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**QUALITY
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**YOUNGER ONSET
DEMENTIA
A PRACTICAL GUIDE**

MAY 2015

5



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A PRACTICAL GUIDE**

MAY 2015

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Younger onset dementia is the development of dementia before the age of 65. In 2015, it is estimated that approximately 25,100 people in Australia are living with younger onset dementia.¹

The impact of dementia on younger people is quite different than the experience of older people with dementia. A diagnosis of dementia can have a major impact on employment, finances and family relationships. People can also experience social isolation as their friends and family and the broader community find it difficult to accept or understand that dementia can occur at a young age. In some cases, people with younger onset dementia may disengage from everyday activities long before the condition requires them to. People with younger onset dementia also often have difficulty accessing appropriate services and supports and can find themselves lost between the gaps of the disability and aged care systems.

On 19 and 20 March 2013, people living with younger onset dementia, their carers, service providers, health professionals and policy makers from across Australia came together at the Alzheimer's Australia National Summit, *Younger Onset Dementia: A New Horizon?* to identify priorities to improve care and support for individuals with younger onset dementia. A number of policy developments began in July 2013 following the summit, such as the major reforms of the disability and aged care sectors, and the Alzheimer's Australia Younger Onset Dementia Key Worker Program. These developments have begun to address the priorities raised at the Younger Onset Dementia Summit and increase the number of available services and supports for people with younger onset dementia.

People with younger onset dementia have had more assistance, choice and control with accessing services and support as a result of the Alzheimer's Australia Younger Onset Dementia Key Worker Program. However the program now

faces uncertainty with the ongoing rollout of the National Disability Insurance Scheme (NDIS), and the proposed integration of the Younger Onset Dementia Key Worker Program into the NDIS. The NDIS represents a major change to the disability sector, and the integration of the Younger Onset Dementia Key Worker Program into the NDIS will have an impact on younger people with dementia, who will be transferred for assistance under the NDIS.

Alzheimer's Australia is keen to ensure that this does not result in a loss of access to specialist services currently provided under the Younger Onset Dementia Key Worker Program such as the Key Workers who support people in obtaining a diagnosis, provide support for families and carers, identify service gaps and facilitate service development to meet a person's unique needs.

People with younger onset dementia and their families require information on dementia and the variety of services and supports they can access. Whereas *QDC4 – Understanding Younger Onset Dementia*¹ provided detailed information about the different types of younger onset dementia and their symptoms, this publication is a practical guide to younger onset dementia, including suggestions and references to the supports currently available for people with younger onset dementia, their carers and families. I hope that these two resources combined are a useful and helpful source of information for people whose lives are affected by younger onset dementia.

I wish to thank Jess Walsh, Kim Taylor and Jane Thompson for the revision of this document, and the consumers who voluntarily provided constructive feedback.

Carol Bennett
CEO, Alzheimer's Australia

28 May 2015

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1. Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

INTRODUCTION

Dementia describes a collection of symptoms which are caused by disorders that affect the brain. These symptoms include progressive change and deterioration in memory, thinking, learning, decision-making, language, behavioural and emotional regulation and functional ability to perform everyday tasks. Most brain disorders that cause dementia occur more commonly in older people but dementia can also occur in younger people.

Younger onset dementia, early onset dementia and presenile dementia are all terms that refer to dementia developed before the age of 65. Younger onset dementia has gradually become the preferred term because early onset dementia can also refer to people in the early stages of dementia at any age.

In 2015, it is estimated that there are approximately 25,100 people with younger onset dementia in Australia. This represents approximately 7% of all those with dementia.

Younger onset dementia may be caused by a number of different types of dementia including Alzheimer's disease, stroke (vascular dementia), frontotemporal lobar degeneration, alcohol, Parkinson's disease, Lewy bodies, Huntington's disease and other neurological conditions. Figure 1 shows the prevalence of different causes of younger onset dementia, each of which can affect functions differently. Figure 2 summarises the extent that various functions are affected by different types of younger onset dementia.

Figure 1. Prevalence of the main causes of Younger Onset Dementia. Withall et al., (2014). *The prevalence and causes of younger onset dementia in Eastern Sydney, Australia. International Psychogeriatric Association, 26:12, 1955-1965.*

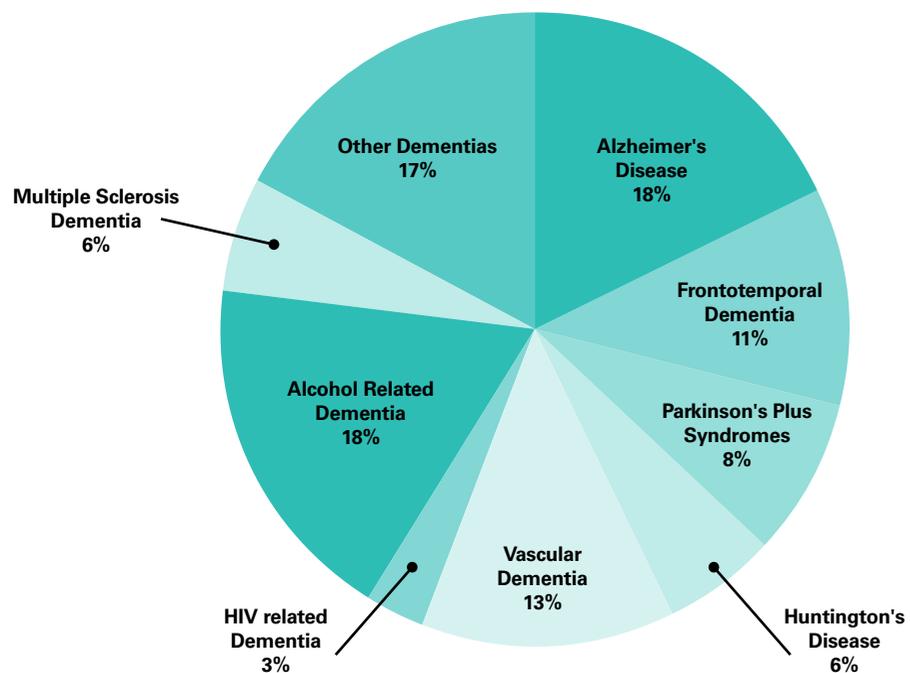


Figure 2. Summary of the extent that various functions are affected by different types of younger onset dementia.

| | Alzheimer's disease | Vascular dementia | Frontotemporal dementia | Alcohol related dementia | Parkinson's with dementia | Lewy body disease | Huntington's disease |
|-------------------------|---------------------|-------------------|-------------------------|--------------------------|---------------------------|-------------------|----------------------|
| Memory storage | •••• | ••• | | •••• | | • | |
| Memory retrieval | | | •••• | •• | •• | | •• |
| Attention | •• | •••• | ••• | •• | ••• | •••• | •••• |
| Language | •••• | •••• | •••• | | •• | •• | •• |
| Verbal Skills | •• | •• | ••• | • | ••• | •• | •• |
| Visuospatial skills | ••• | ••• | • | •• | •• | •••• | •• |
| Information Processing | •• | ••• | •• | ••• | ••• | •••• | ••• |
| Executive function | •• | ••• | •••• | ••• | ••• | •••• | •••• |
| Behaviour & personality | •• | ••• | •••• | •• | •• | ••• | •••• |

Greatly affected •••• Moderately affected ••• Slightly affected •• Midly •

For more information on the different diseases that cause younger onset dementia and their symptoms, please refer to *Alzheimer's Australia Quality Dementia Care 4: Understanding Younger Onset Dementia (2013)*.

www.fightdementia.org.au/common/files/NAT/20130808_QDC4.pdf

A.

PRACTICAL TIPS AND ADVICE FOR PEOPLE WITH YOUNGER ONSET DEMENTIA AND THEIR CARERS

The following section covers practical tips and advice for people living with younger onset dementia and their carers. It discusses key issues and provides suggestions for further reading.

The Alzheimer's Australia website www.fightdementia.org.au has excellent resources about younger onset dementia including practical help sheets www.fightdementia.org.au/about-dementia-and-memory-loss/help-sheets.

For further assistance you can also call the National Dementia Helpline on 1800 100 500.

Younger onset dementia affects each person differently and symptoms vary. Information and other needs will likewise vary. Therefore services and supports need to be tailored to meet the identified needs of the person living with younger onset dementia and their family and carer.²

I. COGNITIVE ABILITIES: WORKING WITH STRENGTHS

Cognition refers to a set of mental processes which includes but is not limited to memory, attention, speech and language and executive functioning. In many types of younger onset dementia, cognitive abilities are the first functions to be impaired.

Many people with younger onset dementia will have an assessment by a neuropsychologist, which identifies a person's cognitive strengths and weaknesses through a variety of tests. This information is important to develop strategies to adjust to the changes in their abilities. Strategies will vary depending on the type of dementia, and the unique strengths of the individual.

While there are promising research initiatives being developed with the aim of restoring cognitive abilities in people with dementia, the current evidence to support 'brain retraining' programs is limited. The most effective ways to manage these difficulties are to focus on strengths, modify communication styles and adapt the environment. Here are some strategies that may be helpful for people with dementia and their carers to cope with affected cognitive processes.

Memory

Dementia commonly causes problems with what is called 'episodic memory' (the ability to remember personally experienced events). This is the hallmark of Alzheimer's disease, but may be experienced in any form of dementia. Dementia can also affect 'semantic memory' (the ability to remember meanings and acquired knowledge) and 'procedural memory' (the ability to remember processes).

Common challenges for people with dementia include:

- forgetting conversations
- misplacing commonly used items
- poor recall of events
- forgetting people's names or identities
- forgetting what an object is used for
- forgetting their way around a familiar area.

Strategies for people with dementia:

- Carry a diary, notepad, phone or tablet for writing down messages, important information or tasks.
- Link information to something that's already known. For example, a person's name might be better recalled if it is associated with that of a relative.
- Set reminders. Try using an electronic diary, calendar or phone/tablet application to remember tasks throughout the day. "It's Done!" is an example of an application which allows reminders to be set, has a checklist of daily tasks and automatically sends messages to a carer when the task is complete.
- Write important phone numbers on a large sign placed next to the phone or store them in the phone's contact list.
- Attach important items to yourself so they cannot be misplaced. For example, clip keys to a belt or wear a lanyard with keys attached.

Strategies for carers:

- Decide on a consistent place to keep bags, keys and wallets.
- Label doors, drawers and cupboards.
- If the person with dementia is continuously repeating themselves, use distraction to change the topic. For example, introduce other enjoyable activities or conversations.
- If the person with dementia keeps asking the same question, try to understand why they may be repeating themselves. Is it due to increasing anxiety about an upcoming event/issue?

- When a person is trying to recall an event, assist them by providing a meaningful context (who was there, what the event was for, when did it occur). Providing cues and prompts can aid recall.
- When assisting the person with dementia to learn or remember something new, use the rule of 'little and often'. Generally, it is better to work at remembering one or two new things that can be repeated several times a day, rather than a number of things in one session.
- When providing information, check that it has been understood by asking the person with dementia to repeat it back to you, or ask them to re-tell it in their own words.
- If the person with dementia continuously misplaces things they may begin to think that people are stealing from them and they may hide their belongings. It is a good idea to lock up valuables such as jewellery or sentimental gifts. Keep photo albums in a safe place, make copies of important documents and back up digital information.
- Ensure the person with dementia has their name, address and emergency contact details in their wallet/purse and consider an identity bracelet or electronic tracking device if disorientation is becoming a problem.

For more information on memory, see the Alzheimer's Australia Help Sheet "Memory Changes" on the website: fightdementia.org.au/common/files/NAT/2012_NAT_HS_AD_12_MemoryChanges.pdf

2. In this publication 'carers' refer to unpaid carers who are close to the person with dementia, for example relatives, friends or neighbours and have assumed responsibility for the person with dementia's physical, emotional or developmental wellbeing.

Attention

Attention refers to the ability to focus and to sustain concentration over prolonged periods of time. Impairments in attention may affect the ability of a person with younger onset dementia to learn new information.

Common challenges for people with dementia include:

- being easily distracted
- having reduced ability to follow through with a task or instruction
- having difficulty completing tasks with several components/steps
- being unable to do more than one task at a time (multi-task).

Strategies for people with dementia:

- Break down tasks into small, manageable parts.
- Focus on only one task at a time.
- Allow breaks in between tasks.

Strategies for carers:

- Remove distractions whenever possible (For example, turn off the TV and radio during conversations).
- Where possible, talk one-on-one rather than in a large group.
- Simplify information and written instructions.
- If possible, present information in both a verbal and written format. The person's ability to read written information may be impeded due to changes in language comprehension or visual perception.
- Allow time for information to be processed.

Speech and Language

Language is a complex human ability, which depends on a network of structures in the brain. Language impairments can affect a person with dementia's ability to speak, read, understand spoken or written words, or speak with meaningful content.

Common challenges experienced by people with dementia include:

- difficulty finding words or constructing sentences
- difficulty reading and understanding written information
- difficulty expressing oneself verbally as well as in writing
- speaking fluently but the words are incomprehensible.
- difficulty understanding the meaning of words
- frustration because of difficulties communicating
- reduced ability to express needs, which can lead to more challenging behavioural and psychological symptoms of dementia.

Strategies for people with dementia:

- Try using more non-verbal forms of communication, such as gestures.
- Talk to your doctor about organising an assessment. An assessment by a speech pathologist can be very helpful in developing strategies to enable effective communication.

Strategies for carers:

- Be patient and allow more time to communicate.
- If the person is struggling to find a word in conversation, allow a reasonable amount of time before offering assistance.
- When communicating, stand in front of the person and at eye level to minimise distractions.
- Only provide small amounts of information at once.

- Ask the person with dementia questions in a format that allows an easy answer, and only ask one question at a time.
- Repeat the message back to the person with dementia to assist comprehension.
- Smile and use humour.
- Inform others about the nature of the language difficulty.
- Gesture and visual aids can be used to enhance communication. Communication boards (where a picture of an action or item is displayed) can be very helpful.
- There are numerous iPad and tablet applications that have been developed to assist people with communication difficulties. A number of these programs were initially developed for individuals who had experienced communication changes due to stroke. They can be modified for people with dementia, who have progressive language difficulties.
- If the person can use a computer, they may prefer to communicate via email, rather than via the telephone. This allows the person extra time to comprehend the information and reply in their own time.

For more information on communication, see the Alzheimer's Australia Help sheets:

Communication: www.fightdementia.org.au/common/files/NAT/2012_NAT_HS_CSD_01_Communication.pdf

Therapies and Communication:

fightdementia.org.au/support-and-services/i-care-for-someone-with-dementia/therapies-and-communication-approaches
www.communicaid.com.au

National Aphasia Association

The National Aphasia Association has a range of communication resources on their website under 'Aphasia Aids'. There is a comprehensive list of assistive technology and tablet and smart phone applications that may be of assistance for people with dementia and progressive language changes
www.aphasia.org/

Executive functioning

Executive functioning refers to higher-level thinking abilities that enable a person to successfully engage in independent, goal-directed behaviour. These abilities guide complex behaviour through planning, decision-making, reasoning and self-monitoring of judgments and impulses. Executive functioning is also involved in complex social interactions, abstract thinking and self-reflection.

Changes to executive functioning are often the hardest of all cognitive problems to manage. A number of strategies may need to be trailed and reviewed regularly.

Common challenges experienced by people with dementia include:

- difficulty with planning and organisation
- difficulty making decisions
- poor judgment
- impulsive behaviour. For example, spending money recklessly or driving dangerously
- disinhibition (losing the ability to control instinctual or socially-inappropriate behaviours, including sexual behaviours)
- rigid or concrete thinking
- difficulty understanding concepts and metaphors
- inability to stop or start an action or activity
- inability to monitor own behaviour or pick up on others' responses
- lack of remorse toward people
- reduced drive or motivation
- unawareness or denial that the behaviour is a problem.

Strategies for people with dementia:

- Try writing down the steps of complex tasks and placing the instructions in relevant locations. For example, keep instructions for how to check emails next to the computer.
- If still working, ensure that there are checks in place to monitor work performance; supervision is crucial.

