A Guide for Carers
2023

Supporting carers to better understand and help people experiencing changed behaviours and psychological symptoms associated with dementia

UNSW SYDNEY

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Supporting carers to better understand and help people experiencing changed behaviours and psychological symptoms associated with dementia

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Disclaimer
This Guide for Carers was funded by the Australian Government represented by the Department of Health and Aged Care and developed by the Centre for Healthy Brain Ageing (CHeBA). The information contained in this Guide is a modified summary of the document *A Clinician's BPSD Guide 2023: Understanding and helping people experiencing changed behaviours and psychological symptoms associated with dementia (Clinician's BPSD Guide 2023)* which was developed as a resource for clinicians supporting people who present with changed behaviours in dementia.

This Guide is provided for general information only and does not claim to reflect all considerations. As with all guidelines, recommendations may not be appropriate for use in all circumstances. It is strongly recommended that carers providing care to a person living with dementia seek assessment and guidance from an appropriate health professional before implementing strategies suggested in this Guide. It is intended that the information included in this Guide be read in combination with and subject to advice from health professionals experienced in addressing changed behaviours and psychological symptoms associated with dementia.

This Guide incorporates information from recent literature, clinical expertise and other sources. Every effort has been made to ensure the accuracy and reliability of the information at the time of publication. Links to a selection of available Internet Sites and resources are identified. Links to Internet Sites that are not under the control of the CHeBA at UNSW are provided for information purposes only. It is the responsibility of users to make their own investigations, decisions and enquiries about any information retrieved from other Internet Sites. The provision and inclusion of these links do not imply any endorsement, non-endorsement, support or commercial gain by UNSW.

While the *Clinician's BPSD Guide 2023* was prepared after an extensive review of the literature, review by an expert advisory committee and consultation, the authors do not bear any clinical responsibility for the practical application of the information contained in this Guide for Carers.

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Contents

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A full list of contributors is available in the unabridged version of the document *A Clinician's BPSD Guide 2023: Understanding and helping people experiencing changed behaviours and psychological symptoms associated with dementia* available via the CHeBA website.

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Purpose of this Guide for Carers

This *Guide for Carers 2023* was developed by the Centre for Healthy Brain Ageing (CHeBA) at UNSW Sydney to replace and update the document *A Guide for Family Carers: Dealing with Behaviours in People with Dementia* (2014). It includes practical information about strategies to address changed behaviours and psychological symptoms associated with dementia for those providing care. The evidence supporting the content of this *Guide for Carers* is included as *Appendix 1* to the unabridged *Clinician's BPSD Guide 2023* which is accessible via the CHeBA website with all appendices.

Each module of this *Guide for Carers* relates to a specific changed behaviour or psychological symptom and includes:

- a description of the changed behaviour or psychological symptom and what it looks like in dementia
- potential causes and when it is more likely to occur
- how it affects the person with dementia and others
- what can be done to help address these
- an example story.

Additional considerations may be necessary when providing care for Aboriginal and Torres Strait Islander people with dementia and people from a culturally and linguistically diverse (CALD) background. Detailed information is available in the unabridged document *A Clinician's BPSD Guide 2023* and some examples are included as stories here.

Care partners and family likely know the person behind the dementia better than others involved in their care. As such, their contribution to addressing changed behaviours and improving the quality of life of the person living with dementia is respected and invaluable.

Terminology

The term *changed behaviours and/or psychological symptoms associated with dementia* is used respectfully throughout this *Guide for Carers*. Other terms such as behaviours and psychological symptoms associated with dementia (BPSD), responsive behaviours, behaviours of concern, behaviours that challenge, neuropsychiatric symptoms (NPS), behavioural and psychological changes in dementia and others are also used and may be terms preferred by people living with dementia carers/family and/or community members or for communication between professionals supporting people with dementia. For information about preferences on terminology, consult the Dementia Australia *Dementia Language Guidelines*.

The term *carers* can refer to family and friends or care staff who provide support and care to people living with dementia. They may also be known as care partners, informal carers or caregivers as well as formal, paid or professional carers.

The terms Aboriginal and/or Torres Strait Islander peoples are used in this document. These terms are used respectfully to refer to Australia’s first people. This includes a wide range of nations, cultures and languages across mainland Australia and throughout the Torres Strait.

The term and abbreviation culturally and linguistically diverse (CALD) are used in this Guide to refer to communities with diverse languages, ethnic backgrounds, nationalities, traditions, societal structures, and religions. The Australian Bureau of Statistics defines people from CALD backgrounds as those born overseas, in countries other than those classified *main English-speaking countries*. It is important to note that people born in English-speaking countries may identify with a different culture. We respectfully acknowledge that these are collective terms which may overlook the complex differences, diversity and nuances within communities.

See *Glossary of Terms (Appendix 1)* of this *Guide* for definitions and/or explanations of other terms used throughout.

For further information to support carers of people living with dementia see:

The *CareForDementia* app (2023)

CareForDementia on the App Store (apple.com)

CareForDementia - App on Google Play

Dementia Services Australia (DSA) for expert support in addressing changed behaviours and psychological symptoms associated with dementia via referral to the Dementia Behaviour Management Advisory Service (DBMAS) or Severe Behaviour Response Teams (SBRT).

Dementia Australia provides support for people living with dementia and those involved in their care.

Module 1: Overview of changed behaviours and psychological symptoms associated with dementia

Key messages

- Structural and chemical changes that occur in the brain during the course of dementia can lead to changed behaviours and psychological symptoms.
- Changed behaviours can present at any point during the course of dementia and vary with dementia type.
- Changed behaviours are typically not deliberate and can be an attempt at communication when people living with dementia have difficulty expressing their needs.
- The presenting behaviours may be avoided or reduced if the triggers or underlying contributing factors are identified.
- Consider the possibility that the person with dementia may be unwell, hungry, thirsty, tired and/or in pain and this could be prompting the changed behaviours.
- The causes of changed behaviours are often complex and strategies to address them are not *one size fits all;* an intervention may help in one situation and not in another.
- Keeping a record of the situations which ultimately lead to changed behaviours or psychological symptoms can assist with identifying possible triggers and developing strategies to address these.
- Ensure you have access to the best level of support available when caring for a person living with dementia.

Overview of changed behaviours and psychological symptoms associated with dementia

What are changed behaviours and psychological symptoms associated with dementia?

Changed behaviours and psychological symptoms commonly occur when a person has dementia. Health professionals may refer to these as behaviours and psychological symptoms associated with dementia (BPSD), responsive behaviours or behaviours of concern. These changes can be very stressful for carers supporting a person living with dementia. The behaviours may also significantly affect quality of life for the person with dementia as well as those living with them and/or providing care. The commonest changed behaviours and psychological symptoms are included in this Guide.

The structural and chemical changes that occur in a person's brain during the course of dementia can lead to changed behaviours and psychological symptoms. Some people living with dementia may not show any of these changes. Where they do occur, the person will display only some of them, and only some of the time. The degree of the behaviour can vary from mild to severe. More than one changed behaviour or psychological symptom may occur at the same time, rather than one after the other; some resolve over time without treatment or intervention.

Although these changes can be distressing, it is important not to take them personally as they are typically not deliberate. The changed behaviours may be the person with dementia's attempt at communicating their needs when they are unable to express themselves verbally. Strategies targeting their unmet needs may be effective in reducing changed behaviours and psychological symptoms.

Many factors can contribute to changed behaviours and psychological symptoms. In combination with brain changes, physical surroundings, time of day and the specific situation as well as the person's health, comfort, interaction with others, previous personality, individual history and stage/type of dementia can also influence behaviours.

The most effective way of supporting the person is to try to identify why this might be happening. It is important to address each of the factors that may be contributing to the changed behaviour. Understanding why it is occurring can help to avoid or reduce changed behaviours in the future.

