allied-health/professionals-and-you/at-home-with-dementia</p> | <ul style="list-style-type: none"> To help locate resources and products to support the person living with dementia to remain living at home for as long as possible. |
| Carers Australia | <p>National Programs http://www.carersaustralia.com.au/how-we-work/national-programs/ CALD Resources http://carersaustralia.com.au/ndis-and-carers/support-for-families-and-carers/culturally-and-linguistically-diverse-carers-cald/</p> | <ul style="list-style-type: none"> Services include a national counselling program and advisory service for carers. State/territory based, culturally-specific services and may arrange for some translation and interpretation services |

Supporting carers

| Service | Contact Information | Services Offered |
|--|---|--|
| Dementia Support Australia | <p>http://dementia.com.au/ 24-hour helpline 1800 699 799</p> | <ul style="list-style-type: none"> • Incorporates the Dementia Behaviour Management Advisory Service (DBMAS) and the Severe Behaviour Response Teams • Provides individualised, clinical support for people caring for someone expressing behavioural and psychological symptoms of dementia (BPSD). |
| My Aged Care | <p>Telephone 1800 200 422 (Extra assistance is available for those with a hearing or speech impairment, or for those who do not speak English) https://www.myagedcare.gov.au/ click 'Getting Started' or on the 'Start here' button</p> | <ul style="list-style-type: none"> • Information on sources of support, services, aged care facilities, and information for carers (e.g. independent aged care advocacy information, counselling, and respite). |
| Carer Gateway | <p>Telephone 1800 422 737 Monday to Friday. 8am to 6pm (A call back can be requested) https://www.carergateway.gov.au/caring-for-someone</p> | <ul style="list-style-type: none"> • A national online and phone service that offers practical information and resources to support carers (e.g. respite care, legal information, services) |
| healthdirect Australia | <p>Counselling Health information and advice online and over the phone (1800 022 222), available 24 hours a day, 7 days a week. Funded by the governments of Australia. https://www.healthdirect.gov.au/dementia Do not enter keywords, just enter the location to search for resources.</p> | <ul style="list-style-type: none"> • A government-funded service which may provide local information on dementia and dementia related services (e.g. aged care, respite/carer support, allied health, community health care). |
| Department of Human Services - Financial Assistance | <p>https://www.humanservices.gov.au/customer/subjects/payments-carers © Commonwealth of Australia</p> | <ul style="list-style-type: none"> • Carers may be eligible to receive financial assistance from the government for their care of a person with dementia. • Forms of support may include carer payment, allowance or supplement, and payments to meet the costs of incontinence. |

Supporting carers

| Service | Contact Information | Services Offered |
|---|---|--|
| Online Training Resource – University of Tasmania (UTAS) | <p>http://www.utas.edu.au/wicking/understanding-dementia</p> | <ul style="list-style-type: none">• UTAS provides an online course on Understanding Dementia.• The Massive Open Online Course (MOOC) draws on the expertise of neuroscientists, clinicians and dementia care professionals, is free, runs for nine weeks and is available to all. |
| Interpreter Services - Department of Home Affairs | <p>Telephone 131 450 (Cost of a local call) 24 hours a day, 7 days a week https://www.tisnational.gov.au/</p> | <ul style="list-style-type: none">• Interpreter services are available through the Translating and Interpreting Services (TIS). This service covers more than 100 languages.• GPs and medical specialists are eligible for free interpreting services and access to the Doctors Priority Line (DPL) when providing services that attract Medicare rebates, delivered in private practice, and provided to non-English speakers who are Australian citizens or permanent residents. |
| Volunteer and other organisations | <p>Further information about working with vulnerable people and appropriate person checks can be found at the Department of Social Services website https://www.dss.gov.au/about-the-department/doing-business-with-dss/vulnerable-persons-police-checks-and-criminal-offences or www.dss.gov.au</p> | <ul style="list-style-type: none">• People with a culturally and linguistically diverse (CALD) background may benefit from contacting CALD Clubs and Migrant Resource Centres for appropriate information/support.• Recognised volunteer organisations (with appropriately vetted members, e.g. criminal record checked) may provide unpaid assistance.• Note: When using voluntary assistance, the carer has the responsibility to check with the voluntary organisation to ensure the volunteers they use have been appropriately vetted. |

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Order of Operations

PEMDAS

1. Parentheses

2. Exponents

3. Multiplication

4. Division

5. Addition

6. Subtraction