Strategies for carers:

- Try to remember that it is the dementia that is causing these changes in thinking, personality and behaviour. The person with dementia is not intentionally trying to be difficult.
- Try to maintain familiarity and routine. Many people with dementia function better in familiar environments where things have been in the same place, or where the same routines have been followed for many years.
- Allow time for decision-making and ensure that the person has access to the relevant information and support. If they need help, try to guide the person through the steps of making a decision.
- If initiation is a problem, start the activity with the person and demonstrate what to do.
- Try not to move back and forth between ideas. Finish one topic of a conversation before moving to the next.
- Try to avoid the use of metaphors or concepts. When explaining something to the person with dementia, use concrete, tangible examples.
- Try breaking tasks down into small steps. Planning difficulties usually occur because the person with dementia cannot cope with all the steps in a complex task. For example, meal preparation with several dishes may pose a big challenge, but completing one step at a time like peeling potatoes, boiling, draining, etc. may be easier.
- Ask for a driving assessment for the person with dementia to ensure that he or she is safe on the road.

For support in making decisions, there is a useful website which helps people through the decision-making process.

www.support-my-decision.org.au

Socially inappropriate behaviour can be very challenging and carers may need assistance.

For expert help, call the Dementia Behaviour Management Advisory Service (DBMAS) Helpline 1800 699 799 or visit dbmas.org.au/

This service is available to carers, care workers and services providing care to people with dementia.

2. BEHAVIOURAL & PSYCHOLOGICAL SYMPTOMS OF DEMENTIA

Most people with younger onset dementia will experience behavioural and psychological symptoms of dementia (BPSD) at some point in the course of the condition. These symptoms include, but are not limited to, depression, anxiety, hallucinations and illusionary perceptions, aggression, wandering and sundowning. Symptoms will range in severity, type and frequency and will have different impacts on the person and their care needs. BPSD vary between individuals and change over time as the illness progresses and as circumstances change.

BPSD can cause distress to both the person with dementia and their carers.

For expert help, call the Dementia Behaviour Management Advisory Service (DBMAS) Helpline 1800 699 799 or visit dbmas.org.au/.

The theory of unmet needs proposes that many challenging BPSD are the consequence of a person with dementia not having their needs met. The theory suggests that people with dementia have an impaired ability to process and communicate information regarding their own needs, so they respond to unmet needs through behavioural symptoms. For example, a person with dementia experiencing muscle pain may be unable to verbalise their pain so they respond to it by behaving aggressively. If the carer is able to assist the person with dementia to meet their need, for example by providing a heat pack to ease the pain, the challenging behaviour may subside.

While there is growing research to support the theory of unmet needs in relation to BPSD, BPSD can also be a direct symptom of changed brain function. Not all BPSD are due to unmet needs, however it is best to assess a person's needs first, develop a management plan and then treat any remaining symptoms.

TYPES OF SYMPTOMS

Depression

Approximately 25-40% of people with dementia experience depressive symptoms. Signs of depression include feelings of sadness and worthlessness, loss of appetite and changed sleeping patterns. A variety of factors can contribute to depression in people with dementia, such as social isolation, environmental factors, a prior history of depression or biological changes in the brain as a result of the dementia. People with younger onset dementia often have a greater awareness of their dementia diagnosis, which has also been associated with greater risk of depression.

Strategies for people with dementia:

- Talk with a family member or carer about any feelings of sadness or mood changes. It is best to alert someone as early as possible so they can help prevent the symptoms worsening.

Strategies for carers:

- If the person with dementia is displaying symptoms of depression, take them to see a medical professional. Depending on the cause of depression, there may be psychosocial or medical treatments available.
- If the person with dementia has awareness of their illness and has recently been diagnosed, supportive counseling may be of assistance. Counseling can be particularly useful when coming to terms with change in abilities, change in roles and the grief associated with these losses.

Anxiety

Anxiety is a feeling of fear, worry or uneasiness about something with an uncertain outcome. As people with dementia understand less of what is happening around them or feel pressured, they may become more anxious. The feelings of pressure may stem from no longer coping with everyday demands or the fear of not completing a task they used to find simple. Anxiety can also be a response to the tension or negative feelings of people and situations around them, or to their awareness of loss and insight that something is not right. Cognitive changes within the brain associated with the condition can also cause anxiety.

Strategies for people with dementia:

- Communicate what you think the source of the anxiety is. This can make it easier for others to help you feel less anxious as well as reduce your anxiety about a thought, situation or person.
- Controlled deep breathing and muscle relaxation can help with reducing anxiety.
- When feeling anxious try to seek a common, familiar environment that makes you feel relaxed and comfortable.
- Regular physical exercise can help reduce anxiety.
- Listening to music can help reduce anxiety

Strategies for carers:

- Try to address the underlying feeling or determine the source of the anxiety.
- Reassure and support the person and try to respond calmly and gently to the behaviour.
- Try to remain relaxed and positive around the person with dementia.
- Tell other people who may interact with the person with dementia any strategies you have found that reduce the person's anxiety, but first check with the person if they are happy for these strategies and their anxiety to be known.

Hallucinations and illusionary perceptions

Hallucinations are sensory perceptions experienced by a person without any stimuli. (That is, when someone sees, hears, feels, tastes or smells something that is not there). Illusionary perceptions are false interpretations of stimuli that are present. People with dementia may experience both hallucinations and illusionary perceptions. Even though a person with dementia may be seeing something that is not there, their feelings and reactions to the hallucination are real.

Strategies for people with dementia:

- Ask a doctor if there are any medications that may help prevent hallucinations. Some antipsychotic medications are available to treat hallucinations. If considering medication, remember to ask the doctor about potential side effects and carefully weigh up the benefits and risks with your carer.

Strategies for carers:

- Do not argue with the person with dementia. Acknowledge the emotions that the person is experiencing.
- Try to validate the person's claims, and then distract them from the hallucination. For example if the person is afraid of something they believe is present, acknowledge their fear and then suggest moving locations.
- Ensure the person with dementia uses aids to alleviate sensory and perceptive challenges. If the person requires glasses or hearing aids, make sure they wear them. This will optimise vision and hearing and may minimise changes in perception.
- Try altering the environment to assist the person with dementia. Make sure areas are well lit and sign-posted. Adjust the volume on the television, radio and phone so the person can easily hear what is being said.

Aggression

People with dementia commonly display aggressive behaviours, both verbal and physical. However, it may be more of a challenge for carers to manage aggression in people with younger onset dementia as younger people tend to be more physically fit and strong, presenting more danger to the people around them. The first step in attempting to reduce the incidence of aggressive behaviour is to identify the cause or trigger. Possible causes include depression, pain, fear and distress. Although there are antipsychotic medications available that are sometimes used to respond to aggressive behaviours, there is limited evidence for their effectiveness and they are also associated with a high risk of side effects.

Strategies for carers:

- Ask a health professional to screen for possible physical or medical causes for aggression, such as pain or depression.
- Investigate and trial psychosocial interventions before considering medication to prevent aggression.

Wandering

Wandering describes a range of behaviours related to the movement of a person with dementia. The person with dementia may have a reason for wandering or they may be moving around without purpose. Examples of wandering include pacing, leaving home for a specific reason but then forgetting what the reason was or trying to leave a care facility. It can lead to a person with dementia becoming separated from their families and carers, becoming lost or injured. Wandering is particularly problematic for people with younger onset dementia as younger people are often more fit and have more energy, so can wander further.

Strategies for people with dementia:

- Ask a doctor about the possible impact that medication could have on wandering (positive and negative effects).
- Consider purchasing an identity bracelet or a GPS device to wear.

Strategies for carers:

- Investigate possible reasons for the person's wandering and try to address these individually.
- Try to reduce the visibility of items that may remind the person to wander, for example handbags and coats.
- Consider purchasing bells or buzzers that alert others to when a door is being opened.
- Try to provide a safe space in the home for wandering, such as a footpath around an enclosed garden. Consider asking the local police to have the person's details recorded.

Sundowning

Sundowning is not a psychiatric condition, but a clinical term used to describe the onset of behavioural and psychological symptoms of dementia in the late afternoon, early evening or night. Possible causes of sundowning include lack of exposure to light during the day, impaired circadian rhythm, impaired sleep patterns, medication side-effects and environmental changes.

Strategies for people with dementia:

- Exercise regularly.
- Spend more time outside and in sunlight during the day.
- Limit intake of high sugar foods, caffeine and alcohol.

Strategies for carers:

- Maintain a daily schedule. As much as possible, encourage the person with dementia to adhere to a regular routine of mealtimes, waking up and going to bed. This will allow for a more restful sleep at night.
- Organise regular physical activity and planned activities in the morning and early afternoon.
- When the person begins to display BPSD, try taking them for a walk or calming them with music.

- If possible, reduce excessive noise and stimulation in the late afternoon and evening. Environmental distractions, particularly during the evening hours can cause distress and agitation (e.g. visits by grandchildren, loud music or noisy TV programs).

Further information on specific types of challenging behaviours can be found online in the Alzheimer's Australia Help Sheets series: [Changed Behaviours and Dementia: fightdementia.org.au/sites/default/files/helpsheets/Helpsheet-ChangedBehaviours01-ChangedBehaviours_english.pdf](https://fightdementia.org.au/sites/default/files/helpsheets/Helpsheet-ChangedBehaviours01-ChangedBehaviours_english.pdf) (in English and available in other languages)

Sexual behaviours

Sexual disinhibition is the loss of a person's ability to regulate and control their sexual behaviour. Examples of sexually disinhibited behaviours include making sexual remarks, removing clothing and performing sexual acts in public. Sexual disinhibition is the loss of a person's ability to regulate and control their sexual behaviour.

Examples of sexually disinhibited behaviours include making sexual remarks, removing clothing and performing sexual acts in public places. Disinhibited sexual behaviours can be very upsetting to family members and friends and are particularly confronting for the children of people with younger onset dementia. Another sexual behaviour associated with dementia is hypersexuality.

This may lead to the person with dementia placing excessive demands on their partner. Partners may feel obligated to engage in sexual behaviours that they no longer feel comfortable with. Feelings of intimacy between partners may change as the dementia progresses. Depending on the type of dementia, the person may have a reduced ability to express empathy and compassion, leading to a loss of emotional connection.

Strategies for carers:

- Try to maintain the dignity of the person with dementia.
- Provide a private, safe space for sexual acts at home or in the residential care facility.
- Be clear and firm with the person with dementia if the sexual behaviour is either inappropriate or unwanted.
- Remove yourself from the situation if you feel uncomfortable.
- Redirect the person to another topic of conversation or activity, or change the environment.
- Seek professional advice if inappropriate sexual behaviour is causing distress to either the person with dementia, the carer or facility staff.
- Family members may be embarrassed to raise concerns regarding sexual behaviour, however solutions and management strategies are available.
- Inappropriate sexual behaviour can be managed effectively once there is clear communication between the person with dementia, carers and relevant health professionals.

TABLE 2. REDUCING THE INCIDENCE AND RISK OF BPSD

There are several ways that families, carers and friends can reduce the likelihood of a person with dementia experiencing BPSD.

a. Maintain the physical health of the person with dementia

When a person with dementia is unwell they are less able to use the skills they still have, which may lead to challenging behaviours. Having regular checkups with the GP, providing good nutrition, encouraging exercise and managing medications will assist with preventing challenging behaviour. If behaviour deteriorates rapidly a GP should be consulted as there may be a medical cause such as urinary tract infection. It may also be beneficial to check the person with dementia's vision and hearing to make sure the person has glasses or hearing aids if needed.

b. Reflect on incidents

Reflecting on past experiences can be a useful learning tool. Think about factors that have promoted the wellbeing of the person with dementia and triggers that contribute to the person's behavioural symptoms. For example, have certain situations elicited particular behaviours? Do certain people elicit particular moods?

c. Be aware of personal limitations

It is important for a carer to acknowledge when they are able to respond appropriately to symptoms and when they need assistance from others. Everyone has strengths and weaknesses; some people may be able to manage particular behaviours better than others.

d. Maintain meaningful engagement with the person with dementia

Studies have shown that people with younger onset dementia who remain engaged in meaningful activity and meaningful social interactions have reduced incidence of challenging behaviours. Meaningful activities give the person with dementia a sense of purpose and increase their self-esteem. The Montessori approach to dementia care provides a set of key principles along with practical tips and advice that can help people with younger onset dementia improve communication and maintain good relationships.

Seek help if necessary

The Dementia Behaviour Management Advisory Service (DBMAS) is available to provide clinical assistance to people caring for a person with dementia who is demonstrating BPSD, especially if those symptoms impact on the safety or care that the person with dementia is receiving.

DBMAS offers a 24-hour helpline to carers: 1800 699 799.

Further information can be found at dbmas.org.au

Alzheimer's Australia's Relate, Motivate, Appreciate: Montessori Resource Promoting Positive Interaction with People with Dementia lists the Montessori principles, along with a large number of suggested activities and video demonstrations. This resource can be obtained from your local Alzheimer's Australia office or online at [www.fightdementia.org.au/common/files/NAT/AlzheimersAustralia_A5_Montessori_Booklet_WEB\(3\).pdf](http://www.fightdementia.org.au/common/files/NAT/AlzheimersAustralia_A5_Montessori_Booklet_WEB(3).pdf)

[http://www.fightdementia.org.au/common/files/NAT/AlzheimersAustralia_Montessori_Resource_WEB\(1\).pdf](http://www.fightdementia.org.au/common/files/NAT/AlzheimersAustralia_Montessori_Resource_WEB(1).pdf)

TABLE 3. TO HELP MANAGE BPSD, SEVERAL FACTORS NEED TO BE CONSIDERED

a. The brain functions that have been affected by the dementia

To manage BPSD the carer needs information from a specialist or GP about what functions of the brain are likely to be affected by the specific form of younger onset dementia the person has been diagnosed with. A neuropsychologist will be able to assess which cognitive functions have been impaired or maintained.

b. The individual

It is important to develop behavioural management plans based on the individual person. This includes his or her personality, age, past experiences, hobbies, likes and dislikes, and the things which are important to him or her. The family and carer are best placed to contribute this knowledge when developing behavioural management plans.

c. The behaviour of the carer

BPSD can be exacerbated when the person with dementia perceives that their carer is stressed. Carers should always try to present themselves as calm and in control when managing symptoms. It is also important to engage the person's attention before speaking and to maintain eye contact.

d. The environment

The environment has an impact on the ability of a person with dementia to use his or her skills. For example an environment that has cues for a person with memory loss and disorientation will assist in meeting their needs and can reduce frustration or fear. Similarly, an environment that is noisy, over-stimulating, too cold or too hot may interfere with a person with dementia's concentration and comprehension, leading to agitation.

3. Restraint

In very rare situations, chemical or physical restraints may be required to assist in managing severe BPSD in hospitals, aged care facilities and other care settings. Restraints refer to any method that restricts the movement of an individual. An example of a physical restraint is the use of bed rails to stop a person from falling out of bed and injuring themselves. Chemical restraint refers to the use of sedating medication to reduce agitation or aggression in a person who is highly distressed or at risk of harming themselves or others. Physical and chemical restraints should only be used as a last resort to manage BPSD or in response to immediate danger of harm. The first line of response should be to investigate unmet needs that may be causing the symptoms and put in place psychosocial interventions. There are clear legal guidelines with regards to the use of physical and chemical restraints that all hospitals and facilities must adhere to. If you have questions or concerns regarding the use of restraints, have a discussion with the treating medical team or facility staff.

Strategies for carers:

- Talk with the residential care staff and facility doctors about your preferences regarding restraints.
- Ask about how severe BPSD is managed and ensure you are involved in decisions regarding the person with dementia's care.
- Try and modify the environment to reduce behaviours of concern and assist in keeping the person with dementia calm and safe. Restraint is always a last resort.

4. Activities of daily living

Activities of daily living refer to basic functional activities involved in a person's self care and independence, such as dressing, bathing and toileting. They can also refer to more complex home and community tasks, such as shopping, cooking meals, paying bills and managing finances. As the dementia progresses, people with dementia typically encounter problems performing activities of daily living. Difficulties can be caused by lack of motivation, planning difficulties, memory decline, language difficulties, BPSD or physical impairment.

It is important to support people with dementia to remain involved in activities of daily living as much as possible. Often the person may require support and encouragement to complete an activity, and once this is provided they can continue to actively participate in their own care. Carers should try not to take over activities unnecessarily. Studies have shown that when a person with dementia continues to utilise the skills that they have, they can maintain those skills for longer and maximise their independent functioning.

Strategies for carers:

When trying to keep the person active:

- keep the person with dementia and others safe
- focus on the person's strengths/ likes
- if possible, start the task or set up the environment to allow maximum participation from the person with dementia.