When dealing with changed behaviours, non-drug (psychosocial) strategies tailored to the individual should be tried first, unless the situation presents a safety risk. If the person living with dementia is very distressed or at risk of harm to themselves or others, it may be necessary to consider medication. Discuss medication options with the person's doctor. Scientific support for medications to reduce changed behaviours is limited and there are risks of side effects. It is important to keep in mind that research evidence is based on comparing groups of people, however each person with dementia is different and individual responses to medication can vary.

Points to consider in addressing changed behaviours and psychological symptoms

- Exclude the possibility that the person living with dementia has an acute physical illness and may be unable to describe the symptoms; consult a general practitioner (GP) for assessment.
- Relieve hunger and/or thirst; the person may no longer be able to express these needs in words or remember when they last had a drink.
- Ensure the person is getting sufficient rest and any chronic or acute pain is well managed.
- Support appropriate expression of emotions such as anger, grief, frustration and/or helplessness.

- Remove or reduce perceived threats to the person's space, dignity, privacy and/or safety where possible.
- Minimise sensory losses with glasses and hearing aids; keep prescriptions current in case urgent replacement is needed.
- Add orienting cues to the home environment e.g. night lights, identifying pictures on doors, labels for drawers.
- Provide supportive social and family contact and/or use video calls; provide positive regard.
- Arrange activities/outings that are individually meaningful to the person. For example, consider the person's occupation before retirement, their hobbies or interests and tailor activities around these.

See *Checklist of potential underlying factors that can contribute to changed behaviours and/or psychological symptoms (Appendix 2)* at the end of this Guide.

Additional information to consider

- A person with dementia may relive past experiences of trauma. For example, a history of displacement, massacre, war, forced removal from family or deprivation may prompt fear of uniforms, being watched, queuing, hunger, being cold, identity tags, corridors, the dark and/or shared spaces for sleeping or eating.
- Fears may not be expressed verbally but may be evident through behaviours such as hoarding food and collecting other people's belongings for times when the person believes they may be needed.
- For some, hospital is a particularly threatening place which can prompt an increase in changed behaviours. A person with dementia may also associate residential care services with hospitals which can be seen as places to die, rather than a place of healing.

- People living with dementia who originally immigrated to Australia or those who have been forced to “forget” their first language may have learnt English as their second language. As dementia progresses, they may revert to their first language. This may lead to isolation, difficulties with communication and increased frustration which can exacerbate changed behaviours. If the person’s second language has been lost, seek resources to enable communication via their first language.

Interventions that can help

- Dementia support services can arrange access to occasional respite care to allow family carers to “recharge their batteries”; the person living with dementia will also benefit if carers are more rested.
- Modifying the person’s environment can make living areas more suitable, for example a home-like environment, avoidance of harsh lighting and reduced noise levels can provide a calming effect.
- Cognitive-behavioural therapies, especially where the therapist, the person with dementia and their carer work together, can help to reduce changed behaviours.
- Reminiscence-based activities can include looking back on past events, and family and friends using videos and/or life storybooks.
- Listening to preferred music, movement or singing may provide pleasure and help to keep the person living with dementia meaningfully occupied.
- Recreational and occupational activities also assist the person with dementia to remain functional. Choose activities that the person does not find stressful. Examples include cooking, gardening, walking together, spending time outdoors or appropriate social events.

- Exercise activities such as walking and movement help to maintain balance and the ability to move around safely as well as channelling the person's energy productively.
- Appropriate, supervised interaction with pets can enable a positive experience for a person living with dementia who is an animal lover.
- Sensory stimulation such as aromatherapy can be pleasant and calming.
- Gentle massage therapies can promote relaxation.
- Attending education sessions to learn new strategies and meet other carers who can provide understanding and friendship is worthwhile. Sessions may also involve activities and/or care for the person with dementia.
- An intervention may assist in a set of circumstances for one situation and not another. The causes of changed behaviours are often complex and strategies to address them are not *one size fits all.*

Support for addressing changed behaviours

It is important to have the best level of support available when caring for a person with dementia. Keep in regular contact with your doctor and/or relevant health care professionals. This can provide opportunities to discuss a workable routine, day-to-day strategies and ongoing review. The more accurate the information you can provide on the situations around changed behaviours and/or psychological symptoms, the more effective individual strategies can be for you and the person living with dementia.

Keeping a record of the situations which result in changed behaviours can assist with developing strategies to address them. It is important to identify specific problems and possible triggers. Be as explicit in your description of the behaviour and/or psychological symptom as you can. For example, rather than simply noting that the person with dementia is “aggressive” or “hallucinating”, describe specific actions or expressions such as “swearing at strangers”, “hiding food in the bedroom” or “talking to his deceased mother”. Likewise, it is important to note the frequency and severity of the changed behaviours and/or psychological symptoms.

When keeping a journal or diary take note of the following:

- relevant personal history, previous trauma, first language, cultural background, personality, likes and dislikes, other people providing support, type of dementia, current medications and whether medications have been helpful
- information about a changed behaviour that links it to specific people, situations, places and times of day; where possible, information should be collected over a week
- situations and interventions that work well and are achievable for carers and the person living with dementia; as well as details of unsuccessful strategies
- circumstances that are becoming increasingly problematic
- usual routine for the person with dementia and the carer
- occasions when changed behaviours DO NOT occur.

It is important that you feel comfortable with the health professionals involved in the care of the person with dementia as they are essential to addressing changed behaviours. Consider the following questions:

- Has the diagnosis been explained in a way that you could understand?
- Have you had an opportunity to ask questions?
- Have you been able to discuss how the diagnosis has affected you?

- Do you have the answers you need?
- Do you feel that you can go back with your questions if you need to?

Health professionals with knowledge of your situation can be of great assistance. To get the most from your appointments, write down your questions beforehand, choose a time of day that works best for the person with dementia if possible and take your journal so that you have an accurate record and history with you. Make brief notes or ask the health professional to write down important points, especially about medications.

Module 2: Aggression

Key messages

- Aggression in a person living with dementia includes physically and/or verbally threatening behaviours.
- Aggression may be a response to feeling unwell, frustrated, uncomfortable, threatened, stressed, bored, agitated and/or lonely.
- Ask the person's doctor for assistance or contact the closest hospital if you feel that you or others are at risk of harm.
- Suggested strategies:
  - Carers and others may need additional specific information around staying safe.
  - Identify potential triggers, frustrations and stressors and avoid these where possible.
  - Don't argue or attempt to reason with the person.
  - Use a non-threatening posture and approach.
  - Divert the person's attention if possible.
  - Modify/simplify the person's environment and routines to reduce frustration.
  - Avoid attempting to restrain the person as this can exacerbate changed behaviours.
  - Seek advice from health professionals and attend carer education.
  - Seek occasional respite care.
  - Ask the doctor about short-term medications which may help to reduce physical aggression only if necessary for safety.

Aggression

What is aggression and what does it look like in a person with dementia?

- Up to one third of people with dementia living at home can occasionally become aggressive and hit out at other people or objects or even at themselves.
- Aggression is most likely to be directed at the main carer.
- Levels of aggression can vary according to the type of dementia.
- Aggression may increase as dementia progresses but decrease during the late stages.

Types of aggression include:

- verbal aggression such as shouting, screaming, saying insulting things and/or using offensive language
- physical aggression such as hitting, punching, kicking, pushing, throwing objects, biting, spitting and/or resisting care
- sexual aggression such as repeated and sometimes threatening demands for sex from partners or other people.

What causes aggression? When is it most likely to occur?

Aggression is a symptom of the physical and psychological changes that happen when a person has dementia. It may result from altered brain chemicals and structures or the interaction of the person with their environment and other people. Changes to the frontal areas of the brain can make it difficult for the person to maintain control over their emotional responses.

People with lived experience of dementia have said that aggression may stem from confusion, frustration, insecurity, self-loathing and/or fear.