If activities create too much distress or conflict for the carer, they should consider taking a break or asking other family members to participate. The carer should only take over the activity as a last resort. However there may come a point in time when the person with dementia is unable to participate in a meaningful way, or participation causes unacceptable levels of anxiety. At this point, the activity should be ceased and more appropriate activities could be trialed.

To assist in supporting a person with dementia to remain active, an occupational therapist can be consulted to assess levels of support and risk, and plan strategies to help the person stay safely in their home as long as possible. This functional assessment can take place in the person's own home or workplace.

Managing finances

A person with dementia may initially only need support to continue managing personal and family finances. If support can be offered without taking over the activity, this is usually very rewarding for all concerned. Decisions should be made earlier in the course of the condition about delegating responsibility for financial decisions once capacity is lost.

Strategies for people with dementia:

- If you use multiple debit or credit cards, it may be useful to arrange one PIN number for all cards or contact the bank and request that the cards require signature only.
- To ensure bills are paid on time, it is often possible to arrange for them to be paid automatically using BPAY or direct debit.

Strategies for carers:

- Start the conversation on who should be appointed substitute decision maker when the person with dementia loses capacity.
- Ensure the appropriate legal documents have been put in place before taking over any financial activity. See section B.2 for further information on legal issues.
- Ensure that all financial matters are well documented.
- If the person with dementia has lost capacity to manage their finances but would still like to have some financial independence, it may be possible to limit the person's access to a single credit card with a low credit limit or a bank account with a set daily spending limit. (This can only be done by the legally delegated substitute decision maker).
- If the person with dementia loses interest or capacity to manage finances, the person that has been legally delegated to make financial decisions on their behalf will need to take over. If this is too overwhelming, a bank manager, family member or trusted friend may be able to assist. Asking for help might be difficult, but it generally prevents unwanted financial problems and reduces stress.

Shopping

For a variety of reasons, many people with dementia have difficulty shopping. The following strategies may allow a person with dementia to continue to do the shopping independently.

Strategies for people with dementia:

- If you feel like you may forget where the car is parked, take a photo on a mobile phone of the colour/number of the car spot or a photo of the shop next to the car park. At the end of the shopping trip, refer back to the photo, or show it to others when asking for directions.
- Go to familiar local shopping centres, where you know the store layout. This will help you avoid getting lost.

Strategies for carers:

- Talk to local shopkeepers and, if you and the person with dementia are comfortable sharing information about the condition, explain the person's dementia diagnosis and the nature of the problem.
- Try writing a shopping list, together with the person with dementia, which is divided by groups of goods or aisles.
- If the person with dementia becomes confused by different brands, a picture or label from cans and packets can be attached to the shopping list.
- Choose quiet times for the person with dementia to go shopping, for example during school hours.
- Give the person with dementia a small, manageable amount of money in their wallet each trip. This will enable them to participate in buying small items, such as a cup of coffee. It lets the person retain a sense of independence, while minimising the risk of financial exploitation.

Household chores

Household chores are often safe, purposeful activities that a person with dementia is able to continue participating in for many years. Remember that the less the person is asked to do, the less he or she will do, and the likelihood of losing that ability is greater. Lack of participation in activities may also create a sense of helplessness for the individual. The person with dementia might start an activity and then leave it, but it is better to involve the person for a short period rather than not involving him or her at all.

Strategies for people with dementia:

- Use a white board or any similar device to write the tasks for the day and tick off each completed task.
- If you are experienced in using a mobile phone, iPad or tablet, this technology can be used to assist you with remembering events and planning your day. There are a variety of tablet, iPad and iPhone applications that can assist with daily reminders and scheduling. An example of such an application is 'Do It'. You can also use the electronic diary on your phone and add appointments with set reminders.

Strategies for carers:

- If the person with dementia initially refuses to participate in an activity, begin the activity in front of them and demonstrate what is involved. The person may then join in.

Taking medications

People with dementia are often prescribed several different medications that need to be taken at specific times. It's important to remember that a person with dementia that has decision-making capacity has the right to refuse medication.

Strategies for people with dementia:

- Try using a Webster-pak, which houses medications in sealed pockets arranged by day and time. To obtain a Webster-pak, simply bring your prescription to a participating pharmacy and ask for the pharmacist to dispense the medication into a Webster-pak (some pharmacies may also require a medical report signed by your doctor before arranging a Webster-pak). The costs of Webster-paks vary, so compare the prices of local pharmacies before purchasing.
- Keep an up-to-date medicines list that contains the name of each medication, dosage instructions and the date the medicine was begun, as well as the review date. Take this list to clinical and hospital appointments.
- To prepare for when you lose decision-making capacity, Advanced Care Plans can be used to state your wishes regarding medications and treatments. There is more information on Advance Care Planning in Section B.1.

Strategies for carers:

- Set up a reminder system to ensure the correct dosage of medication is taken, at the correct time. Electronic reminders can be set up to assist the person with dementia to take their medications independently. There will come a time where administration of medication has to be supervised by a carer.
- If the person with dementia does not have decision-making capacity and refuses to take a prescribed medication without understanding the impact of their refusal, speak to a pharmacist about alternative forms of the same medication, for example powder or liquid forms. It is important not to change the medication form (e.g. crush a tablet) before consulting a doctor or pharmacist because this may significantly alter the medication's effects.

For further information on Webster-paks visit <http://www.webstercare.com.au/>.

Travelling

It is possible for families to travel with a person with dementia; however, a number of potential hazards and challenges need to be considered. To determine whether travel is feasible, it might be useful to try going on a trial "holiday" close to home. This will help establish the person with dementia's ability to be away from home, their reaction to new experiences and their capacity to be in transit.

Strategies for people with dementia:

- When planning a long or overseas trip, consult a doctor on issues such as medical insurance and how much medication should be bought in advance.

Strategies for carers:

- Keep a list of emergency contact numbers of the destination, the locations of nearby doctors, hospitals and pharmacies and any nearby friends or family.
- Take with you a typed document outlining the person with dementia's diagnosis, existing medical conditions, current medications and special needs. This can be translated into another language, if required.
- Itineraries should be simplified with allocated rest days.
- Reduce your expectations. Try and pick one or two locations to assist with adjustment and re-orientation. Try to minimise long haul flights and changing time zones.

If anxious about the person with dementia wandering while away, consider having an ID bracelet made. Extensive tips on travelling can be found on the Alzheimer's Australia Helpsheet: Travelling, which can be accessed online at https://fightdementia.org.au/sites/default/files/helpsheets/Helpsheet-CaringForSomeone08-Travelling_english.pdf.

5. PERSONAL CARE

People with dementia slowly lose the ability to take care of their own personal care needs. This can lead to increased strain on the carer and feelings of loss of independence or embarrassment for the person with dementia. These challenges may also bring about confrontation or resistance to care.

Strategies for people with dementia:

- Use reminders. For example, in the bathroom, keep a list of steps for getting ready in the morning. Use pictures to illustrate each step, if this helps.

Strategies for carers:

- If the person with dementia is still able to perform an activity themselves, use prompting and encourage them to participate in their own care.
- Be responsive to the person's emotions and reactions.
- Respect the person's dignity.
- Modify the environment to assist the person with dementia. The amount of assistance required will change over time. Label wardrobes contents. Lay out clean clothes each morning. Take dirty clothes away immediately after bathing.

Bathing

Bathing is an intimate activity that, when assistance is required, involves the carer to enter into the personal space of the person with dementia, potentially causing discomfort or anxiety. Hair washing may be particularly difficult as water on the face may cause distress and eye irritation may occur. The bathroom can also present safety risks for less mobile people. The following strategies may help carers manage bathing

Strategies for carers:

- Prepare everything needed for bathing in advance such as towels, washers, and toiletries.
- Ensure the room and water temperature are not too hot or too cold for the person with dementia. Perception of temperature can be affected by dementia, so try not to make assumptions.
- Many people habitually shower at specific times, for example, always after dinner. Maintaining the person's self care routines may reduce resistance to care.
- Use hotel-sized plastic containers of shampoo and body wash.
- A bath chair to allow the person to sit while bathing may be easier and safer.
- A washcloth could be used to soap and rinse hair in the sink to reduce the amount of water on the person's face. Shampoo that does not cause stinging if it gets into the person's eyes could also be used.
- Have a washcloth to cover the person's eyes to prevent stinging.
- A hand held shower may be more effective in keeping water out of the person's eye or if the person finds the overhead shower frightening and disorientating.

Oral care

Oral care can become difficult for people with dementia as they may forget to clean their teeth, forget how to clean their teeth or they may change their eating habits, resulting in greater risk of tooth decay. Some medications can also cause dry mouth, which can impact on dental health. The following strategies may help with managing oral care:

Strategies for people with dementia:

- If you have dentures, it is ideal to remove and clean the dentures every night.
- Book regular check-ups at the dentist.

Strategies for carers:

- Provide the person with dementia short, simple instructions on how to clean teeth. If the person still needs help, try demonstrating the actions.

Incontinence

Incontinence is the loss of control of the bladder and/or bowel; a common symptom of dementia that may occur for a variety of reasons. When a person with dementia first presents with incontinence, it is recommended that they visit a doctor to rule out any treatable causes, such as infection. If the cause is not medically treatable, the next step is to discover what is causing the problem. Possible causes include that the person with dementia does not recognise when they need to go to the toilet, that they forget where the toilet is, signage on the toilet is confusing or that their medication is affecting bowel movements. Depending on the cause, the following strategies may help manage incontinence

Strategies for people with dementia:

- Ensure clothes are easy to remove. Pants with a drawstring may be difficult to undo.
- Leave the toilet/bathroom light on at night.

Strategies for carers:

- Place signs around the house directing to the toilet and on the toilet door.
- Take note of when incontinence occurs and schedule toileting according to any regular patterns.
- Always toilet the person with dementia prior to going out and upon your return. This will assist in avoiding toilet stops or accidents when on outings.
- If the person with dementia requires continence products, ensure that the pad is the appropriate size and absorption level for the individual. It is also important to change the pad regularly to prevent infection or skin rash. Also consider purchasing the pads from direct suppliers.
- Consider purchasing a wet/dry vacuum cleaner which can be effective in cleaning up messes associated with incontinence.

For help with personal care, contact the National Dementia Helpline on 1800 100 500, or the National Continence Helpline on 1800 33 00 66.

For further information on personal care, including nutrition, sleeping and dressing, see the Alzheimer's Australia Help sheet series *Caring for someone with dementia* available at <https://fightdementia.org.au/about-dementia-and-memory-loss/help-sheets>.

For information on incontinence visit <http://www.continence.org.au/index.php>.

6. DEMENTIA-FRIENDLY ENVIRONMENTS

The environment in which a person with dementia lives can have a significant impact on their independence, quality of life and wellbeing. A well-designed garden or an interior planned with consideration to cognitive impairment can provide essential prompts, improve accessibility and reduce risks for a person with dementia. The Dementia Enabling Environment Project has developed practical tips, guides and resources to help make living spaces more dementia enabling. It contains ideas for simple modifications that anybody can make to their home, to landscaping and architectural designs for dementia-friendly environments.

Examples of simple modifications that can be made to the home include removing rugs, chairs or clutter that may obstruct walkways, installing grab rails, reducing sharp-edged furniture and ensuring items and furniture have contrasting colours so that they are easily seen. Mirrors can be particularly confusing and frightening for people with dementia, therefore covering mirrors with a blind may also be helpful in creating a more friendly home environment for the person with dementia.

To find out more please visit the Dementia Enabling Environment Project website: <http://www.enablingenvironments.com.au/>.

7. EMPLOYMENT

Many people with younger onset dementia are employed at the time of their diagnosis, and have financial responsibilities such as supporting a family or paying a mortgage. Deciding whether to continue employment and whether to tell an employer about a younger onset dementia diagnosis is very complex and there are no rules that will work for everyone. Factors that may affect a person's decision include safety and duty of care, the extent to which symptoms affect the person's ability to do their job, the pace at which symptoms are progressing, and the support that is required of (or likely to be offered by) employers.

Staying at work

Employers are legally obligated to make "reasonable adjustments" to allow a person with a disability to do their work, so long as those adjustments do not cause major difficulties or costs to the employer (and cognitive impairment associated with dementia falls under disability legislation).

Suggestions for people with dementia:

- If your work performance is affected by dementia, try to negotiate changes to the position description or the work environment to assist with performance.
- Closely self-monitor work and ask for regular supervision.
- In some professions you are required by law to report any illness that may affect your capacity to work to your registration board or regulatory body. This is to ensure your personal safety and the safety of the greater public. Talk to your employer about your rights and responsibilities.

For free information and assistance with a disability, contact Job Access on 1800 464 800 or visit <http://jobaccess.gov.au/>.

Receiving a diagnosis after leaving work

If a person with dementia has left the workforce due to their dementia symptoms prior to receiving a diagnosis, they may still be eligible for retrospective claims under their superannuation policy's disability insurance cover.

Strategies for people with dementia:

- Call your superannuation provider to check your eligibility for disability insurance cover.
- For assistance with making a claim, seek legal advice.

Leaving work after a dementia diagnosis

If a person with dementia decides to leave their job after receiving a dementia diagnosis, it is recommended that they seek a medical and neuropsychological assessment to confirm the progression of the dementia and its impact on work capacity. As this workforce departure is health related, an employee may be entitled, on the production of a medical certificate, to utilise sick leave. There may also be a disability component attached to the person's superannuation. People with dementia should seek advice from their Superannuation Fund regarding the application process for disability benefits.

Suggestions for people with dementia:

- Remember to claim unused sick leave.
- Check the waiting time for superannuation and disability claims before resigning.
- Seek financial and legal advice prior to resignation if possible. Ask for assistance from your financial advisor, lawyer and/or union representative. Talk to your employer if they are supportive.
- Know your legal rights and responsibilities.

For assistance with employee disability management and workplace rehabilitation contact CRS Australia on 1800 277 277 or visit <http://www.crsaustralia.gov.au/>.

For more information about employment and decision making see the Alzheimer's Australia Help sheet: Making Employment Decisions and can be accessed online at <https://fightdementia.org.au/support-and-services/i-have-dementia/employment-and-dementia>.

8. VOLUNTEERING

Many people with younger onset dementia who have ceased employment find that volunteering is a valuable alternative to paid work. Volunteering is a purposeful and often social activity that allows people to contribute to and remain engaged in society. Some examples of volunteer work undertaken by people with younger onset dementia in Australia include participating in buddy programs at various organisations and volunteering at the Botanical Gardens.

Strategies for people with dementia

- It may be possible to discuss remaining at your prior place of employment on a volunteer basis.

Strategies for carers.

- Have a discussion with the person with dementia about their areas of interest, hobbies and talents, it may be possible to arrange supported volunteer work in a field of their choosing. Focus on previous skills and interests, as well as being realistic about their current level of function.

To find out about volunteering opportunities that are available in your area, contact the National Dementia Helpline on 1800 100 500.

9. SOCIAL ENGAGEMENT AND RESPITE

People with younger onset dementia, like all people, need social and community engagement opportunities in order to maintain well-being. Participation in such activities can increase a person's sense of identity, belonging and purpose. For example, art and music groups allow people with dementia to enjoy a hobby/skill with others, while community volunteer programs allow people to contribute to society. Both of these examples can lead to improved self-esteem and social interaction, including the formation of new friendships. Local councils and churches often provide community engagement activities such as social events and organised outings. These activities are sometimes unofficial so it may be beneficial to ask local councils or churches directly about the social opportunities they provide and whether they would be suitable for the person with dementia.

Respite and day care centres have the potential to provide social engagement opportunities in a safe and enjoyable way; however, many respite centres in Australia do not offer age-appropriate activities for people with younger onset dementia. In order for the experience to be optimal for the person with dementia, activities should be meaningful and reflect the individual skills, likes and dislikes of the person.

There is a need for more younger onset dementia-specific respite centres in Australia, which provide suitable, stimulating activities for people with younger onset dementia. Consumers at the Alzheimer's Australia 2013 Younger Onset Dementia Summit identified and reported the need for increased opportunity for social participation by individuals with younger onset dementia in their local community. People with younger onset dementia at the summit explained that regular social engagement allows them to contribute and feel a part of the community, and is an overall rewarding experience.