People living with dementia may react with aggression because they are:

- frustrated if they are unable to convey a physical need such as hunger or pain
- feeling unwell or have a fever
- physically uncomfortable, constipated or dehydrated
- feeling threatened during personal care tasks where physical contact may be perceived as too close and where they do not recognise the person assisting them
- frightened and feeling the need to defend themselves
- stressed due to misunderstandings with carers
- bored, agitated or lonely
- unsettled by changes in their familiar routine, carers and/or surroundings
- distressed/agitated by the actions of others around them but they are unable to move away
- responding to environmental stressors such as intense lighting or uncomfortable temperatures and/or too much stimulation e.g. loud noises or constant background chatter.

How does aggression affect the person with dementia and others?

- Aggression is associated with considerable carer burden, stress and reduced quality of life for the person with dementia and their carers.
- Aggression can also prompt earlier admission to residential care.
- Although not common, harm to the person with dementia and/or others can be a serious consequence.

What can be done to address aggression?

Ask the doctor:

- for urgent assistance if you feel that you or others are at risk of harm; health professionals can assess the severity of aggression with specialised tools
- to check if the person living with dementia has symptoms of underlying depression, delusions, hallucinations, allergic reaction, physical illness or infection which could increase their irritability; in the meantime consider relief from pain and fever
- to check if the person has pain that they may be unable to describe; research indicates some evidence for decreased aggression with better pain management
- to check for side effects or a reaction to the person's regular medication
- for information about short-term medications which may help to reduce physical aggression if necessary for the safety of the person and/or others.

Apart from some emergencies, medication is never the first strategy for aggression. Medications have limited benefits, may not be appropriate for aggression and can cause side effects. Non-drug interventions are recommended as the first strategy unless it is an emergency.

Strategies to try:

- Care partners and others around the person including care staff may need additional, specific support and information around staying safe.
- Try to identify the cause of the aggression; identify individual triggers, frustrations and stressors for the person so these can be reduced and/or avoided.

- Note the frequency, severity and details of each aggressive incident to help identify potential causes and patterns.
- It is important to know the person's story and find out what has previously been meaningful and pleasurable to them.
- Consider how they the person is feeling at the time when planning the duration and degree of difficulty of an activity; choose the best time of day and stop before they show signs of fatigue, agitation or distress.
- Recognise cues that indicate increasing upset, for example background noise or a TV nearby; intervene to de-escalate or change the situation where possible.
- If the person is in no immediate danger, sometimes excusing yourself politely and leaving them alone for a couple of minutes may help calm the situation; continue to observe the person discreetly.
- Speak clearly (without shouting) and calmly while reassuring the person; don't argue or attempt to reason.
- Use non-threatening posture and movement; consider gentle touch where appropriate and safe.
- Divert the person by engaging them in another activity or focusing their attention elsewhere.
- Modify/simplify the person's living environment and routines to avoid/limit frustrating scenarios; consider their current abilities.
- Seek advice from health professionals about individualised interventions and activities.
- Attend carer education and training courses to increase skills as well as meet other carers for friendship and mutual support.

- Seek occasional respite care.
- Avoid attempting to restrain the person with dementia as this can exacerbate the aggression.

Andreas' story

Andreas, an 89-year-old man who migrated from Italy 60 years ago, lives with his wife Rosa in their Sydney home. Rosa has been his primary carer since Andreas was diagnosed with dementia two years ago. They have a large extended family who visit regularly and are supportive. Andreas is unable to read or write English and he now tends to speak in his first language. His children understand a little but are unable to speak Italian, although some elderly relatives do. Rosa says that sometimes even Andreas' Italian words don't make any sense to her.

Andreas is becoming increasingly frustrated with being unable to communicate with his family and friends. This frequently causes Andreas to become verbally abusive and, at times physically aggressive. On occasion, he has used his walking stick as a weapon. When Rosa attempts to reason with him, Andreas becomes more frustrated. Rosa is distressed and ashamed that her previously gentle husband of 65 years is acting this way. She has tried to hide the situation from her children, but they have noticed the changes in their father.

Andreas resists Rosa's help when he is agitated, and Rosa is losing confidence in her ability to assist her husband with his showering and grooming. Rosa is worried that Andreas will be placed in a nursing home if she is seen as not managing his care. The couple are becoming increasingly isolated from their friends.

The following have been checked:

- pain, discomfort, illness, infection and/or constipation that may be contributing to Andreas' aggression
- medication effects such as drug interactions, dosage, recent prescription changes, side effects
- underlying depression, psychosis and delirium
- general health concerns including blood tests, urine tests and/or cognitive assessment as needed.

Other potentially contributing factors have been considered:

- too much stimulation from noise, people and/or activities in his surroundings
- Andreas' decreased ability to communicate with others which is negatively affecting his interaction with family members and friends
- whether too much is expected of him for his current level of dementia
- stress caused by any aspects that are unfamiliar or may have changed in Andreas' home environment and/or routine
- Andreas' reduced ability to cope with stress due to his advancing dementia.
- Andreas has been a proud man who has always maintained a position of respect in the family and their local community; he finds it difficult to accept assistance from others.

A health professional has suggested the following strategies:

- Encourage/support Andreas to express his needs and concerns as far as he is able; allow him extra time to communicate.

- Andreas becomes anxious and distressed when he does not know what is about to happen; explain what will happen beforehand and remind him along the way.
- Look for triggers for Andreas' agitation and aggression so that these situations/people can be minimised or avoided wherever possible.
- Be aware of Andreas' nonverbal signs of increasing frustration or irritation e.g. fidgeting or restlessness so he can be distracted from the situation before he becomes aggressive.
- Family members could seek carer education to learn the most effective ways of supporting Andreas.
- Explain about Andreas' dementia and his need for positive social interaction and encourage extended family members who speak Italian to visit more often.
- Record significant aspects of Andreas' life history/events so friends and family can share in some of his past experiences and achievements when they visit; prompts such as photos, preferred music, films and/or family videos can make conversation easier and more rewarding.
- Consider activities in line with Andreas' previous interests such as Italian TV programs, opera and radio as well as playing cards and gardening.
- Family members and friends may be able to help reduce the couples' growing isolation by planning joint social activities and outings with them.
- Seek occasional respite care.

Some outcomes

- The Multicultural Aged Care Service was able to provide some resources in Italian and direct the family to further Italian materials provided by their local library, including Italian newspapers and magazines; Andreas enjoyed browsing these for short periods and Rosa was also able to use them to distract him at times.
- Andreas' mobility assessment was conducted at home; his stick was replaced with a safer mobility aid and the physiotherapist advised the family on how to reduce the risk of Andreas using the aid to hit out at others.
- Additional aids were installed in the home to reduce safety risks and assist Rosa to care for Andreas.
- While Rosa was reluctant to accept additional help in the form of services, she liked the care worker who was introduced; she initially accepted the visits as extra company for Andreas and in time allowed the worker to assist her with some household chores.
- The family continued to visit regularly and were happy to incorporate life history and Italian items into their interaction with Andreas.
- Andreas' outbursts were not completely eliminated however, Rosa was more aware of what could trigger the aggression and how to intervene early; she felt better supported and her confidence to continue caring returned.
- Rosa also came to understand that the aggression is a symptom of Andreas' dementia; she no longer felt she had to be ashamed or hide the situation from others.

Module 3: Agitation

Key messages

- Agitation in a person living with dementia presents as restless and repetitive behaviours that cause distress and typically appear purposeless.
- Agitation may worsen during the late afternoon or early evening; this is known as sundowning.
- People with dementia may react with agitation for many reasons, such as feeling unwell, uncomfortable, frustrated, tired, confused, bored and/or isolated.
- Suggested strategies:
  - Carers and others may need additional specific information around staying safe.
  - Identify triggers, frustrations and stressors so these can be reduced and/or avoided.
  - Recognise early cues that indicate increasing distress.
  - Acknowledge the person with dementia’s concerns.
  - Speak clearly and calmly while providing reassurance; don’t argue or attempt to reason.
  - Use a non-threatening approach.
  - Modify/simplify the person’s environment and routines.
  - Provide distraction through individually meaningful activities where appropriate.
  - Seek advice from health professionals and attend carer education.
  - Seek occasional respite.