10. DRIVING AND THE LAW

A diagnosis of dementia does not necessarily preclude someone from driving in the early stages of the dementia. However, it will bring forward the time when a driver needs to carefully consider their driving ability, limit the conditions in which they drive and eventually retire from driving. This can cause the person considerable distress as driving is strongly associated with independence and autonomy and will also result in substantial changes to the person's daily routine.

This can also impact on the person's family members as they adjust their roles and routines to accommodate the person's diagnosis of dementia and consequent possible cessation from driving.

Frequently, it is family members that first notice changes in the driving skills of the person with dementia, but many find it difficult to broach such a sensitive topic. In some cases, the person with dementia may be unaware of these problems but even those who do realise that their driving skills are deteriorating may be reluctant to report this in fear of losing their driving licence.

Warning signs that dementia may be affecting a person's driving skills include³:

- forgetting how to get to and from familiar places
- getting lost or losing the car
- failing to observe traffic signs
- making slow or poor decisions in traffic
- slow reaction times
- driving at an inappropriate speed
- misjudging speed, distance or turns
- becoming angry, stressed, agitated or confused while driving
- hitting curbs
- poor lane control
- making errors at intersections
- confusing the brake and accelerator pedals
- returning from a routine drive later than usual
- an increased number of dents and scratches on the car.

Reporting to the Driver Licensing Authority

Legislation is in place in all states and territories that requires a driver to advise their driver licensing authority of any long-term or permanent injury or illness that may affect their safe driving ability.

There are legal and financial consequences for drivers who fail to notify their driver licensing authority (these vary between states and territories). Drivers may also be held legally accountable if they continue to drive knowing they have a health condition that impacts their ability to drive safely. Refer to Table 4 to see state and territory differences in reporting.

Suggestions for people with dementia:

- Advise driver licensing authority that you have dementia as soon as possible.

Similarly, legislation is in place in each state and territory for health professionals in relation to reporting any ongoing medical conditions to the driver licensing authority. The Australian Capital Territory, New South Wales, Queensland, Tasmania, Victoria and Western Australia statute states that health professionals who make such reports to the relevant driver licensing authority, without a patient's consent but in good faith that the patient is unfit to drive, are protected from civil and criminal liability. South Australia and the Northern Territory have legislation in place which imposes mandatory reporting. A positive duty is imposed on health professionals to notify the relevant driver licensing authority in writing of a belief that a driver is physically or mentally unfit to drive safely.

Conditional Driver Licence

A diagnosis of dementia will mean that the person is no longer deemed fit to hold an unconditional driver licence and will be issued a conditional licence. This provides the driver with an alternative to licence withdrawal and enables individual case-based decision making. A conditional licence is subject to a minimum annual review by a health professional which may increase in frequency as the dementia progresses. This may also result in the application of specific restrictions to the conditional licence (for example, the need for medical treatments, vehicle modifications and/or driving restrictions such as a fixed driving radius from home or only driving during daylight hours).

In addition to the minimum annual review with a health professional, there may also be instances where the driver is required to undertake a practical driver assessment in order to determine their ability to drive safely.

Practical driving assessments

If necessary, the driver may be required to undertake a practical driving assessment in order to determine their fitness to drive. Practical driving assessments can be initiated by the examining health professional, other referrers (for example police, self, family) or by the driver licensing authority.

Suggestions for carers:

- If there is concern that it may be unsafe for the person with dementia to drive, you can refer them to undertake a practical driving assessment.

A range of practical driving assessments is available including off-road, on-road and driving simulator assessments, each subject to its own strengths and limitations. Assessments may be conducted by an Occupational Therapist who is trained in driving assessments or by others approved by the relevant driver licensing authority. The costs associated with practical driving assessments are paid by the driver.

To find out more about assessing fitness to drive, visit: <http://www.austroads.com.au/drivers-vehicles/assessing-fitness-to-drive>

Alternative transport options

Considering alternatives to driving when a diagnosis of dementia has been received is important to ensure that informed choices can be made and plans can be put in place.

Suggestions for people with dementia:

- Consider alternative modes of transport to driving. For example:
 - Lifts from family, friends or neighbours
 - Public transport, such as a train or bus
 - Taxis

Depending on the state or territory, people with dementia may be eligible for discounted taxi fares through a taxi subsidy scheme. To find out eligibility requirements and how to apply, visit your state or territory government website. See Table 5 for the relevant government websites.

Language difficulties and driving

Sometimes there are no changes in driving abilities, but the individual may feel concerned about his or her ability due to language difficulties. These difficulties are generally worsened by stress.

Suggestions for people with dementia:

- Carry a letter explaining the nature of the language difficulties to help others understand the situation.
- Wear a necklace or bracelet that lists your address and emergency contact numbers.

For more information about driving and dementia, visit the Driving and Dementia section on the Alzheimer's Australia website at <http://www.fightdementia.org.au/research-publications/driving-and-dementia.aspx>

Visit www.commcarelink.health.gov.au to find out more about which community, disability or other support services are available for driving.

3. 'Staying on the move with dementia' (2014). NRMA/Alzheimer's Australia NSW E-Publication <http://www.mynrma.com.au>

TABLE 4. STATE COMPARISONS: REPORTING TO LICENSING AUTHORITIES

| State | Mandatory reporting for health professional | Time frame within which a person must report an injury or illness to the driver authority |
|-------|---------------------------------------------|----------------------------------------------------------------------------------------------------|
| NSW | No | As soon as practicably possible |
| QLD | No | As soon as the condition develops or if there is a long term increase to the condition |
| VIC | No | As soon as practicably possible |
| NT | Yes | No time frame specified, but individuals must notify the authority |
| SA | Yes | A reasonable time frame after the occurrence of an injury or illness. Must be reported in writing. |
| WA | No | As soon as practicably possible |
| ACT | No | As soon as practicably possible |
| TAS | No | As soon as practicably possible |

TABLE 5. TAXI SUBSIDY SCHEMES

| State | Website |
|-------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| NSW | http://www.transport.nsw.gov.au/ttss |
| QLD | http://www.qld.gov.au/disability/out-and-about/taxi-subsidy/ |
| VIC | http://www.taxi.vic.gov.au/passengers/mptp |
| NT | http://www.transport.nt.gov.au/taxi/taxi-subsidy-scheme |
| SA | https://www.sa.gov.au/topics/transport-travel-and-motoring/public-transport-and-travel/getting-around-with-a-disability/taxi-fare-subsidy-scheme |
| WA | http://www.transport.wa.gov.au/taxis/15155.asp |
| ACT | http://www.assistance.act.gov.au/adult/transport_and_registration/taxi_subsidy_scheme |
| TAS | http://www.transport.tas.gov.au/concession_information_and_forms |

10. MEDICAL TREATMENT OF DEMENTIA

At present, there are no medications that can cure younger onset dementia, although there are a number of medications that may help people to manage their symptoms and slow the progression of the condition.

Treatments for Alzheimer's disease

Acetylcholinesterase inhibitors target the main neurochemical abnormality in Alzheimer's disease, that is the reduction in acetylcholine neurotransmission. They are also useful in treating Dementia with Lewy bodies, which shares this deficit.

Three acetylcholinesterase inhibitors are currently available. They are Galantamine (Reminyl), Donepezil (Aricept) and Rivastigmine (Exelon). All three drugs primarily work by reducing the breakdown of naturally occurring acetylcholine in the brain. They do this by inhibiting the enzyme that is responsible for its breakdown and recycling.

Studies have shown that while these treatments do not work for everyone, a significant proportion of people experience an improvement in various aspects of cognition, for a period of time, perhaps over a year. For some individuals there may be striking improvements so a trial of treatment with at least one of these agents is worthwhile.

As with all medications an individual may experience adverse effects and there are contraindications (reasons for not prescribing the medication). Common adverse effects include, gastrointestinal upset, with nausea or loose stools, dizziness and sleep disturbance. But these are often mild and settle quickly or can be managed by increasing doses more slowly or by adding treatment to counteract the adverse effects. Significant cardiac or respiratory problems may be a relative contraindication to trying these medications.

In addition to drugs which act on the acetylcholine system, Memantine (Ebixa) acts on an important receptor in the brain, the NMDA receptor, and is thought to have a neuroprotective effect. Again studies have shown improvements in areas of cognition and function. This agent is licensed for moderate to severe Alzheimer's disease. Common adverse effects are visual problems, gastrointestinal disturbance and agitation. Sometimes an acetylcholinesterase inhibitor is combined with Memantine with good clinical effect.

Other non-prescribed agents that are used include Gingko Biloba, Vitamin E and Folic acid, but the clinical evidence from trials to support their use is weak.

Pharmacological treatment of behavioural and psychological symptoms of dementia (BPSD)

Behavioural and psychological symptoms of dementia may occur at any point during the course of dementia. These symptoms include depression, anxiety, irritability, agitation, aggression or psychotic symptoms such as hallucinations or delusion (abnormal beliefs). They may be relatively short-lived or mild but may, on occasion, be severe and/or persistent and cause distress to the individual or their carer.

Before any pharmacological treatment is considered it is important to make a thorough assessment of the concerning symptom or behaviour. This assessment should consist of a physical review to exclude new medical problems as a potential cause of the symptoms. For example constipation or pain may cause irritability or aggression, and an unidentified infection, such as a urinary tract infection, can be a cause of a superimposed delirium or confusional state resulting in delusions or visual hallucinations. A repeat brain scan may be requested if there is a sudden deterioration in cognition. If there is no apparent physical cause for the change in mental state or behaviour, then environmental triggers need to be considered.

Tensions in the relationship between the carer and the person with dementia, or changes to the care staff if the person is in a nursing home, may trigger anxiety or depressive symptoms. In the early stages of dementia, soon after diagnosis, an individual may experience considerable emotional distress that, if sufficiently severe, may need to be considered for pharmacological therapy if general support, education or counselling is insufficient.

Antidepressants

At any stage of dementia, antidepressant medication may be considered for an individual who has depression or anxiety. They may also be considered if the individual has become irritable or aggressive as this can sometimes be due to underlying depression or anxiety. There are a number of antidepressants that may be tried and the choice of agent used is often dominated by the possible side-effect profile of the medication.

Antipsychotic medication

Antipsychotics are occasionally used when an individual has developed psychotic symptoms, for example hallucinations, delusions or severe agitation. Examples of such agents include Risperidone, Olanzapine and Quetiapine. There is concern about the use of these agents for a number of reasons. The use of antipsychotics is particularly problematic in people with dementia with Lewy bodies and other Parkinsonian dementias as they can cause significant, and sometimes irreversible, deterioration. In other dementias there is concern that they may hasten deterioration. Despite these concerns if the behavioural symptoms are severe and causing the individual distress or preventing them from receiving the necessary care, then it may be appropriate to undertake a cautious trial.

The risk/benefits should be discussed with the person with dementia (when possible) and the carer or guardian. Arrangements for review of their effectiveness should be made.

Other medications

Other medications may be used to try and treat BPSD. These include mood stabilisers and anti-anxiety medications. See Table 6 for a comprehensive list of medications commonly used in dementia care.

By minimising distress and agitation it may be possible to avoid the use of drugs for the treatment of challenging behavioural symptoms.

TABLE 6.

MEDICATIONS USED IN YOUNGER ONSET DEMENTIA

Taking medications

If medications are being used, remember:

- Always ask the prescribing doctor why the drug is being prescribed, what the side effects may be and what you should do if they occur.
- All drugs have side-effects. It is important to weigh the benefits against the likelihood of side-effects when considering the use of drug treatments.
- Side-effects are usually related to the dose given, for example higher doses are usually associated with a greater risk of side-effects. For some medications the doctor will usually 'start low and go slow', gradually increasing the dose until the desired effects are achieved.
- Don't assume that a drug that has proved to be useful once will continue to be effective. Dementia is a degenerative condition. The chemistry and structure of the brain will change during the course of the illness.
- Remind the GP if other medications are being taken. Certain combinations of drugs may counteract each other or increase cognitive impairment.
- If a drug is prescribed, check with the doctor that there is a clear plan to review the medication. Do not expect immediate results. Benefits may take several weeks to appear.
- Once treatment has been established it is important that it is reviewed regularly.
- Keep an up-to-date medicines list that contains the name of each medication, dosage instructions and the date the medicine was started as well as the review date. Take this list to clinical and hospital appointments.

- Remember that some of the drugs taken to control behavioural symptoms can be dangerous if accidentally taken in large quantities. Make sure medicines are kept safe and secure.

If symptoms are difficult to control, the GP may refer to a specialist for further advice.

Any adverse reactions to medicines should be reported to the Adverse Medicine Events Line: 1300 134 237

For more information on medications used to treat dementia visit <http://www.fightdementia.org.au/understanding-dementia/drugs-used-to-relieve-behavioural--psychological-symptoms-of-dementia.aspx>.

or read Quality Dementia Care 4: Understanding younger onset dementia http://www.fightdementia.org.au/common/files/NAT/20130808_QDC4.pdf.

For more information on any prescription, over the counter or complimentary medicines call 1300 MEDICINE (1300 633 424) or visit <http://www.nps.org.au/>.

| Medication purpose | Medication type | Examples of drugs |
|------------------------------------------------------------------------------------|---------------------------------|-------------------------------------------------------------------------------------------------------------------|
| To delay the progression of Alzheimer's disease and other types of dementia | Acetylcholinesterase inhibitors | Donepezil (Aricept) Rivastigmine (Exelon) Galantamine (Reminyl) |
| | NMDA antagonists | Memantine (Ebixa) |
| To treat behavioural and psychological symptoms of dementia | Antidepressant medications | Sertraline Paroxetine Venlafaxine Citalopram Escitalopram Mirtazapine Fluvoxamine Fluoxetine |
| | Mood stabilising agents | Valproate Lithium Carbamazepine |
| | Antianxiety agents | Diazepam Oxazepam Lorazepam Temazepam Clonazepam |
| | Antipsychotic medication | Risperidone Olanzapine Quetiapine Haloperidol |

B.

PLANNING FOR FUTURE CARE OF THE PERSON WITH DEMENTIA

II. ALZHEIMER'S AUSTRALIA PROGRAMS AND SUPPORT

Alzheimer's Australia delivers a multitude of services and supports to people with younger onset dementia, their families and carers. These include counselling, information and advice and facilitation of support groups. Below is a list of some of the services, activities and resources available through Alzheimer's Australia.

For further information on specific services, visit the website at <https://fightdementia.org.au> and choose your state or territory or call the National Dementia Helpline on 1800 100 500.

The Younger Onset Dementia Key Worker Program

The Younger Onset Dementia Key Worker Program provides individualised information and support to improve the quality of life for people with younger onset dementia. The key worker acts as a primary point of contact for the person with younger onset dementia, their families and carers. They provide information, support, counselling and advice and help the person with dementia, their carer and family effectively engage with services appropriate to their individual needs. The principle underpinning the key worker model of service delivery is consumer-directed care. The Younger Onset Dementia Key Worker Program is funded by the Australian Government.

The National Dementia Helpline: 1800 100 500.

The National Dementia Helpline is a free and confidential telephone information and support service available across Australia. The helpline is staffed by trained professionals, ensuring callers receive accurate, local information and advice. The helpline may be accessed for general enquiries, counselling, requests for resources or referral to Alzheimer's Australia and other dementia programs. The National Dementia Helpline is funded by the Australian Government.

Living With...

The "Living With Memory Loss", "Living with Younger Onset Dementia" and other "Living With..." programs are early intervention programs designed for people with early stage dementia, their family members and friends. The programs deliver education on dementia including symptoms, practical strategies and early planning. They allow participants to ask questions, receive advice and establish a peer support network. The "Living With..." programs are funded by the Australian Government.

The HOPE Newsletter

HOPE Newsletter is written for people with younger onset dementia, their carers, family and friends, health professionals, care staff and everybody with an interest in younger onset dementia.

HOPE stands for Helping Other Possibilities to Emerge and can be accessed online at: <http://www.fightdementia.org.au/research-publications/hope-newsletter.aspx>.

The Alzheimer's Australia Younger Onset Dementia Forum

The Younger Onset Dementia Forum provides a place where younger people with dementia, their families, carers and friends can gather and share information. It provides a place to share stories, connect with others in a similar situation, ask questions and share information. The forum was made possible by The Wood Family Foundation

The Younger Onset Dementia Forum can be accessed via <http://www.talkdementia.org.au/>.