Agitation

What is agitation and what does it look like in a person with dementia?

Agitation in people living with dementia presents as very restless and repetitive behaviours that cause distress and typically appear purposeless. Aggression is often linked to strong feelings of unease and impacts significantly on functioning. Agitation which worsens during the late afternoon or early evening is known as sundowning.

Agitated behaviours include:

- irritability and tension
- restlessness and/or repeated pacing
- excessive fidgeting and repetitive actions
- distressed calling out and/or resisting care.

People with lived experience of dementia have said that agitation may be a way of expressing frustration, fear, stress, worry, empathy, panic, anxiety, loss of confidence, intolerance, impatience and/or annoyance.

What causes agitation? When is it more likely to occur?

Agitation is a symptom of the physical and psychological changes that occur in a person with dementia due to altered brain chemicals and structures, particularly in the frontal and temporal parts of the brain. If the environment is confusing or unfriendly this may cause or exacerbate agitation in a person who is confused. Agitation is one of the most commonly occurring changed behaviours in dementia, tending to increase with dementia severity.

Agitation can be a sign that the person with dementia is:

- frustrated if they are unable to convey a physical need such as hunger, thirst or pain
- physically uncomfortable, unwell, dehydrated and/or

constipated

- disturbed by particular people and/or a situation in their environment
- lack of familiar people and/or surroundings e.g. someone they recognise or being unable to find a toilet
- tired or confused because of sleep disturbances and/or insufficient exposure to natural daylight
- bored, lonely or isolated
- overstimulated by factors in the environment e.g. too much noise, too many people, too much information
- frustrated by declining abilities e.g. unable to complete a task or activity
- attempting to communicate in their first language due to increasing difficulty speaking English i.e. only speaking in a language not understandable to others.

How does agitation affect the person with dementia and others?

Agitation is often viewed as one of the most challenging and persistent changed behaviours of dementia. Agitation is associated with significant carer burden and reduced quality of life for the person with dementia and their carers. Agitation can also prompt earlier admission to residential care and inappropriate use of restraint, including psychotropic medications.

What can be done to address agitation?

Ask the doctor:

- for urgent assistance, if you feel that the person living with dementia, you or others are at risk of harm
- to check for, and treat, underlying depression, delusions, hallucinations or an allergic reaction which could increase their irritability and/or restlessness

- to check if the person has symptoms of an underlying physical and/or psychiatric illness, pain or infection
- to consider relief from pain or fever
- to ensure that the person with dementia is not experiencing an acute delirium which has been misdiagnosed as agitation; delirium requires urgent medical attention
- to rule out medication side effects as a contributing factor
- for information about short-term medications which may help to reduce agitation if necessary for the safety of the person and/or others.

Non-drug interventions are recommended as the first strategy for agitation. Medication often provides limited benefit and should only be trialled when non-drug approaches have been unsuccessful. The risk of side effects limits the use of these medications.

Strategies to try:

- Care partners and others around the person including care staff may need additional, specific support and information around staying safe.
- Try to identify the cause of the agitation; identify individual triggers, frustrations and stressors for the person so these can be reduced and/or avoided.
- Note the frequency, severity and details of each agitated incident to help identify potential causes and patterns.
- It is important to know the person’s story and find out what has previously been meaningful and pleasurable to them.
- Consider how the person is feeling when planning the duration and degree of difficulty of an activity.

- Choose the person’s best time of day for an activity and stop before, or as soon as, they show signs of fatigue, agitation or distress.
- Recognise cues that indicate increasing upset, for example a reaction to background chatter, a nearby TV or roadworks outside the window; intervene to de-escalate or change the situation where possible.
- Choose priorities carefully; avoid causing the person stress over tasks that can wait until they are more settled and possibly better able to cope.
- Validate the person’s concerns by being reassuring, empathetic and attempting to allay their fears, rather trying to orientate or correct them.
- Speak clearly and calmly while reassuring the person with dementia; don’t argue or attempt to reason.
- Use non-threatening posture and movement in your approach.
- Modify/simplify the person’s home environment and routines to avoid frustrating situations where possible.
- Some research evidence has shown that recreational, music and sensory activities can help to reduce agitation.
- Seek advice from health professionals about calming, meaningful interventions relevant to the person’s interests which support their current strengths.
- Be aware that some forms of stimulation may provoke agitation e.g. group socialisation activities; consider a one-to-one walk or gentle hand massage.
- Attend carer education and training courses to increase skills and meet with other carers for friendship and mutual support.

- Seek occasional respite care.

Betty’s story

Betty is a 76 year old woman who lives in a residential care facility. She was diagnosed with dementia five years ago and in the past year has become increasingly agitated. Betty is sometimes considered by staff to be “difficult”. At times she is seen sitting at the dining table on her own, continuously rubbing the table top with her fingertips. She often flicks imaginary objects away with the back of her hand, while muttering to herself.

Staff ignore this behaviour and tend to leave Betty alone until she leaves the dining room and walks into other residents’ rooms. She repeatedly touches items on their walls and the situation can become risky when they are angry with Betty for intruding into their rooms. If the resident approaches her the tension tends to increase as Betty becomes increasingly upset and argumentative. Betty further reacts to the situation by becoming agitated and verbally aggressive. At times it appears that she may hit out.

The following have been checked:

- pain, discomfort, illness, infection and/or constipation that may be contributing to Betty’s agitation
- medication effects such as interactions, dosage, recent prescription changes and side-effects
- underlying depression, anxiety and delirium
- general health concerns including blood tests, urine tests and/or cognitive assessment as needed.

Other possible sources of irritation for Betty have been considered:

- too much stimulation from noise, people and/or activities in Betty's surroundings
- stress caused by any aspects that are unfamiliar or may have changed in Betty's immediate surroundings, carers and/or routine
- Betty's decreased ability to communicate effectively with others
- whether too much is expected of her for her current level of dementia and her ability to interpret aspects of her surroundings accurately
- Betty's reduced ability to cope with stress due to her advancing dementia
- tension when Betty is stopped from doing what she sees as necessary tasks.

A health professional has suggested the following strategies:

- Look for triggers for Betty's agitation so these situations can be minimised or avoided wherever possible.
- Encourage Betty to express her needs as far as she is able and allow her extra time to communicate.
- Be aware of Betty's nonverbal signs of increasing frustration or restlessness; try to avoid the situation from reaching a point where her agitation becomes a problem.
- Offer activities related to Betty's previous interests.
- Record significant aspects of Betty's life history and her achievements so that visitors, family and staff

can share these experiences with her and divert her from agitated thoughts; consider photos, preferred music and/or family videos as prompts for engaging Betty.

Some outcomes

- When asked, the family reported that when Betty was rubbing the table she wanted to finish paintings in time for an art exhibition; this was consistent with Betty’s previous work and lifestyle.
- When she was touching items on the wall in other residents’ rooms Betty was reportedly checking that her paintings had been hung ready for an exhibition.
- At times, showing Betty pictures hung on the walls in various communal spaces of the facility appeared to reassure her that her paintings were ready and in place for the exhibition.
- Betty responded well to being given large sheets of paper and safe art materials to do new artwork.
- Staff hung Betty’s new artwork throughout the facility and praised her efforts to other residents and visitors; Betty responded positively to these interactions.
- Library books on art with large pictures sometimes provided a useful distraction and helped family members connect with Betty during their visits.
- Although these strategies helped to reduce Betty’s agitation the incidents were not completely eliminated; staff understand that agitation is a symptom of her dementia.