I. ADVANCE CARE PLANNING

An advance care plan is a document prepared by an individual, while they have capacity, which identifies their end of life care wishes. It can be difficult to determine the end of life wishes of someone with dementia, as they are likely to lack the ability to express their wishes or make medical and care decisions. Doctors have a legal obligation to make medical decisions that are in the person's best interest. If the person has lost ability to make and communicate their preference for these decisions it is important for the doctor to be able to refer to an advance care plan. These plans help doctors determine what the person would have chosen if they still had capacity. For this reason it is important for people with dementia to be encouraged and supported to discuss and record their end of life care wishes and prepare an advance care plan.

Advance care plans are prepared by a person while they have legal capacity that states their preference about health and personal care. It is important for advance care plans to name the preferred decision maker when the person has lost capacity to make decisions.

Terminology of advance care plans is different in each state and territory and can include the following:

- Health Direction
- Common Law Advance Directives
- Advance Directive
- Advance Health Directive
- Living Will
- Refusal of Treatment Certificate.

Some people may find it helpful to have a family member or close friend help them complete an advance care plan. Doctors and other healthcare

professionals can also provide information and discuss the various decisions that may arise for people with dementia at end of life. Types of end of life care decisions can include:

- venue of care
- reasons that would necessitate a transfer to hospital
- refusal or withdrawal of medical treatment
- refusal of food or fluids
- 'not-for-resuscitation' order.

A doctor can sign the advance care plan to make it more certain that other doctors and health professionals will follow the person's wishes in the future. However, these plans can be changed and require regular review by the family and the person to respond to changes in wishes and needs as the dementia progresses. An up-to-date copy of the advance care plan needs to be provided to the person's regular GP and carer.

For more information on advance care planning, and to view lectures by Professor Julian Hughes and Colleen Cartwright about end of life care for people with dementia, please visit: <http://www.fightdementia.org.au/services/advance-care-planning-1.aspx>.

TABLE 7.

LEGAL AUTHORITIES AND USEFUL WEBSITES FOR LEGAL INFORMATION

2. LEGAL ISSUES

A diagnosis of younger onset dementia does not necessarily mean that a person is unable to make decisions, however there will come a time when impairments in memory, language, thinking, and judgment affect their decision making capacity. It is therefore important that a person with younger onset dementia establishes an up-to-date Will and appropriate Enduring Powers of Attorney and Guardianship (i.e. appointment of another person(s) to make decisions on their behalf if required). The progressive nature of dementia makes it important that these documents are prepared early while the capacity of the person with younger onset dementia to make decisions is not in question. Early planning and documentation of a person's wishes enables them to make choices about their own future and helps to reduce the risk of serious financial, medical, and lifestyle implications for themselves, their families, and their employers.

Some of the major issues that need to be considered are:

- financial management
- business/workplace affairs
- decisions regarding medical treatment
- property management
- making a Will
- guardianship.

Powers of Attorney may be covered by one document or several different documents depending on the state or territory laws. Each state and territory has a tribunal and/or court that reviews and regulates the conduct of Powers of Attorney.

To begin the process of managing legal issues, contact the National Dementia Helpline: 1800 100 500. If anyone has concerns regarding the decision-making capability of a person with dementia, or the behaviour and responsibilities of a substitute decision-maker, the appropriate state or territory legal authority should be contacted. Table 7 provides further information about the legal authorities in each state and territory and useful websites on legal processes.

Further information on legal planning is provided in the **Alzheimer's Australia Position Paper 5, Legal Planning and Dementia** which can be accessed on the website at: http://www.fightdementia.org.au/common/files/NAT/20050400_Nat_NP_5LegPlanDem.pdf.

The **Alzheimer's Australia Helpsheet, Early Planning** provides information on who can help with various legal issues and can be accessed online at: https://fightdementia.org.au/sites/default/files/helpsheets/Helpsheet-InformationForPeopleWithDementia02-EarlyPlanning_english.pdf.

| State | Authority | Useful websites |
|-------|---------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| NSW | NSW Civil and Administrative Tribunal | http://www.ncat.nsw.gov.au |
| QLD | Civil and Administrative Tribunal | http://www.justice.qld.gov.au/justice-services/guardianship |
| VIC | Victorian Civil and Administrative Tribunal | http://www.publicadvocate.vic.gov.au/powers-of-attorney/ or http://www.vcat.vic.gov.au/ |
| NT | Local Court (Guardianship) and Supreme Court (Finances) | http://www.nt.gov.au/justice/bdm/land_title_office/power.shtml |
| SA | Guardianship Board | http://www.guardianshipboard.sa.gov.au/ |
| WA | State Administrative Tribunal | http://www.sat.justice.wa.gov.au/G/guardianship_and_administration.aspx or http://www.dotag.wa.gov.au/ |
| ACT | Guardianship and Management of Property Tribunal | http://www.acat.act.gov.au/guardianship/guardianship_management_of_property or http://www.publicadvocate.act.gov.au/ |
| TAS | Guardianship and Administration Board | http://www.guardianship.tas.gov.au/home or http://www.publicguardian.tas.gov.au/ |

*These Authorities and websites were accurate at the time of publication but may change

Why appoint an Enduring Power of Attorney and Enduring Guardian?

By planning ahead and appointing an Enduring Power of Attorney and Guardian soon after diagnosis, a person with younger onset dementia can make sure that the individual selected to make decisions on their behalf is a trusted friend or family member who understands their personal priorities and wishes.

If a person does not make legal arrangements to appoint another person to make decisions on their behalf once they lose capacity, the relevant state or territory government body may need to appoint a family member, friend, or official body (such as the Public Advocate) to make decisions.

What powers does the appointed person have?

Powers, and the documents that cover powers, differ depending on the state or territory. However there are generally three types of powers:

Financial:

A person(s) appointed to make financial, property and legal decisions. This may include accessing the person with dementia's bank accounts to pay their bills, lodging their tax returns or selling the person's house to pay for residential care. In some states, the person may be fined if he or she doesn't keep proper records or look after the financial responsibilities carefully.

Medical:

A person(s) appointed to make decisions about medical treatment. If a person with younger onset dementia no longer has legal capacity to make medical decisions but has not appointed a medical power of attorney/ guardian, some states and territories allow family members or doctors to make medical decisions on the person's behalf. It is recommended that people with dementia and their carers discuss what

laws apply in their state or territory with their doctor and lawyer.

Lifestyle:

A person(s) appointed to make personal or lifestyle decisions. The type of decisions can be specified but they are usually about practical issues that affect daily life.

How to make an Enduring Power of Attorney and Enduring Guardian

The requirements of making an official, registered Enduring Power of Attorney and Guardian are different in each state and territory.

Further information can be found at the websites listed in Table 7 or by calling the National Dementia Helpline on 1800 100 500.

How to change an Enduring Power of Attorney and Enduring Guardian

A person can revoke or change an Enduring Power of Attorney if they have legal decision-making capacity. If the person with Powers of Attorney is no longer able to act as decision-making substitute, or if there are any concerns regarding the care or safety of a person with dementia, the relevant state or territory court or tribunal should be contacted. If deemed necessary, powers will be appointed to a different person if they think that is in the best interests of the person with dementia.

Wills

A Will lets a person choose and document what happens to their belongings and property after death. It may also document arrangements for the care of dependent children or pets.

It is important for a person to make a Will in the early stages of dementia to ensure their legal capacity to make decisions is not in question and ensure that the Will is valid. To avoid future challenges to their Will, a person with younger

onset dementia should seek medical verification of their decision-making capacity from a medical professional. A lawyer or state or territory Public Advocate should also be consulted prior to writing the document. Free advice on Wills and other legal issues can be sought from Legal Aid or a local Chamber Magistrate.

Further information, assistance and advice on legal issues, Enduring Power of Attorney and Wills can be obtained from:

- lawyers and solicitors
- Legal Aid. Information and links to state and territory Legal Aid offices can be found at: <http://www.nationallegalaid.org/>
- Chamber Magistrate
- National Dementia Helpline 1800 100 500.

3. FINANCIAL ISSUES: WHERE TO GO FOR ADVICE AND HELP

A diagnosis of younger onset dementia during a person's working years may impact greatly on financial plans. Financial advice and assistance may be obtained from:

- financial advisors
- financial counsellors
- accountants
- superannuation companies
- lawyers
- workplace unions. For financial advice regarding leaving the workforce and making claims, contact your union representative.

Information on financial counsellors and service locations can be found at: <http://www.financialcounsellingaustralia.org.au/Corporate/Financial-Counselling>.

4. PAYMENTS FOR PEOPLE WITH DEMENTIA

People with younger onset dementia may be eligible for either the Disability Support Payment or the Age Pension. Both pensions have residency requirements, and payment rates depend on the circumstances of the individual and their spouse.

The Disability Support Pension: The Disability Support Pension (DSP) provides financial support to people who have a physical, intellectual or psychiatric condition that stops them from working. To receive the DSP, the person with dementia must be under the Age Pension age (explained below), even if they have a diagnosis or symptoms of younger onset dementia. To be eligible for the DSP, the person with dementia must also be assessed as having a severe impairment (this requires a diagnosis of dementia and a severe impact of the dementia on activities of daily living) OR the person with dementia must be unable to work more than 15 hours per week within the next two years and have actively participated in a program of support. The DSP is income and assets tested.

For further information on the Disability Support Pension, contact Centrelink on 132 717 or visit www.dss.gov.au/our-responsibilities/disability-and-carers/benefits-payments.

The Age Pension:

The Age Pension provides financial support to older Australians. The age of eligibility for the Age Pension is currently 65 years for men and women (as at Jan 2015), however the age of eligibility will be gradually increased from 65 to reach 67 years of age by 2023. The Age Pension is income and assets tested.

For further information on the Age Pension, contact Centrelink on 132 717 or visit <http://www.dss.gov.au/our-responsibilities/seniors/benefits-payments/age-pension>.

5. PAYMENTS FOR CARERS

There are two types of payments available from Centrelink for carers of people with younger onset dementia.

The carer payment: The carer payment provides income support for people who are unable to work in substantial paid employment because they provide full-time daily care to a person with a severe disability, such as younger onset dementia, or someone who is frail and aged. The person receiving care must be a pensioner or part pensioner. The amount of financial support a carer is eligible to receive is dependent on an income and assets test.

The carer allowance: The carer allowance provides supplementary payments to carers who provide daily care and attention to a person with a disability (younger onset dementia) or severe medical condition, as long as the care provided is done so in either their own home or the home of the person they are caring for. There is no income or assets test associated with the carer allowance, however the care provided must amount to at least 20 hours per week.

For further information on carer payments, contact Centrelink on 132 717 or visit the website: www.dss.gov.au/our-responsibilities/disability-and-carers/benefits-payments.

6. NATIONAL DISABILITY INSURANCE SCHEME

The National Disability Insurance Scheme (NDIS), formerly known as DisabilityCare Australia, is the new planning and service system that assists Australians with a disability. People with younger onset dementia may be eligible for support through the NDIS if they are under the age of 65, live in a NDIS launch site and their dementia affects their functional capacity. If someone with younger onset dementia living in a launch site does not meet functional impairment access requirements, the NDIS may be able to provide the person with information about other supports that could be beneficial. It is planned for the NDIS to be fully rolled out across Australia by 2020. My Access Checker can be used to provide an idea of whether someone with younger onset dementia lives in a current launch site and can access support through the NDIS.

My Access Checker:
<http://www.disabilitycareaustralia.gov.au/my-access-checker>.

Participants of the NDIS undergo a planning process to outline their goals and identify reasonable and necessary supports to meet their needs and achieve their goals. The NDIS then provides funding to the participant to access the agreed reasonable and necessary supports. The outcome of the plan and supports are monitored, and if circumstances change, such as a steep decline in cognitive function, the plan can be reviewed and supports changed as required. The funding and implementation of the plan can be managed by the participant themselves with as much assistance as they would like or need from the NDIS, another service intermediary or nominee.

The NDIS is about people with disabilities having choice and control over the supports they receive. There may be a time when a person with dementia may lack the ability to make decisions and therefore, a nominee may need to be appointed to assist the person with dementia in making decisions or to act on their behalf. Nominees have a duty to determine the wishes of a participant and to act in a way that promotes the participant's personal and social wellbeing.

Once a participant of the NDIS turns 65, they can choose to continue to receive services through the NDIS or transfer to the Aged Care system. However, if a participant receives community care packages or enters residential care permanently, after the age of 65, the person will cease to be a NDIS participant.

For more information about the NDIS, call 1800 800 110 or visit the website: <http://www.ndis.gov.au/>.

7. PRACTICAL SUPPORTS IN THE HOME

A variety of supports are available within the community to enable a person with dementia and their carer to maintain quality of life at home for as long as possible. Supports within the community include; assistance with personal care, domestic duties, shopping, clinical care, transport, outings, home respite and accompanying people to appointments. As supports for people under the age of 65 are funded by state or territory government

disability services, the names of the support programs vary. However, Commonwealth Respite and Carelink Centres are national resource centres that are able to provide contacts to local services.

To contact the Commonwealth Respite and Carelink Centres, phone 1800 052 222, or visit www.commcarelink.health.gov.au to find out more about support services available in your local community.

Alternatively, disability services may be contacted directly. The contact details of different state and territory disability services can be found in Table 8.

If a person with younger onset dementia is unable to receive appropriate support (in terms of type, model or intensity of care) through the state or territory disability services or through the NDIS, they may be able to receive support through Home Care Packages.

Aged Care Assessment Team (ACAT)

An Aged Care Assessment Team (ACAT) or Aged Care Assessment Service (ACAS) will need to assess the needs of the person with younger onset dementia before they are able to obtain a Home Care Package or become a resident at an aged care facility. An ACAT usually involves a doctor, nurse, social worker and/or other health professionals who will help work out which services the person with dementia needs, and assesses whether they are eligible to receive certain services. However, before an ACAT can assess the person with younger onset dementia, they may require the person to be assessed for disability services to ensure that there are no equivalent supports that could be provided through disability services. The contact details of different state and territory disability services can be found in Table 8.

For more information on ACATs, visit: <http://www.myagedcare.gov.au/eligibility-and-assessment/acat-assessments>.

To organise a visit with an ACAT, call MyAgedCare on 1800 200 422.

or visit: <http://www.myagedcare.gov.au/service-finders#block-finder-assessment-finder-assessment>.

Home Care Packages

A range of services that provide home and community supports, as well as supports for personal and clinical care can be included in a Home Care Package. People with dementia are eligible for the Dementia and Cognition Supplement in Home Care Packages, which provides additional financial assistance to service providers. This supplement was developed in recognition of the additional costs associated with caring for people with dementia and mental health conditions.

There are four types of Home Care Packages available:

- Level 1: supports people with basic care needs
- Level 2: supports people with low-level care needs (equivalent to the former Community Aged Care Packages)
- Level 3: supports people with intermediate care needs
- Level 4: supports people with high-level care needs (equivalent to the former Extended Aged Care at Home and Extended Aged Care at Home Dementia packages).

Some Home Care Packages currently operate on a consumer directed care basis, and from July 2015, all Home Care Packages will be delivered on this basis. Consumer directed care gives the person with dementia and their carer more control and choice about the types of care and services they receive, how care is delivered and who delivers it. The level as to which the person with dementia or their carer wants to be involved in managing their package is determined by them. A personalised budget will be provided through the consumer directed home care package so the amount of funding available for services can be observed and managed.

For more information on Home Care Packages, visit: <http://www.myagedcare.gov.au/home-care-packages>.

TABLE 8.

DISABILITY SERVICES CONTACT NUMBERS

| State | Name | Phone |
|-------|----------------------------------------------------|--------------|
| VIC | Disability Services (State wide) | 1800 783 783 |
| NSW | Home Care Service Referral and Assessment Centres: | |
| | Sydney Metropolitan | 1800 350 792 |
| | Hunter and Central Coast | 1300 731 556 |
| | Rural areas | 1300 881 144 |
| | Aboriginal Access and Assessment Team | 1300 797 606 |
| NT | Office of Disability Access Point | 1800 139 656 |
| SA | Disability Information Service | 1300 786 117 |
| ACT | Guardianship Board | 02 6207 1086 |
| QLD | Community Access Point | 1800 600 300 |
| WA | Local Area Coordination Program | 1800 998 214 |
| | Disability Services Commission General Enquiries | 9426 9200 |
| TAS | Gateway Services | 1800 171 233 |

8. RESIDENTIAL CARE

There may come a time when permanent care needs to be considered for the person with dementia. Placement in permanent care typically occurs when there are substantial problems with self-care and mobility or challenging behaviours, which can no longer be managed in the person's home. The person with dementia or their carer may want to discuss this with family and health professionals. The decision about when it is appropriate to place the person with dementia into a residential facility is a personal one and can be stressful, challenging and emotional. It depends on many factors, such as the carer's health, employment, impact on family members, availability of support networks, behavioural issues and functional abilities of the person with dementia.

Aged care facilities can provide both low and high level care. Low level residential care provides a supported environment with extra help in some everyday tasks such as cleaning, laundry and meals. Whereas, high level residential care provides assistance for most everyday activities, as well as care from registered nurses and care workers at all hours of the day.

To organise residence in a care facility it is necessary to obtain an assessment from an ACAT (or ACAS in Victoria). An ACAT should be able to provide information about aged care homes in the local area, explain the differences between the types of care available, and assess and approve the individual's eligibility for an aged care home.

For more information on ACATs, visit:
<http://www.myagedcare.gov.au/eligibility-and-assessment/acet-assessments>.

To organise a visit with an ACAT, call My Aged Care on 1800 200 422 or visit: <http://www.myagedcare.gov.au/service-finders#block-finder-assessment-finder-assessment>.

For more information on aged care homes or to find out which homes may be available you, call My Aged Care on 1800 200 422 or visit <http://www.myagedcare.gov.au/aged-care-homes> for general information and <http://www.myagedcare.gov.au/service-finders> to find a home.

Aged care homes primarily cater for older people, and given that people with younger onset dementia have different needs, it is widely accepted that such facilities are often inappropriate for younger people with dementia. The best way to find out if a place may suit the needs of the person with dementia is to visit the residential home. Visiting residential homes will help determine what to expect and provide an insight into what the accommodation is like, as well as which types of care, services and activities are on offer.

It is not compulsory for the person with dementia to become a resident when a room becomes available in a residential facility. It is important for the transfer into a residential facility to occur when the person with dementia, their carer and family are ready. ACAT approval for a residential facility remains valid unless a time restriction was applied. If the care needs or personal circumstances of the individual change then another assessment may be required.

Cost of Residential Aged Care

It is expected that the person with dementia will contribute to the cost of their care if they can afford to. The cost of aged care for an individual is determined by the level of care that they require (low or high), their income and assets and their pensioner status. There are 3 types of fees that a person may be asked to pay.

Everyone is required to pay a basic daily fee, which covers the costs of day-to-day expenses such as meals and heating. The Australian Government regulates maximum daily fees to ensure that aged care is affordable to everyone.

For more information on respite and residential care, visit the Alzheimer's Australia website:

<http://www.fightdementia.org.au/services/information--support-about-residential-care-issues.aspx> Or read **The most difficult decision: dementia and the move into residential aged care. Alzheimer's Australia, Discussion paper 5, October 2012.**

http://www.fightdementia.org.au/common/files/NSW/20121016-NSW-PUB-Moving_To_Res_Care.pdf Or visit **MyAgedCare:** www.myagedcare.gov.au or call: 1800 200 422.



CHANGING ROLES & RELATIONSHIPS

A diagnosis of younger onset dementia has a wide ranging impact not only on the person but also on their partner, children, extended family and social networks. Roles and relationships within and beyond the family will inevitably change. These role changes may elicit feelings of anxiety and uncertainty, and cause tension within the family.

It may have taken some time to get a diagnosis and this can cause considerable frustration and even changes to the way people think of the person with dementia. A diagnosis of dementia can come as a shock, particularly because dementia is usually associated with older people. In the initial stages – for both the person receiving the diagnosis and their family – shock, sadness, anger, disbelief or relief are common reactions.

To help cope with the emotional impact of the diagnosis, the individual and their family may consider taking time off work and spending quality time with loved ones. Talking about their experience and feelings with a doctor or counsellor may help.

Other people’s reactions to the changes they see in the person with dementia will vary and their ability to support and help will also vary. Every person is an individual with different coping mechanisms. Denial of the illness by both the person with dementia and family is common, especially in the early stages. Providing information about dementia to family and friends will help them to understand the disease and assist the person with dementia.

1. THE EXPERIENCE FOR THE PERSON WITH YOUNGER ONSET DEMENTIA

The experiences of people with younger onset dementia will be different from those of older people with dementia. At the time of diagnosis, most people with younger onset dementia will be productively engaged in work, family life and other community and social engagements. Their self-confidence and mastery may be at their peak, but

their dementia may eventually erode their self-confidence in mastery of expected roles.

Younger people with dementia may have greater awareness that something is wrong because they and others who depend on them have higher expectations of their abilities and capacities. Any changes in work and social roles of the younger person with dementia will have considerable effects on others.

Work is often a primary function and an important part of self-identity for people in the fourth and fifth decades of life. The work place may be the first place where cognitive deficits become apparent and publicly noticed. As well as the negative psychological consequences for the younger person with dementia, the progressive inability to perform usual job-related tasks may lead to premature loss of income and loss of retirement benefits.

Social isolation is a concern for people with dementia regardless of age, however for younger people it is likely to be compounded because of the perception of dementia as a condition of older age. As abilities decline and behavioural changes become apparent, friends and family may be discouraged from visiting, thereby further increasing social isolation. Additionally, there may be a lack of appropriate engaging activities beyond the home. The sense of abandonment may be profound. The younger person with dementia who has no partner or family may be in most need.

2. CHANGING FAMILY ROLES AND RELATIONSHIPS

Within the family unit, both the person with younger onset dementia and those who take on the primary caring role have to adjust to major shifts in their roles and in their relationship. Hopes, dreams and expectations regarding the future will inevitably need to be altered.

Partners may feel anger and sadness about the loss of the planned future together. They may feel guilty about negative feelings they have toward their partner as the cause of their lost career, income, social life, holidays and/or companionship.

For couples with children, the typical transition involving grown children leaving home and regeneration of the spousal relationship may be disrupted. Children may feel a responsibility to remain at home and may have already taken on a significant care-giving role. In single parent families, children may feel that they have no choice but to take on this role and remain at home.

Individuals with younger onset dementia are likely to become more dependent on others as their illness progresses. If they previously had primary responsibility for the caring and nurturing of the family, their inability to continue in this role may lead to feelings of helplessness and frustration. Role reversal where the children assume responsibility for their parent is common. The parent living with younger onset dementia may experience guilt, not only because of the role changes, but also because of fear and uncertainty associated with the possibility of their children developing an inherited form of dementia.

There will come a time when the person with younger onset dementia becomes unable to care for or provide income for the family. This can lead to financial difficulties within the family. Financial advice needs to be obtained early so decisions and plans can be made about the future. Please refer to Section B.3 Financial issues: where to go for advice and help.

Impact on children

Many people with younger onset dementia will have dependent children who may still be at school. Children are likely to have difficulty understanding the illness and adjusting to the change in roles

within the family. They may not understand the changes in behaviour of the person with dementia and may think that they are causing the behavioural problems. They may benefit from counselling to assist with many conflicting emotions, including fear, grief, frustration, and loss. A three-stage process model of adapting to dementia has been proposed, with children moving through grief to emotional detachment and increased maturity. It may be beneficial to advise the child’s school teacher or counsellor about the situation. There are books explaining dementia that have been written especially for children, and these may also be helpful. Books include:

- Why Did Grandma Put Her Underwear in the Refrigerator? An Explanation of Alzheimer’s disease for Children by Max Wallack and Carolyn Smith Given.
- Still My Grandma by Veronique Van Den Abeele.
- The Memory Box by Mary Bahr.

Alzheimer’s Australia has a collection of books and videos for loan that are specifically for children.

Children often experience their parents’ grief and loss and may feel shame about their parents’ behaviour, anxiety about stress in the parents’ relationship, loneliness because the healthy parent needs to devote added attention to the person with younger onset dementia, and worry about developing dementia themselves.

Partners of people with younger onset dementia may feel they are parenting both their children and their spouse and feel protective of both.

Families with adult children living with them may find the children a source of support. The prevalence of young people as primary carers may rise with the increasing number of single parent families. These young people need to be equipped with support services.

Impact on sexuality and relationships

Sexuality is the expression of sexual desires, instincts and activities, however it may also refer to a broad range of behaviours and attitudes, as well as feelings about oneself or others. Sexuality is an important part of self-image.

Younger onset dementia is likely to impact significantly on many aspects of sexuality for both the person with dementia and their partner. The strain on partner relationships may be intense and often require renegotiation of sexual roles, identity and intimacy within their relationship. The transition to roles of carer and care recipient may be difficult even for couples with very healthy relationships.

Sexual challenges can significantly affect the dynamic of a relationship and bring feelings of loss relating to this area of a couple's lives. Challenges include lessening of sexual interest or increased sexual demands (which do not correspond with the partner's needs). For example, some forms of dementia (such as behavioural variant fronto-temporal lobe dementia) may be associated with heightened interest in sexual activity to the point of causing distress to spouses, carers, family and friends.

Anxiety and stress may have an impact on the physical expression of affection, love and sexual desire. Having dementia may cause apathy (reduced motivation) resulting in a disinterest in sexual desires. It may also cause the person to be less caring and affectionate which reduces the partner's willingness to be sexually expressive. If the person with dementia needs assistance with personal care this too may affect sexual desire. As the illness progresses, the partner can be confronted with feelings of loss relating to this area of their lives together. The partner may also feel that he or she is taking advantage of the person with dementia by desiring intimacy. Finding ways that suit you

and your partner to express affection and intimacy will assist in adjusting to these changes gradually. Counselling may also assist in these adjustments.

Further information on sexuality, including enabling sexual expression, rights and responsibilities and sexuality in residential care can be found in Quality Dementia Care: Understanding Dementia Care and Sexuality in Residential facilities and can be accessed online at: http://www.fightdementia.org.au/common/files/NAT/20101001_Nat_QDC_6DemSexuality.pdf.

3. ASSUMING THE CARING ROLE

Caring for someone with younger onset dementia can be very challenging. People with younger onset dementia are generally active, mobile and physically capable. As a consequence, caring for a younger person presents different demands than caring for an older person. Carers may find themselves having to juggle caring for the person with dementia, employment and raising children.

Many people never imagine being a carer for a partner, parent, relative or friend in early or mid-life. Similarly, a parent would never imagine being a carer for their adult child with dementia but this may occur with younger onset dementia. Carers often find the change of roles difficult to adjust to and may feel a sense of resentment that comes with the responsibility of looking after someone. For some, the person they are caring for is 'not the same person' anymore. Feelings of resentment, anger, guilt, frustration, love, hate, loss, and grief are common.

Everyone feels differently about becoming a carer. People react in different ways. "Why me?"; "Why our family?"; "What did we do to deserve this?"; "What caused the disease?" are very common questions, often with no answers. This uncertainty can lead to feelings of anger and frustration.

Of course, feelings and experiences are very individual and may vary between carers. An accurate dementia diagnosis allows the family to be informed of causes, symptoms and future prognosis.

A carer may be in good health at the time of diagnosis, but the stress of caring can lead to a need for additional social and emotional support. Research findings indicate that younger onset dementia carers may experience high levels of burden, stress, and depression. These high levels of psychological suffering and specific problems may relate to their phase in life. They may be at the peak of their career, have financial commitments and often a young family. The carers of younger people with dementia may also experience intense feelings of grief, especially as the condition can deteriorate people with younger onset dementia quicker than in older people with dementia. Appropriate services may not be available to support them. For spousal carers, there may be marriage difficulty or breakdown due to changes and behaviours of dementia.

Social isolation is also a concern for carers. As the carer is required to spend increasing amounts of time in a caring role, opportunities for social interaction outside the home are reduced and friends may distance themselves.

Caring and personality types

Some people are 'born carers' while others may not be suited to the caring role. Carers need to be honest with themselves and think carefully about their strengths and weaknesses. Why are you the main carer? Is it because you love the person you are caring for? Do you feel a sense of duty or obligation to take on the caring role? Is there an expectation from either the person with dementia or extended family or friends? Are there financial reasons why you are the carer? Or is it because there is no one else available? It is important for carers to understand the reasons behind their decision to become a carer, and be clear about their limitations.

Caring can be a rewarding and positive experience for some individuals. They surprise themselves by finding inner strength, resilience, and an ability to tolerate adversity, and they find a sense of humility and purpose. But for some people the responsibility and work involved is overwhelming and mentally and physically exhausting. Every carer needs regular breaks to avoid burn out. How the carer is managing the multiple demands needs to be continually assessed. Some people will not be able to continue as a carer for the sake of their own health and well-being.

Coping styles

There are a number of different ways for carers to cope when caring for someone with younger onset dementia. Carers who use an active 'problem-focused' approach tend to cope better over time. This means they experience greater levels of well-being and lower levels of depression and burnout. Examples of a problem-focused approach include:

- making a plan of action and following it
- brainstorming different solutions to a problem
- expressing emotions in an appropriate forum (support groups/counselling)
- seeking social support.

Various challenges can arise when caring for someone with younger onset dementia, and problem-focused approaches are likely to be most helpful. For example, it can be helpful to analyse the challenge and write down observations;

- When did the challenge occur? (late in the day?; when the person with dementia was in strange surroundings?)
- Who was present?
- What emotion was expressed?
- How was the challenge responded to?

It is also important to determine and record what has helped previously and what may help in the future. Strategies to cope with the challenge should be trialed, compared and assessed. If the strategy does not work, then consideration should be given to why it did not work before another strategy is trialed.

‘Emotional’ coping styles tend to be less productive, but are very common. Examples of emotional coping styles are:

- avoidance and/or denial
- hoping for a miracle
- wishful thinking
- blaming yourself or others for the situation
- keeping feelings bottled up inside.

Often carers will adopt different approaches to different situations. Coping styles may change over the course of the condition as well.

If a carer is having difficulties coping and adjusting to their role, it is important to seek assistance. Often the act of talking to someone can help the carer to understand that they are not alone and that there are potential solutions to common problems. It is very hard to make sensible decisions and to solve problems when under considerable stress. There are many places to seek help (see Further Information list). Many carers benefit from seeking professional counselling to assist in the adjustment process.

Well-being for Carers

The importance of carers looking after themselves cannot be overemphasized. If the carer is not physically and emotionally healthy then it will be very difficult to continue in their role of carer.

Carers need to look after themselves by ensuring they have pleasurable activities for themselves and that they continue to keep in contact with people

who are supportive and positive in their life. Ways to manage stress should be considered. This may be through relaxing activities and techniques such as yoga, pilates or tai chi. Many carers find regular exercise – either alone or with a friend or family member – a great way of reducing stress. Some people may find support groups beneficial, as these groups provide a network of people who are in similar situations caring for people with similar problems. In these groups people typically support each other and share useful tips on how to manage.

The Alzheimer’s Australia younger onset dementia forum provides a place where younger people with dementia, their families, carers and friends can gather and share information. It provides a place to share stories, connect with others in a similar situation, ask questions and share information.

To access the younger onset dementia forum, visit the website: <http://www.talkdementia.org.au/>.

Making a call to the National Dementia Helpline on 1800 100 500 can also put carers in touch with other carers of people with younger onset dementia or provide links to carer support groups.

For more information on supports for families and carers, visit: <http://www.fightdementia.org.au/services/support-for-families-and-carers.aspx>.

For more information on caring for someone with dementia, visit: <http://www.fightdementia.org.au/services/i-care-for-someone-with-dementia.aspx>.

For more information on the role of being a carer and supports, visit: <http://www.carersaustralia.com.au>.

Respite for Carers

It is important for carers to have a break from their caring role. Respite services allow carers to have

a break and should also provide meaningful and stimulating activity and social engagement for the person with dementia.

Respite can be provided informally by friends, family and neighbours or via more formal services. Respite services can provide a few hours of respite or overnight stays of one night or more, depending on the needs of the carer. Respite can take place in the home where the person with dementia lives, a day centre or an overnight respite cottage or residential home.

To find out more about respite options available, contact the Commonwealth Respite and Carelink Centre on 1800 052 222. They will connect the carer and the person with dementia with a range of organisations in their area that may provide the services they require.

4. GRIEF AND LOSS

Feelings of grief and loss are very frequent among dementia carers. Grief includes both anticipatory grief (a complex concept that encompasses grief in anticipation of the future loss of a loved one, in addition to previously experienced and current losses as a result of the terminal illness) and ambiguous loss (a particular form of grief that centres on the fact that the carer has lost the person they know and love as their personalities, memories and ability to function are overtaken by their dementia; the notion that the person is still living but they are increasingly gone).