- Staff felt better able to intervene to help reduce her agitation when Betty showed early signs of restlessness; these strategies also provided staff with opportunities for positive interaction with Betty.
- Betty’s family expressed some relief that she appeared to be less distressed and more comfortable living in the facility.

Module 4: Anxiety

Key messages

- Anxiety in a person living with dementia can present as tearfulness, excessive worrying, fear of abandonment, repeated questioning, distractibility, muscle tension, hand wringing and/or over-concern.
- Dementia reduces a person's capacity to make sense of their environment which can cause distress and anxious thoughts.
- Changes in the brain due to dementia make it difficult for them to control their emotional response to anxiety.
- Suggested strategies:
  - Carers and others may need additional support when excess anxiety is distressing.
  - Identify triggers, frustrations and stressors so these can be reduced or avoided.
  - Learn to recognise early signs of increasing anxiety and intervene where appropriate.
  - Speak slowly and reassuringly, don't argue or persist with attempts to reason with the person.
  - Provide reassuring structure and routine in the person's day.
  - Encourage safe walking if this eases anxiety.
  - Trial activities which support cognitive losses and build on the person's remaining skills.
  - Seek advice from health professionals and attend carer education.
  - Seek occasional respite care.

Anxiety

What is anxiety and what does it look like in a person with dementia?

Anxiety is a common and disabling condition in people living with dementia. It can present as tearfulness, fear of abandonment, repeated questioning, distractibility, excessive worrying about their health and/or over-concern. Agitation can occur in response to anxiety.

Signs of anxiety include:

- facial expressions and body language which indicate worry, distress and/or fear
- thoughts reportedly marked by worry, anguish and/or apprehension
- emotions such as fearfulness, unease and/or dread
- physical sensations such as feeling on edge, muscle tension, tremor, fatigue, nausea, over- or under-breathing, sweating, shortness of breath, headaches, sleeplessness and/or heart palpitations
- actions such as constant watchfulness, avoiding specific situations or people, hand wringing, pacing, restlessness and/or repeatedly asking for help
- searching for an absent carer or family member
- not wanting to be alone and as a result following the carer closely (*shadowing*).

What causes anxiety? When is it more likely to occur?

Excessive anxiety is a symptom of the physical and psychological changes that occur in a person with dementia due to altered brain chemicals and structures. Changes in the frontal and temporal areas of the brain can make it difficult for them to control their emotional response to anxious thoughts and feelings. Anxiety tends to vary with dementia type and levels of anxiety may increase as dementia progresses and then decrease during the late stages of the disease.

People with lived experience of dementia have said that anxiety may stem from worry over making errors, failing, forgetting, not recognising people, not following conversations and not finding a toilet in time.

Anxiety in a person with dementia may increase with:

- changes to their familiar routine or environment
- separation from a primary carer, feeling abandoned
- unrealistic deadlines, feeling rushed or pressured
- overstimulation, feeling overwhelmed, confused or frightened
- fatigue, dehydration or hunger
- fear of forgetting faces, names and/or significant information during interaction with others
- attempting to navigate an unfamiliar environment, for example finding the toilet in a restaurant
- isolation, lack of company and/or activities

How does anxiety affect the person with dementia and others?

People living with dementia may become anxious when dementia reduces their capacity to make sense of their environment. Those with early dementia and an awareness of their increasing difficulties may experience

high anxiety levels around the diagnosis. They may be concerned about making errors and/or failing at previously simple tasks. With advancing dementia, increased dependence in the form of shadowing or constantly seeking reassurance can be very stressful for carers.

What can be done to address anxiety?

Ask the doctor:

- about potentially untreated physical symptoms, such as illness, infection, constipation and/or chronic pain
- to assess for possible medication reactions, side effects or interactions which may contribute to the symptoms
- to check for other conditions which may overlap with the symptoms of anxiety such as depression, panic attacks or phobias
- to check for, and treat, underlying delusions or hallucinations where indicated
- to check for medical conditions such as overactive thyroid and/or anaemia
- about measuring the severity of the anxiety symptoms
- if very short-term treatment with medication is indicated for severe anxiety where non-drug strategies provide little benefit.

Non-drug interventions are recommended as the first strategy for anxiety. Evidence of benefit for medication is limited and side effects are common.

Strategies to try:

- Where others around the person find their excess anxiety distressing, additional, specific support and information may assist.
- Identify triggers, frustrations and stressors that may increase anxiety so these can be minimised and/or avoided where possible.
- Recognise signs of increasing anxiety in the person living with dementia and intervene to de-escalate or change the situation where appropriate.

- Simplify the environment and avoid overstimulation to reduce distress.
- When distress is evident, speak slowly and reassuringly, use non-threatening posture and movement; consider gentle touch where appropriate.
- Provide familiar structure and routine in the person’s day; reduce the need for them to make challenging decisions.
- Provide opportunities for safe walking or gentle exercise if this eases anxiety.
- Try activities which support the person’s cognitive losses, build on their remaining skills and are meaningful to the individual.
- Research provides evidence that recreational, reminiscence and music activities can help to reduce anxiety.
- Consider individual activities where other forms of stimulation e.g. group socialisation provoke anxiety.
- Attend carer education and training courses to increase skills as well as meet with other carers for friendship and mutual support.
- Seek occasional respite care.

Minh’s story

Minh is an 86 year old lady of Vietnamese background who lives at home with three generations of her family. When she migrated to Australia three years ago the family noticed that Minh had difficulties with her memory. This ultimately led to a diagnosis of dementia.

Extended family members live in the same street and visit socially but they do not provide assistance with her care.

Minh does not speak, read or write English. Her daughter is her main carer and she has become concerned about her mother's increasing anxiety. Minh is often unable to sit still, constantly follows her daughter around the home and repeatedly asks for assistance. Minh's spiritual beliefs have been important throughout her life. Her family is embarrassed when Minh becomes restless and walks around the church during services. Because of this, she no longer attends church with the family.

Her doctor has previously prescribed medication for Minh's anxiety. A culturally specific, in-home service has recently been cancelled and the family has become largely isolated from the local Vietnamese community. Minh's granddaughter is the only fluent English speaker in the home and the family often relies on her to interpret for them. The granddaughter reports that many of those in the community lack an understanding of dementia and the family is concerned that others will think that Minh is "crazy".

The following have been checked:

- pain/discomfort/illness/infection that may increase Minh's distress and anxiety
- medication effects such as interactions, dosage, recent prescription changes, side effects
- underlying depression and delirium
- general health concerns including blood tests, urine tests and/or cognitive assessment as needed
- if Minh is taking the antianxiety medication as prescribed.

Other potentially contributing factors have been considered:

- any recent changes to Minh’s surroundings and/or routine at home
- whether too much is expected of Minh for her current level of dementia; this may be increasing her distress
- Minh’s reduced ability to cope with stress due to her advancing dementia.

Minh’s granddaughter told the doctor that Minh was not taking her prescribed medication because other family members are unfamiliar with western medical practices and did not assist her to take it.

A health professional has suggested the following strategies:

- Observe for triggers that increase Minh’s anxiety so these situations/interactions can be avoided and/or addressed.
- Encourage Minh to talk about her concerns and fears as far as she is able and allow extra time for her to communicate.
- As Minh’s granddaughter is the only English speaker in the family, access to an interpreter who speaks the same dialect is important for assessment whenever possible.
- Ask staff from the recently cancelled community service if they have observed situations which may have contributed to Minh’s anxiety during their visits.
- Reduce Minh’s increasing isolation by providing pleasant, social activities and outings that she is comfortable with.

- Record positive aspects of Minh's life history and her achievements so visitors and family can share these experiences with her to distract her from anxious thoughts; consider photos, preferred music and/or family videos.
- Family members could seek carer education to learn information about changed behaviours and psychological symptoms associated with dementia and ways of assisting Minh.
- Be aware of strong community expectations that family must care for their aged relatives without assistance from "outsiders"; information on dementia for the extended family and community members may help.
- Seek occasional respite care.