Grief and loss experienced by carers should be recognised and appropriate support sought. Some of the suggestions below for dealing with grief after the person has died may be helpful.

The person with dementia may also experience grief in response to the diagnosis, loss of previous lifestyle, social isolation and other changes associated with dementia.

Grief after the person has died

When a person with dementia dies, their family and carers often experience a range of feelings. The family and carers usually do not wish for the person to go on living with dementia but still feel an overwhelming sense of loss. Some people find that they have grieved so much during the course of the illness that they have no strong feelings left when the person dies. However strong feelings may surface at a later time, sometimes quite unexpectedly.

Some carers may experience complicated grief, with symptoms including a sense of disbelief, anger and bitterness, recurrent painful emotions, with intense yearning and longing for the deceased. Some carers also experience preoccupation with thoughts of the loved one, often including distressing intrusive thoughts related to the death.

People have different reactions to emotional experiences. Some reactions to the death of a person with dementia may include:

- sadness for what could have been, or for what has been lost
- shock and pain
- disbelief and an inability to accept the situation
- guilt about something in the past
- relief, both for the person with dementia and for themselves
- anger and resentment about what has happened
- lack of purpose in life.

Whether you experience some, or all, of these feelings and how long you feel them will vary from person to person. There are no rules for grieving – we all react to the losses in our life in our own way. Whatever your reaction to the death, you will deal with it in your own way and in your own time.

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CONTRIBUTING TO DEMENTIA RESEARCH

After the death

You may feel shocked and vulnerable in the immediate period after the death, so it's important to:

- try to avoid making any major decisions
- accept that, even though you may generally be coping, there may be times when you will feel sad or upset
- talk to your doctor. You are more likely to become physically ill or depressed following bereavement.

Getting back on your feet

It is not always easy for carers and families to move on with their life, however there will be a time when they are ready to re-establish their life and move forward. The following suggestions are ideas that may help family and carers get back on their feet.

Take time off

The length of time needed to adjust to life changes varies from individual to individual. Be patient and don't try to rush the process.

Accept assistance

Other people can help provide extra support and an opportunity to express your feelings, reflect and talk. Over time this will help you to understand and adjust to the loss.

Share your experience

Friends and family also benefit from the opportunity to share their feelings.

Write in a journal

Recording your thoughts and feelings in a journal or diary can help you come to terms with grief and loss.

Remember the person

Many people like to talk about the person they have lost, especially in earlier times before dementia affected them. Reminiscing about happy times can help. Celebrate the person with family and friends, perhaps on birthdays or anniversaries.

Re-establish social networks

Start to see old friends again or look around for new friends.

Keep trying

You may not feel confident at first and may find it difficult to make decisions, chat about ordinary things or cope with social gatherings. But don't give up, your confidence will gradually return.

If you would like to talk about your feelings or would like help coming to terms with your grief, it may be useful to talk to a professional. Your doctor may be able to help, or you could contact your local Alzheimer's Australia office to arrange to speak to a counsellor.

Call the National Dementia Helpline on 1800 100 500 or the Commonwealth Carer Resource Centre on 1800 242 636 for further information about counselling.

1. RESEARCH PARTICIPATION

Many people diagnosed with dementia and their carers may consider being a participant in health and medical research studies. People with dementia may view involvement in research as a way to help improve the scientific understanding of the causes of younger onset dementia and help reduce the future impact of dementia. Advances in treatment have been slower than scientists would like, however progress is being made in our understanding of these diseases, and there are good prospects that we will see the first treatments for Alzheimer's disease and other types of dementia within the next 10 to 20 years, or possibly even sooner.

There are a number of issues and questions that the person with younger onset dementia and their carers needs to consider when thinking about participating in dementia research. These include:

- Are there any potential benefits for me?
- What are the potential risks, and do my family and friends understand these too?
- What are the practicalities, and will I/my carers be able to handle these? (This may be particularly relevant for research that takes place over a longer period of time; potentially several years, with regular or semi-regular assessments or participation requirements.)
- Will the researchers properly support me? (For example, providing parking/transport if relevant, and ensuring that they appropriately cater for what I can and can't do.)
- Is the research being conducted by a university or an accredited research organisation, and does the project have an official ethics approval?
- Who will provide informed consent to participate in the study? Mostly, the person with younger onset dementia will be able

to do this themselves. However, if they have been assessed as lacking capacity to provide informed consent, they will need an authorised proxy decision maker to consent to participation in research on their behalf. Proxy decision makers can only consent to research or procedures that are in the person's best interest. This may rule out participation in some kinds of research.

- What is the intention of the research? Is it a big international study trialling new drugs or a survey trying to understand the experience of dementia?

Many of these questions will be addressed in the information received from the researchers. However, the question about potential benefits and risks is something that depends in many cases on the person's motivations and values.

Potential benefits of participating in research

The biggest benefit most people experience from participating in research is the opportunity to contribute to the effort to better understand and reduce the impact of dementia for future generations. It can help to give people some sense of purpose in relation to their condition, as well as the hope that advances in medical research might allow those close to them to avoid the impact of their condition.

For those taking part in clinical research trials (research projects involving medications, or other forms of treatment or intervention), there is also a chance of benefiting personally. This might happen if the participant is fortunate enough to be taking part in a trial that makes a 'breakthrough', and develops a new approach to slowing or reversing the disease process, or to improving quality of life through reducing symptoms.

Potential Risks

While all research is carefully monitored, and overseen by a range of safety and ethics committees to make sure that research projects that go ahead are well designed and worthwhile, there is always a small chance that things might go wrong, or that people might experience negative outcomes. This might be as simple as experiencing fatigue; if the person is participating in a study requiring attendance at a hospital and then asked to answer a series of questions. It might involve a mild sense of claustrophobia if the person is undergoing a research brain scan, or it could be side-effects from an experimental medication. In all cases, the researchers will monitor these risks and any adverse outcomes, and will have processes in place to provide appropriate supports and minimise risks and harm.

And most importantly, if an individual signs up for a research project and decides later that it is not for them, they will always be able to pull out of the project at any time.

IN SUMMARY

Dementia researchers rely on the support of volunteers with dementia and their carers. There are many potential benefits involved in taking part in a research project. One of the most critical factors limiting our pace of progress in dementia research is not just a lack of funding, but insufficient numbers of volunteers.

2. ACTIVE INVOLVEMENT IN THE RESEARCH PROCESS

Some people with dementia and their carers want to have a more active role in the dementia research effort, beyond volunteering as participants for individual research projects.

Alzheimer's Australia's Consumer Dementia Research Network brings together people with dementia and carers from around Australia to work closely with researchers and research funding organisations across a range of issues.

To find out more, visit Alzheimer's Australia's Quality Dementia Care website: www.qualitydementiacare.org.au.

3. BRAIN DONATION, THE ULTIMATE GIFT TO FUTURE GENERATIONS

Much of our knowledge about dementia has come from the post-mortem study of brains donated by people with dementia. This knowledge is what underpins the efforts of medical scientists around the world to develop new medical treatments for these devastating diseases. However, in order to make progress with such treatments, researchers need to be able to study brain tissue, particularly from people who had less common forms of dementia such as those that affect younger people.

Volunteering for a brain donation program is one of the most valuable contributions to medical science that can be made by a person with dementia. Such programs generally require people to be enrolled from a relatively early stage of the disease, and in many cases involve a number of interviews, tests and brain scans. When the person with dementia does die, the treating doctor or family members are requested to notify the brain donation program as soon as possible, and arrangements will be made

to transfer the person with dementia to a hospital where their brain can be surgically removed through a limited autopsy procedure. Ideally, this should happen within 24 hours of the person's death, but it is possible to do so if necessary within two or three days. The surgical procedure does not leave visible signs that would be upsetting to family or friends.

If the person with dementia is interested in this aspect of research it is important for them to consider enrolling in a program early, and they can talk to their doctor or specialist to find out more. Information can also be found on the website of the Australian Brain Bank Network (ABBN) at www.austbrainbank.org.au. The ABBN is a collaboration of brain banks across Australia.

4. HOW TO FIND OUT MORE

One of the best ways to learn more about dementia research, and about studies you might be able to volunteer for, is to subscribe to Alzheimer's Australia's fortnightly Dementia News e-newsletter.

A list of previous Dementia News e-newsletters can be found at: <http://www.fightdementia.org.au/research-publications/dementia-news-1.aspx>.

You can also search the Alzheimer's Australia website: www.fightdementia.org.au for a list of research projects looking for volunteers.

For more information for people with dementia and their families, on brain banks and brain donation, see Alzheimer's Australia's Q&A Sheet 17: www.fightdementia.org.au/understanding-dementia/update-sheets.aspx.

FURTHER INFORMATION

PRACTICAL INFORMATION (IN ORDER OF APPEARANCE IN BOOKLET)

Alzheimer's Australia
1800 100 500
www.fightdementia.org.au

Quality Dementia Care 4:
Understanding Younger Onset Dementia (2013):
http://www.fightdementia.org.au/common/files/NAT/20130808_QDC4.pdf

Younger onset dementia help sheets:
<http://www.fightdementia.org.au/understanding-dementia/help-sheets-and-update-sheets.aspx>

Memory changes:
http://www.fightdementia.org.au/common/files/NAT/2012_NAT_HS_AD_12_MemoryChanges.pdf

Communication:
http://www.fightdementia.org.au/common/files/NAT/2012_NAT_HS_CSD_01_Communication.pdf

Therapies and communication:
http://www.fightdementia.org.au/common/files/NAT/2012_NAT_HS_CSD_02_TherapiesAndCommunication.pdf

Decision making support:
<http://www.support-my-decision.org.au>,

Dementia Behaviour Management Advisory Service (DBMAS):
1800 699 799
<http://dbmas.org.au>

Maintaining good relationships:
<http://www.fightdementia.org.au/research-publications/quality-dementia-care-papers.aspx>

Changed behaviours and dementia:
<http://www.fightdementia.org.au/understanding-dementia/section-5-changed-behaviours-and-dementia.aspx>

Travelling:
http://www.fightdementia.org.au/common/files/NAT/2012_NAT_HS_CSD_08_Travelling.pdf

Quality Dementia Care:
Understanding Dementia Care and Sexuality in Residential facilities: http://www.fightdementia.org.au/common/files/NAT/20101001_Nat_QDC_6DemSexuality.pdf

Job Access:
1800 464 800
<http://jobaccess.gov.au/>

Commonwealth rehabilitation:
1800 277 277
<http://www.crsaaustralia.gov.au/>

Employment decisions:
http://www.fightdementia.org.au/common/files/NAT/2012_NAT_HS_INFO_10_MakingEmploymentDecisions.pdf

Assessing fitness to drive:
<http://www.austroads.com.au/assessing-fitness-to-drive>

Driving and dementia:
<http://www.fightdementia.org.au/research-publications/driving-and-dementia.aspx>

Commonwealth Respite and Carelink Centre:
1800 052 222
www.commcarelink.health.gov.au

Adverse Medicine Events:
1300 134 237

Prescription, over the counter or complimentary medicines:
1300 MEDICINE (1300 633 424)
<http://www.nps.org.au>

Medications used to treat dementia:
<http://www.fightdementia.org.au/understanding-dementia/drugs-used-to-relieve-behavioural-psychological-symptoms-of-dementia.aspx>

Aboriginal and Torres Strait Islander people resources:
<http://www.fightdementia.org.au/understanding-dementia/aboriginal-and-torres-strait-islander-resources-and-publications.aspx>

National Aboriginal and Torres Strait Islander Dementia Advisory Group (NATSIDAG) Aboriginal and Torres Strait Islander News:
<http://www.fightdementia.org.au/research-publications/atsi-dementia-news.aspx>

Aboriginal and Torres Strait Islander HealthInfoNet:
<http://www.healthinonet.ecu.edu.au/>

National Cross Cultural Dementia Network (NCCDN) Cultural News:
<http://www.fightdementia.org.au/research-publications/cultural-news.aspx>

Culturally and Linguistically Diverse Backgrounds resources:
<http://www.fightdementia.org.au/understanding-dementia/culturally-and-linguistically-diverse-cultural-backgrounds.aspx>

Lesbians and gay men living with dementia:
http://www.fightdementia.org.au/common/files/NAT/20091000_Nat_NP_15DemLesbGay.pdf

Support needs of people living with dementia in rural and remote Australia:
http://www.fightdementia.org.au/common/files/NAT/20070200_Nat_SUB_SuppNeedsPplLivDemRurRemAus.pdf

Relationships Australia:
1300 364 277
<http://www.relationships.org.au/>

Younger Onset Dementia Forum:
<http://www.talkdementia.org.au/>

Supports for families and carers:
<http://www.fightdementia.org.au/services/support-for-families-and-carers.aspx>

Caring for someone with dementia:
<http://www.fightdementia.org.au/services/i-care-for-someone-with-dementia.aspx>

Advance care planning:
<http://www.fightdementia.org.au/services/advance-care-planning-1.aspx>

<http://www.respectingpatientchoices.org.au/>

Legal processes and authorities in each state and territory:

NSW <http://www.ncat.nsw.gov.au>

QLD <http://www.justice.qld.gov.au/justice-services/guardianship>

VIC <http://www.publicadvocate.vic.gov.au/powers-of-attorney/> or <http://www.vcat.vic.gov.au/>

NT http://www.nt.gov.au/justice/bdm/land_title_office/power.shtml

SA http://www.sat.justice.wa.gov.au/G/guardianship_and_administration.aspx

WA <http://www.dotag.wa.gov.au/>

ACT <http://www.publicadvocate.act.gov.au/>

TAS <http://www.publicguardian.tas.gov.au/>

Legal planning and dementia:
http://www.fightdementia.org.au/common/files/NAT/20050400_Nat_NP_5LegPlanDem.pdf

Legal Aid:
<http://www.nationallegalaid.org/>

Financial Counsellors:
<http://www.financialcounsellingaustralia.org.au/Corporate/Financial-Counselling>

Centrelink:
132 717
<http://www.humanservices.gov.au/customer/themes/carers?from=theme-bar>

DisabilityCare:

1800 800 110

<http://www.disabilitycareaustralia.gov.au/>

Commonwealth Respite and Carelink Centres:

1800 052 222

www.commcarelink.health.gov.au

Aged Care Assessment Team:

<http://www.myagedcare.gov.au/eligibility-and-assessment/acat-assessments>

<http://www.myagedcare.gov.au/service-finders#block-finder-assessment-finder-assessment>

My Aged Care:

1800 200 422

<http://www.myagedcare.gov.au/>

Dementia Enabling Environments Project:

<http://www.enablingenvironments.com.au/>

Respite and residential care:

<http://www.fightdementia.org.au/services/information-support-about-residential-care-issues.aspx>

The most difficult decision: dementia and the move into residential aged care. Discussion paper 5, October 2012:

http://www.fightdementia.org.au/common/files/NSW/20121016-NSW-PUB-Moving_To_Res_Care.pdf

Helping Other Possibilities to Emerge (HOPE) newsletter:

<http://www.fightdementia.org.au/research-publications/hope-newsletter.aspx>

Australian Brain Bank Network (ABBN):

www.austbrainbank.org.au

Younger Onset Dementia: A New Horizon?:

http://www.fightdementia.org.au/common/files/NAT/NATIONAL_CONSUMER_SUMMIT_-_FINAL_March_2013.pdf

INFORMATION FOR DIVERSE GROUPS

Aboriginal and Torres Strait Islander people:

A range of Aboriginal and Torres Strait Islander resources and publications, including Helpsheets, films, learning resources and reports can be accessed via the Alzheimer's Australia website <http://www.fightdementia.org.au/understanding-dementia/aboriginal-and-torres-strait-islander-resources-and-publications.aspx>

The National Aboriginal and Torres Strait Islander Dementia Advisory Group (NATSIDAG) provide Alzheimer's Australia with consultation and advice. They also produce a newsletter entitled Aboriginal and Torres Strait Islander News, which can be accessed at <http://www.fightdementia.org.au/research-publications/atsi-dementia-news.aspx>

For further information on Aboriginal and Torres Strait Islander Health, visit Australian Indigenous HealthInfoNet at <http://www.healthinfonet.ecu.edu.au/>

People from culturally and linguistically diverse backgrounds:

Information and Alzheimer's Australia Helpsheets are available in languages other than English at <http://www.fightdementia.org.au/understanding-dementia/information-in-other-languages.aspx>

A series of films titled It's not a disgrace...It's dementia are available on the Alzheimer's Australia YouTube channel. These films, with English subtitles, aim to support and educate the specific communities that they have been produced for in understanding that dementia is a medical condition.