Referrals were also made for the following:

- to try Minh in a day respite program that offers activities and outings for people with dementia including others from a Vietnamese background
- to the *Dementia Australia* website for *Help Sheets* available in Vietnamese.

Some outcomes

- Minh's family was provided with strategies to help ease her anxiety and avoid increasing her distress; they were often able to distract her from anxious thoughts by offering activities, food and/or company she enjoyed.
- Information about dementia and changed behaviours was provided in Vietnamese in written and electronic

format so this could be shared with extended family, friends and interested neighbours as appropriate.

- It was discovered that the family cancelled the community services because they feared Minh might be removed from the family home by “officials”; information and reassurance was provided to encourage them to accept assistance and talk about concerns they may have in the future.
- Family members were able to suggest activities that Minh previously enjoyed and/or are related to her spiritual beliefs.
- The family was provided with further information around the purpose of the medication and how long Minh needs to take it before her symptoms may reduce; her daughter is also aware of the need to prompt her mother to take it.
- Extended family members were willing to assist when made aware of the situation and Minh was able to resume attendance for part of the church service with others helping to supervise her; the family also chose a service that was less crowded.
- Minh’s trial at the day respite centre was arranged during school holidays so her granddaughter could initially travel with her on the bus and help her to settle in.
- Minh was able to interact successfully with a lady at the centre who had migrated from an area close to where Minh lived in Vietnam.

Module 5: Apathy

Key messages

- Apathy in a person living with dementia is marked by a lack of interest, reaction and/or distress in response to their environment and/or other people.
- Apathy is one of the most commonly occurring psychological symptoms of dementia and tends to increase as dementia progresses.
- Although a person with apathy in dementia may appear lazy, this is not the case.
- Apathy is a symptom of the physical and psychological changes that occur in the brain.
- Apathy can also occur as a reaction to a lack of stimulation, social contact and/or sensory impairment.
- It is important to distinguish apathy from depression.
- Suggested strategies:
  - Encourage activities that are tailored to the person's abilities, do not require initiative and can be shared with others.
  - Ensure activities offered are individually meaningful and reflect the person's previous interests.
  - Consider reminiscence, multisensory, cognitive rehabilitation and music activities to help reduce apathy.
  - Allow the person flexibility and extra time to attempt and complete tasks.
  - Attend carer education and seek occasional respite.

Apathy

What is apathy and what does it look like in a person with dementia?

When a person living with dementia has apathy, they may become passive, inactive, show less emotion and lack initiative and/or reactions, as well as lose interest in everyday activities. It is important to keep in mind that apathy is NOT a normal part of ageing, and it differs from depression in that the person with apathy is typically neither sad nor distressed.

Symptoms of apathy include:

- diminished emotional reactivity or expression
- indifference to their surroundings and other people
- absence of willpower and drive
- low energy and lack of motivation, appearing to be 'stuck' sitting in one place for long periods of time
- reduced spontaneity, ability to self-start everyday activities and conversations
- poor persistence when attempting tasks
- adopting a submissive role (passivity) in many situations
- little or no interest in, or engagement with, other people.

Apathy may be most evident when:

- a display of feelings and emotions is typically called for such as when greeting friends and family or receiving sad or happy news; the person's reactions can seem flat and uncaring
- initiative is required such as spontaneously attending to activities of daily living; the person's actions appear passive and uninterested
- a quick reaction or response is required such as in a

situation where personal safety is at risk; the person may display no sense of urgency or awareness of danger.

What causes apathy? When is it more likely to occur?

Apathy is a symptom of the physical and psychological changes that occur in a person living with dementia due to altered brain chemicals and structures. Changes in the frontal areas of the brain are associated with loss of motivation. Apathy is one of the most commonly occurring symptoms of dementia and it tends to increase as dementia progresses. Apathy can also occur as a reaction to a lack of stimulation in the person's physical and/or social environment due to isolation or a lack of opportunities for meaningful interaction as well as sensory impairment due to poor hearing or vision.

People with lived experience of dementia report that apathy may arise from cognitive overload, dependency, memory loss, communication difficulties, and lost confidence.

How does apathy affect the person with dementia and others?

Carers and families can find it difficult to understand that apathy is not laziness but that it is due to brain changes which cause the person to lose voluntary control. Family life and relationships are often disrupted as a result. Apathy is associated with increased disability and frustration as well as poorer quality of life for both those living with dementia and their carers.

Apathy leads to reduced independence particularly as those who are living alone may neglect themselves and be unable to follow their medication regimen. Those with dementia and apathy living in residential care tend to be undemanding and hence receive less attention.

What can be done to address apathy?

Ask the doctor:

- to check for other conditions which may overlap with the symptoms of apathy such as underlying depression or a reaction to grief

- about potentially untreated physical symptoms, such as infection, illness, constipation and/or poorly managed chronic pain
- to assess for possible medication reactions, side effects or interactions and investigate whether the onset of apathy coincides with starting new medication
- to check for medical conditions such as underactive thyroid or adrenal gland and high calcium levels in the blood
- if potential non-compliance with the person's regular medications due to apathy could be affecting their well-being.

Non-drug interventions are recommended as the first strategy for apathy. Evidence of benefit for medication is limited and side effects are common.

Strategies to try:

- Arrange activities that do not require initiative and can be shared with others; people with dementia and apathy may retain their capacity to undertake activities even when unable to start or continue independently.
- Choose activities that are tailored to the person's abilities and hence, not too difficult for them to feel some sense of achievement and boost confidence.
- Ensure activities reflect the person living with dementia's previous interests and current abilities.
- Use a structured routine; it may help by providing a framework for activities to engage the person.

- Consider a trial of reminiscence, multisensory, cognitive rehabilitation and/or music activities as research provides some evidence that these interventions can help to reduce apathy.
- Attend carer education and training courses to increase skills and meet with other carers for friendship and mutual support.
- Seek occasional respite care.

While the benefits of activities and/or therapies may not be evident when an intervention ceases, the person with dementia may continue to experience some subtle but positive effects to their well-being.

Liz's story

Liz, 66 is a recently retired mother of two who was diagnosed with dementia soon after retirement. She has always been a very busy and active lady. Her partner Bev has previously worked long hours. This has meant that in the past year Liz has been by herself at home for long periods of time. Liz's daughters usually come in the evenings or on weekends but occasionally they visit when Bev is at work during the day. Bev's son also visits with his young children. The family have recently noticed that Liz is doing less during the day when she is home alone.

After she retired, Liz was preparing meals so dinner was ready when Bev came home from work. Liz also enjoyed the company of long-term friends a few times a week.

Over the past couple of months, Liz appears to have lost interest in cooking and eating. She no longer initiates contact with her children. When they visit she seems quiet and uninterested. Bev has noticed that Liz is no longer taking pride in her appearance and does not shower as often as she used to. Her family are concerned that Liz has become "lazy" although they have noticed that she can still complete tasks quite well if they start them for her. Liz's daughters are frustrated by the change in their mother.

The following have been checked:

- pain, discomfort, illness, infection and/or constipation that may be contributing to Liz's lack of motivation
- medication effects such as interactions, dosage, recent prescription changes or side effects
- possible hypoactive delirium
- underlying depression or a grief reaction such as Liz feeling the loss of her work role
- untreated hearing or vision impairment
- general health concerns including blood tests, urine tests and/or cognitive assessment as needed.

Other potentially contributing factors have been considered:

- boredom, not enough stimulation from the home environment/activities relative to the demands of Liz's previous work role
- Liz's reduced ability to start activities for herself
- activities that Liz previously enjoyed may have become too difficult for her to plan and organise so her response is to avoid them
- previous personality and interests.

A health professional has suggested the following strategies:

- Work within the limits of Liz's level of motivation as the family now understands that she has not become lazy and her symptoms are associated with her advancing dementia.
- Consider whether Liz made a choice to retire or if she was asked to retire; this may affect her response to the situation.
- Increase family visits during the week to provide Liz with more company.
- Liz's daughters could seek carer education to learn the most effective ways of supporting her and meet other carers for friendship/support.
- Reduce Liz's increasing isolation by planning social activities and outings with her.
- Seek occasional respite care.

Referrals were also made for the following:

- Additional community services to provide a care worker who can encourage and assist Liz to engage in her daily activities and household tasks.
- Encourage Liz to attend a weekly group that offers activities and outings for people with dementia.
- Hearing and vision assessments as these have not been done for some time.

Some outcomes

- Liz's daughters and Bev's son planned their visits so Liz would have company on more days of the week when Bev is at work.

- The family have discussed potential ways to motivate Liz to re-engage with past interests; because she used to love gardening her daughter bought seedlings and they made plans to plant them together.
- Bev's daughter in-law now regularly calls in after she collects her children from school one afternoon a week; Liz responds positively to the children's requests for her attention.
- The family have contacted Liz's friends to explain the effects of her dementia and apathy; they now actively initiate and include Liz in social activities because they realise that she is no longer able to do this for herself.
- Community services were able to provide a care worker two mornings a week as well as someone to take her out for an afternoon.
- Bev has re-evaluated her ongoing time commitment to her job and reduced her working hours by one day a week to spend more time with Liz.
- Bev and Liz now do the meal planning and shopping together.
- They are now going out to see a movie or show each weekend as they did in the past.
- Liz appears to enjoy the additional social contact and activities she can share with her family and friends.

Module 6: Calling out

Key messages

- When a person living with dementia calls out or makes continuous or intermittent noises this can be referred to as vocal disruption.
- Calling out can occur in response to a change in environment and/or routine, unmet needs, social isolation, communication difficulties, feeling unwell, hallucinations and/or delusions.
- Repetitive questioning, screaming and/or other forms of calling out can be irritating, distressing and exasperating for others around the person with dementia, which can place them at risk of harm.
- Calling out can peak in the afternoon/early evening when associated with sundowning.
- Suggested strategies:
  - Identify and relieve frustrations, stressors and irritants where possible.
  - Recognise signs that indicate increasing upset and consider strategies to intervene.
  - Modify the person's environment to support orientation.
  - Positively reinforce appropriate behaviours.
  - Minimise perceived threats to the person with dementia's space, dignity, privacy and/or safety.
  - Consider appropriate social contact as well as relaxing/calming activities.
  - Attend carer education.
  - Seek occasional respite care.

Calling out

What is calling out and what does it look like in a person with dementia?

People living with dementia may make continuous or intermittent noises such as calling out or uttering other sounds. These are commonly quite loud. Health professionals may refer to this as vocal disruption.

Calling out can include:

- cursing, swearing, verbal aggression
- screaming, shouting
- repetitious sentences/questions/actions
- complaining, groaning, sighing
- constantly requesting attention, calling for a loved one
- singing at times when this disturbs others
- grunting, making odd noises that appear purposeless.

Calling out can be classified as one of the following:

- a response to the environment
- apparently directed towards eliciting a response
- chatterbox noises
- apparently purposeless
- those which occur in the context of hearing impairment.

What causes calling out? When is it more likely to occur?

Calling out or vocal disruption is a symptom of the physical and psychological changes that occur in a person with dementia due to altered brain chemicals and structures. As brain functioning becomes increasingly impaired with the progression of dementia, calling out tends to occur more frequently. It may peak in the afternoon or early evening when associated with sundowning.

This is a period of increased confusion, restlessness and/or distress in the person living with dementia which tends to occur at the end of the day.

Calling out may occur in response to:

- an unsettling change to the person's familiar environment and/or routine
- unmet needs such as hunger, thirst, pain, discomfort, fatigue and/or constipation
- discomfort, pain, distress or anxiety during personal care activities such as bathing, feeding or toileting
- social isolation, boredom and/or communication difficulties
- reliving or remembering previous/ongoing experiences of trauma
- forgetting information they have been told previously
- forgetting, or anxiety associated with, what may be happening, planned and/or expected of them
- hallucinations or delusions.

People with lived experience of dementia have said that calling out can stem from memory lapses, anxiety, agitation and/or fear.

How does calling out affect the person with dementia and others?

Calling out tends to cause carers, family and others in their environment significant distress, frustration and stress, particularly when it is repetitious. Likewise, neighbours and visitors can be disrupted when the calling out is loud. When the person with dementia is living in residential care, this can be distressing for other residents and care staff. The person living with dementia may be at risk of harm from others in their environment who find it difficult to tolerate their prolonged periods of calling out.

What can be done to address calling out?

Ask the doctor:

- to check for other conditions which may cause the vocalisations such as delusions, hallucinations, depressed mood, delirium, hearing loss or increased confusion
- about potentially untreated physical symptoms, such as infection, acute illness, constipation and/or poorly managed chronic pain
- to assess for possible medication reactions, side effects or interactions.

Where there is no safety risk to the person or others non-drug interventions are recommended as the first strategy for reducing calling out. Good evidence for medication is lacking, unless treating other conditions which may be contributing to the calling out.

Strategies to try:

- It is important to know the person's story and find out what has previously been meaningful and pleasurable to them.
- Avoid confrontation which can exacerbate the situation.
- Identify and relieve, where possible, individual triggers, frustrations, irritants and stressors such as uncomfortable clothing, excess noise or glare.
- Research indicates some evidence for decreased calling out with modifying the person's environment to support orientation.
- Provide orientating cues and structure to the immediate environment to help reduce confusion and misinterpretation.

- Recognise signs in the person living with dementia which suggest increasing distress and intervene to de-escalate or change the situation where possible; consider activities they find calming.
- Monitor for fatigue and relieve with rest periods.
- Relieve discomfort wherever possible; consider access to the toilet, adequate food and fluids, lighting as well as environmental temperature.
- Facilitate expression of the person’s emotions such as anger, grief, frustration and helplessness in a more appropriate way.
- Provide positive reinforcement during times when the person vocalises appropriately and/or is quieter.
- Minimise perceived threats to the person’s space, dignity, privacy and/or safety.
- Provide positive social contact and interaction.
- Some forms of stimulation may provoke calling out e.g. group music therapy; consider individual sessions of relaxation, favourite music and/or time spent outdoors.
- Check that glasses and hearing aids are working, fitted correctly (if the person agrees) and their prescription is current.
- Attend carer education and training courses to increase skills as well as meet with other carers for friendship and mutual support.
- Seek occasional respite care.

Gwen’s story

Gwen, an 82-year-old lady with chronic arthritis and dementia, has been a resident of an aged care facility for several years. Her advancing dementia has led to her being unable to communicate verbally but her calling out for no apparent reason has increased. When staff attend to Gwen's showering or toileting she screams loudly. Staff looking after Gwen are aware that she experiences pain from arthritis. Her medication chart indicates that she is prescribed pain relief as required.

Gwen's repeated calling out now causes significant distress to others around her, particularly her fellow residents. Staff members frequently express their frustration and despair while trying to avoid Gwen's room. Families of other residents have complained that their relative should not have to put up with the noise.

On occasion, neighbours have made complaints to police requesting investigation of possible maltreatment. Gwen's only visitors are her niece and an elderly friend who now visit less often because they are embarrassed by the reaction of others in the aged care facility.

The following have been checked:

- illness, pain, infection and/or constipation that may be contributing to Gwen's distress
- medication effects such as interactions, dosage, recent prescription changes, side effects
- underlying depression, delusions, hallucinations and delirium
- general health concerns including blood tests, urine tests and/or cognitive assessment as needed.