<http://www.youtube.com/user/AlzheimersAustralia>

The National Cross Cultural Dementia Network (NCCDN) provides advice to Alzheimer's Australia on dementia information provision, resource development and service delivery for culturally and linguistically diverse communities. The Network have a newsletter entitled Cultural News, which can be accessed at <http://www.fightdementia.org.au/research-publications/cultural-news.aspx>

A range of other resources and links to relevant organisations are available on the Alzheimer's Australia website and can be accessed at <http://www.fightdementia.org.au/understanding-dementia/culturally-and-linguistically-diverse-cultural-backgrounds.aspx>

Lesbian, Gay, Bisexual, Transgender and Intersex people:

The paper Dementia, Lesbians and Gay Men was commissioned by Alzheimer's Australia to promote informed discussion on issues affecting lesbians and gay men with dementia or caring for someone with dementia. It can be accessed online at http://www.fightdementia.org.au/common/files/NAT/20091000_Nat_NP_15DemLesbGay.pdf

People living in rural and remote areas:

Alzheimer's Australia staff are able to travel to rural and remote areas, deliver services over the phone or online. Contact the National Dementia Helpline on 1800 100 500 to find out more about how to access services in your area.

The Alzheimer's Australia report Support needs of people living with dementia in rural and remote Australia can be accessed at http://www.fightdementia.org.au/common/files/NAT/20070200_Nat_SUB_SuppNeedsPplLivDemRurRemAus.pdf

WEBSITES

Alzheimer's Australia:

<http://www.fightdementia.org.au>

2013 Younger Onset Dementia Summit:

<http://www.fightdementia.org.au/services/2013-younger-onset-dementiasummit-a-new-horizon.aspx>

Carers Australia:

<http://www.carersaustralia.com.au/>

Creutzfeldt-Jakob Disease (CJD):

<http://www.cjdsupport.org.au>

Frontier (frontotemporal dementia research group):

<http://www.neura.edu.au/frontier>

Frontotemporal Dementia Toolkit:

<http://ecdc.org.au/ftd-toolkit.htm>

Huntington's Disease Association:

VIC - <http://www.huntingtonsvic.org.au>

NSW/ACT - <http://www.huntingtonsnsw.org.au>

QLD - <http://www.qahda.com>

SA/NT - <http://www.huntingtonssa.org.au>

WA - <http://www.huntingtonswa.org.au>

TAS - <http://www.huntingtonstasmania.asn.au/>

Lewy Body Disease Help Sheets:

<http://www.fightdementia.org.au/understanding-dementia/lewy-body-disease.aspx>

Lovell Foundation:

<http://www.lovellfoundation.com.au>

Melbourne Young Onset Dementia Service (MYOD):

<http://www.machmedical.com/nu2/>

Multiple Sclerosis Australia:

<http://www.msaustralia.org.au>

Parkinson's Australia: <http://www.parkinsons.org.au>

Posterior Cortical Atrophy Australia:

<http://www.pcaaustralia.org>

Australian Aphasia Association: www.aphasia.org.au

RESEARCH WEBSITES

Australia Dementia Research Foundation:
<http://dementiaresearchfoundation.org.au/>

Dementia Collaborative Research Centres:
www.dementia.unsw.edu.au or
<http://www.dtsc.com.au/>
<http://www.neura.edu.au/>

FILMS

2 Young 4 Dementia, 2008. A film produced by Alzheimer's Australia and funded by the Department of Health.

The Music in Hugh: A look at younger onset dementia. Available on youtube at:
http://www.youtube.com/watch?v=8h1pcx0RT_Y

Tracey and Jess: Living with early onset Alzheimer's disease. Available on youtube:
<http://www.youtube.com/watch?v=wcJMBhXATRU>

People's stories. Watch interviews with people that care for loved ones with dementia on the healthtalk.org website: <http://www.healthtalkonline.org/>

Is it dementia?. A series of films funded by the Department of Health and Ageing, produced by Alzheimer's Australia SA and created by Short Focus Films, that highlight how dementia can affect every day Australians at work. The films can be viewed at: <http://isitdementia.com.au/>

My name is Lisa. By Shelton films 2010. A film about a young girl looking after her mother who has dementia. Available on YouTube at <http://www.youtube.com/watch?v=ZiRHyzjb5SI>

Max: A young person's journey with dementia. A film produced by Alzheimer's Australia WA, available from Alzheimer's Australia libraries.

Social Care TV has produced a series on dementia including *Living with young onset dementia*, a film about the experiences of Ian Grant and Sandy Reed, who were both diagnosed with dementia in their 50's. Available at <http://www.scie.org.uk/socialcaretv/>

Graeme Atkin has produced *Songs while I can: aspects of dementia.* These DVDs are available for loan from Alzheimer's Australia libraries.

Driving with dementia. A teaching resource for medical and other health professionals produced by Professor Joseph Ibrahim, Dr Prateek Bandopadhyay and Mr Jeremy Ley. Available at <http://www.dtsc.com.au/free-online-video-driving-with-dementia/>

BOOKS

Alzheimer's Association [U.S.] *Early onset dementia: A national challenge, a future crisis* Chicago, IL: Alzheimer's Association, 2006.

Alzheimer's Association Australia *The young mind: issues in relation to young people and dementia* Sydney, NSW: Alzheimer's Association Australia, 1994.

Baldwin, Robert and Michelle Murray (eds) *Younger people with dementia : a multidisciplinary approach* London, UK: Martin Dunitz, 2003.

Boden, Christine, *Who will I be when I die?* HarperCollins, 1998.

Cox, Sylvia; Keady, John. *Younger people with dementia: planning, practice and development* Jessica Kingsley, 1999.

Cox, Sylvia; McLennan, Jane M. *A guide to early onset Dementia*, Stirling, Scotland: Dementia Services Development Centre, 1994.

DeBaggio, Thomas *Losing my mind : An intimate look at life with Alzheimer's* New York, NY: Free Press, 2002.

Imperial College of Science and Medicine *Young onset dementia: epidemiology, clinical symptoms, family burden, support and outcome* North Thames: NHS Executive, 1998.

Valenta, Tom. *Remember Me, Mrs V? Hill of Content Publishing Co Pty Ltd, 2007.*

The carer experience: Information and ideas for carers of people with dementia, Australian Government Publishing Service, ACT.

ALZHEIMER'S AUSTRALIA PUBLICATIONS SPECIFIC TO YOUNGER ONSET DEMENTIA

For more information on younger onset dementia and to view these resources, please visit: <http://www.fightdementia.org.au/services/younger-onset-dementia.aspx>

Acetylcholine: This is a chemical (a neurotransmitter) which is found within our brain. It works to transmit messages from one brain cell (neuron) to another brain cell; this enables us to think. Acetylcholine is important in learning and remembering new information, due to its effects on enhancing attention and concentration.

Acetylcholinesterase inhibitors: This is a chemical which prevents acetylcholine from being broken down within the brain. This means that there is (a) more acetylcholine within the brain and that (b) the acetylcholine has longer to act (i.e., more time to transmit signals between brain cells). In Alzheimer's disease, this type of medication is used as there is believed to be a lack of acetylcholine within the brain which causes some of the symptoms.

ADLs (Activities of Daily Living): Daily activities which we all perform (e.g., bathing, dressing, grooming, housework, employment and leisure activities). These tasks vary in difficulty from the simple (e.g., grooming – brushing your teeth, combing your hair) to the complex (e.g., employment and leisure activities). This term is often used by health care professionals in the hospital or care environment to measure the level of support an individual requires.

Anti-anxiety agents: These are medications which are used to treat anxiety disorders and also as tranquilizers. There are many different types of anti-anxiety agents; your health professional will choose a specific type of medication based on the symptoms and their severity, side effects, other health conditions which you may have and any other medications you currently take. These medications can also be used to treat specific symptoms of BPSD including agitation and aggressive behaviours.

Anti-depressants: These are medications which are designed to help treat the various symptoms of depression. They can also be prescribed for other related conditions, such as anxiety, sleep disorders and chronic pain. There are many different types of antidepressants; your health professional will choose a specific type of medication based on the symptoms and their severity, side effects, other health conditions which you may have and any other medications you currently take.

Anti-psychotics: These are medications which are used to treat symptoms of psychosis, such as hallucinations and delusions. There are many different types of antipsychotics; your health professional will choose a specific type of medication based on the symptoms and their severity, side effects, other health conditions which you may have and any other medications you currently take. In people with dementia, antipsychotics may be used to treat symptoms of BPSD including agitation, aggression and psychotic symptoms (delusions and hallucinations).

Behavioural and psychological symptoms of dementia (BPSD): BPSD are a range of symptoms and behaviours that can occur in people with dementia. Behaviours can include wandering, verbal outbursts, agitation and disinhibition. There are also mood symptoms, which include anxiety, delusions, hallucinations and low mood. Such symptoms are considered to be "challenging" when they have negative implications (e.g. causing harm or distress) to the person with dementia or their carers.

Cognition: A person's thinking and memory skills. This includes their ability to concentrate, use and understand language, learn and remember new information, plan and problem solve.

Delusion: A delusion is a strong belief that is held even though there may be lots of evidence to suggest that it is false. Religious beliefs and alternative beliefs (e.g., aura reading, spiritual healing), for example, are not delusions, even though there may be a lack of evidence to support them. Delusions may be bizarre (e.g., "I believe that my brain has been removed") or non-bizarre (e.g., "My things have been stolen by the nurses"; "they are trying to harm me"). Delusions are another symptom of BPSD and may be related to unfamiliar environments, sensory overload or trying to "make sense" of things; for example, if a patient keeps losing their possessions but does not believe that they have a memory problem, they may believe that their things are being stolen.

Dementia: A progressive decline in a person's thinking and memory skills which is severe enough to interfere with their ability to carry out daily activities. There are many possible causes of dementia. The rate of decline can vary between individuals and types of dementia.

Episodic memory: memory for personal and autobiographical events

Executive functioning: Executive function can be thought of as the CEO or General Manager of the brain. This is an umbrella term which includes cognitive skills such as: planning and problem solving; organization; understanding alternative perspectives or points of view; time management; impulse control; self-regulation and multi-tasking. Executive function also involves something called social cognition, that is, our understanding of the social nuances and conventions in the roles around us. This includes things like appreciating jokes, understanding sarcasm and understanding other people's emotions.

Frontal cortex: The frontal cortex (or frontal lobe) is the largest area of our brain and is seated behind our forehead. The frontal cortex is involved with executive functioning and social cognition as well as with motor skills. It has many connections to other areas of the brain which are specialized for language and memory; if these connections are damaged you can see weaknesses in these areas.

Glutamate: This is a neurotransmitter found within the brain which is involved in learning and memory processes. Excessive amounts of glutamate are thought to be one way that brain cells become damaged and die, which is one explanation for the brain damage that occurs in Alzheimer's disease.

Hallucination: A hallucination is a perception of something (e.g., a noise, a voice, a figure or a taste) in the absence of a real object or stimulus. Hallucinations can involve any of the senses. These occur when the person is awake (i.e., they are not in a dream), cannot be controlled by the person (i.e., it's not their imagination or day dreaming) and can range in severity. Hallucinations are one symptom of BPSD and are commonly associated with Lewy Body Dementia and Parkinson's disease. Hallucinations can also occur when a person becomes delirious.

IADLs (Instrumental Activities of Daily Living): These are daily activities which allow a person to live independently within the community, including, housework; managing medications; managing money; shopping; using the telephone and accessing the community (either through driving or using other forms of transport).

Mini-mental state examination (MMSE): The MMSE is a short, standardized assessment which is primarily used by GPs to make a quick assessment about a person's level of cognitive function. It assesses orientation to time and place; learning and memory; concentration and language. The MMSE can also be used to make a judgment about disease severity, monitor disease progression and to inform treatment decisions regarding medication.

Mood stabilising agents: These are medications which are used to treat rapid and intense mood swings, such as those found in bipolar disorder. Sometimes these medications are used to treat BPSD symptoms, such as agitation.

Neuropsychologist: A psychologist who has specialized in the study of cognition and holds an endorsement in this area. They have specialized training in cognitive assessment and diagnosis of disorders affecting the brain. Neuropsychologists use standardized assessment tools to assess a person's thinking and memory skills in order to determine their strengths and weaknesses.

NMDA antagonists: These are medications that reduce the action of receptors on brain cells which respond to a chemical called NMDA (N-Methyl-D-aspartate). One such medication is used in moderate-to-severe Alzheimer's disease, or in patients who have had reactions to other Alzheimer's treatments.

Procedural memory: our knowledge of how to perform a particular task, from the basic (e.g. tying a shoe; doing up a button) to the complex (e.g. how to drive a car).

Semantic memory: long-term memory for general knowledge; knowledge which we have learned over our lifetime (e.g. geography, sporting events etc.)

ALZHEIMER'S AUSTRALIA

PUBLICATIONS

Quality Dementia Care Series

- 1 Practice in residential aged care facilities for all staff. February 2007.
- 2 Practice for managers in residential aged care facilities. February 2007.
- 3 Nurturing the heart: creativity, art therapy and dementia. September 2007.
- 4 Understanding younger onset dementia. June 2013.
- 5 Younger onset dementia: a practical guide. February 2009.
- 6 Dementia and sexuality – an important topic for all carers of a person with dementia. October 2010.
- 7 No time like the present: the importance of timely diagnosis. September 2010.
- 8a Relate, motivate, appreciate – Introduction. July 2013.
- 8b Relate, motivate, appreciate: a Montessori resource. July 2013.

Numbered Papers

- 1 Dementia: A Major Health Problem for Australia. September 2001
- 2 Quality Dementia Care. February 2003
- 3 Dementia Care and the Built Environment. June 2004
- 4 Dementia Terminology Framework. December 2004
- 5 Legal Planning and Dementia. April 2005
- 6 Dementia: Can It Be Prevented? August 2005 (superseded by paper 13)

- 7 Palliative Care and Dementia. February 2006
- 8 Decision Making in Advance: Reducing Barriers and Improving Access to Advanced Directives for People with Dementia. May 2006
- 9 100 Years of Alzheimer's: Towards a World without Dementia. August 2006
- 10 Early Diagnosis of Dementia. March 2007
- 11 Consumer-Directed Care – A Way to Empower Consumers? May 2007
- 12 Dementia: A Major Health Problem for Indigenous People. August 2007
- 13 Dementia Risk Reduction: The Evidence. September 2007
- 14 Dementia Risk Reduction: What do Australians know? September 2008
- 15 Dementia, Lesbians and Gay Men. November 2009
- 16 Australian Dementia Research: current status, future directions? June 2008
- 17 Respite Care for People Living with Dementia. May 2009
- 18 Dementia: Facing the Epidemic. Presentation by Professor Constantine Lyketsos. September 2009
- 19 Dementia: Evolution or Revolution? Presentation by Glenn Rees. June 2010

- 20 Ethical Issues and Decision-Making in Dementia Care. Presentation by Dr Julian Hughes. June 2010
- 21 Towards a National Dementia Preventative Health Strategy. August 2010
- 22 Consumer Involvement in Dementia Research. September 2010
- 23 Planning for the End of Life for People with Dementia Part 1. March 2011
- 24 Timely Diagnosis of Dementia: can we do better? September 2011
- 25 National Strategies to Address Dementia. October 2011
- 26 Evaluation of NHMRC data on the funding of Dementia Research in Australia. March 2012
- 27 Alzheimer's Organisations as agents of change. April 2012
- 28 Exploring Dementia and Stigma Beliefs. June 2012
- 29 Targeting Brain, Body and Heart for Cognitive Health and Dementia Prevention. September 2012
- 30 Modelling the Impact of Interventions to Delay the Onset of Dementia in Australia. November 2012
- 31 Dementia Friendly Societies: The Way Forward. May 2013
- 32 Cognitive Impairment Symbol: Creating Dementia Friendly Organisations. May 2013

- 33 Respite Review – Policy Paper. May 2013
- 34 Wrestling with Dementia and Death. June 2013
- 35 Dementia Care: Person-centred, Palliative and Supportive. June 2013

These documents and others available on www.fightdementia.org.au

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