Other potentially contributing factors have been considered:

- too much stimulation from excess noise, people or activities in Gwen’s immediate surroundings
- Gwen’s decreased ability to communicate her needs or concerns
- whether too much is expected of her for her current level of dementia; she is unable to understand the impact of her calling out on those around her
- stress caused by changes to her carers, routine and/or surroundings
- Gwen’s reduced ability to cope with stress due to her advancing dementia.

A health professional has suggested the following strategies:

- Undertake a pain assessment for review of Gwen’s chronic pain management due to osteoarthritis.
- Bring staff together who know Gwen well to brainstorm possible reasons for the calling out, other than personal hygiene tasks.
- Complete a behavioural observation chart to identify further triggers and possible strategies that may reduce the calling out.
- Review continence aids to reduce the need for frequent changes as care tasks obviously increase Gwen’s distress.
- Consider additional non-drug ways to relieve pain such as gentle heat and massage.

Some outcomes

- Pain assessment indicated that Gwen was receiving medication for pain relief less frequently than she did when she was previously able to request it herself.
- Assessment also indicated that her pain relief was inadequate; medication was reviewed and increased to better meet her needs and long-acting patches were added to the regimen.
- Personal hygiene activities were an obvious source of Gwen’s pain; a standing medication order was put in place for pain relief to be given approximately 30 minutes before her shower.
- Staff members were aware of helping Gwen to shower at the scheduled time whenever possible as this was also easier for them when Gwen was cooperative.
- Staff also felt that Gwen was isolated and perhaps starved of positive human contact.
- Behavioural observation revealed that Gwen responded positively to gentle touching and stroking; a kind volunteer was trained to provide gentle touch to Gwen’s hands and arms regularly.
- Her niece and friend were also happy to provide gentle touch when they visited; as they became more confident that they could do something to help Gwen they visited more often.
- While no strategy was successful on every occasion, playing Gwen’s favourite music and aromatherapy were sometimes effective in reducing her calling out.
- Improved management of Gwen’s pain substantially

reduced her calling out; when Gwen did call out staff and her visitors felt better able to help reduce her distress.

Module 7: Delusions and hallucinations

Key messages

- People living with dementia may experience disturbances in the way they see and/or understand reality; this experience is known as psychotic symptoms.
- It is important to confirm that the claims of the person are neither true nor actually happening before seeking treatment e.g. claims of theft may be true and/or a person who claims that “others are living in my home” may be correct if they are living in residential care.
- Delusions and/or hallucinations may be experienced as neutral or distressing; those experiencing distress require more urgent and active treatment.
- Suggested strategies:
  - Identify potential triggers in the physical environment; where possible modify or eliminate.
  - Avoid overreaction, arguing and/or attempting to correct the person living with dementia.
  - Seek information and support as observing these symptoms may be distressing for those close to the person with dementia.
  - Where possible distract the person from a situation which is increasing their distress.
  - Consider activities which support the person’s current strengths and are individually meaningful to them.
  - Attend carer education.
  - Seek occasional respite care.

Delusions and hallucinations

What are delusions and hallucinations and what do they look like in a person with dementia?

People living with dementia may show disturbances in the way that they see and/or understand objective reality. These disturbances, known as psychotic symptoms are a common feature of dementia. They fluctuate in intensity, occur intermittently and may return again once present.

Psychotic symptoms can include:

- delusions - fixed false beliefs that are not shared by others and cannot be swayed by logical arguments
- hallucinations – are typically auditory or visual; hearing or seeing things that are not there i.e. without an external stimulus; they can also occur in other sensory modes such as touch, smell or taste
- misidentification – occurs when external stimuli such as items and/or people are actually present in the person’s environment but mistaken for something or someone they are not.

The content of false beliefs and perceptions can include:

- delusions of theft, suspicion, abandonment, danger, misidentification, infidelity, believing that one’s house is not one’s home or that a loved one is an imposter
- thoughts linked to religious/spiritual beliefs and/or cultural background
- misinterpretation of the environment which can be exacerbated by sensory impairment such as poor eyesight or hearing.

What causes delusions and hallucinations? When are they more likely to occur?

Delusions and hallucinations are symptoms of the physical and psychological changes that occur in a person with dementia. These changes are due to altered brain chemicals and structures. Psychotic symptoms tend to increase in frequency initially and then decrease in the later stages of dementia.

Delusions and hallucinations can occur if the person living with dementia is in pain, unwell or has a fever. They can also occur with infection and in delirium. Seek medical advice and in the meantime consider relief from pain and fever.

Delusions are the most frequently reported of the psychotic symptoms, followed by hallucinations and then misidentification. Hallucinations are more common in particular types of dementia such as Lewy body dementia.

How do delusions and hallucinations affect the person with dementia and others?

Psychotic symptoms are associated with increased carer burden as well as reduced quality of life and physical health for both the person living with dementia and the carer. Delusions and hallucinations can also prompt earlier admission to residential care.

Not all hallucinations and delusions cause distress for the person with dementia. For example, hallucinations can include images of a much loved, deceased parent which may actually provide some comfort. If the psychotic symptoms are neutral or *benign* it may be appropriate to enlist education and support for the others involved but not necessarily seek treatment for the person with dementia.

What can be done to address delusions and hallucinations?

Psychotic symptoms may be experienced as neutral or distressing; those experiencing distress require more urgent and active treatment. It is important to initially confirm that the claims of the person with dementia are neither true nor actually happening before proceeding.

Ask the doctor:

- for help, if you feel that the person living with dementia, yourself or others are at risk of harm
- to check if the person has symptoms of depression, infection, delirium, the effects of drugs or alcohol or an underlying, medical condition e.g. disturbances of the endocrine and/or metabolic systems
- to check if the person has pain that they may be unable to describe as research provides some evidence that better pain management can decrease delusions
- about the relevance of the person's psychiatric history such as previous depression, schizophrenia, bipolar disorder or psychosis
- to check if symptoms coincide with starting or stopping medication
- to refer for assessment of sensory impairments and/or review of hearing aids and/or glasses
- whether short-term medication is indicated where the person is distressed by the delusions or hallucinations and/or the person living with dementia and/or others are at risk.

Where there is no distress or safety risk, medications are not recommended for delusions or hallucinations; medications have limited benefits and risk causing side effects.

Strategies to try:

- Try to avoid overreaction and/or arguing to correct the person with dementia which can induce humiliation, agitation and/or aggression; be aware that the experience is *real* for them.

- Where possible distract the person from a situation which is increasing their distress by offering activities, food and/or company they enjoy.
- Identify potential triggers for misidentification in the physical environment so these can be modified or eliminated; for example, areas of shadow or patterned floor coverings and curtains can be misinterpreted; mirrors can be alarming when the person does not recognise their own reflection.
- Seek information and support as observing psychotic symptoms may be more distressing for others than for the person living with dementia.
- Try activities which support the person’s current strengths and are meaningful to them as well as tailored to their individual interests as these may provide some relief from symptoms.
- Attend carer education and training courses to increase skills as well as meet with other carers for friendship and mutual support.
- Seek occasional respite care.

People with lived experience of dementia have said that educating others about dementia and accepting the reality of the person can be helpful.

Jack’s story

Jack is a 68-year-old Aboriginal man from a remote community in the Northern Territory. He has a diagnosis of dementia and cataracts in both eyes. He is dependent on his daughters for care, but they are currently finding it difficult to meet his increasing needs and their other family responsibilities.

Jack recently started attending a day respite service. He is wary of care staff at the centre, particularly those who are from non-Aboriginal or Torres Strait Islander backgrounds, telling his family that they try to beat him. He believes staff at the day respite centre want to take him away from his community.

His family also report that Jack has recently been distressed by seeing “evil spirits” and feeling “snakes coming out of his eyes”. At times Jack has attempted to run away from staff at the day respite centre, which places him at risk.

The following have been checked:

- pain, discomfort, illness, infection and/or constipation that could be contributing to Jack’s distress and symptoms
- possible delirium
- medication effects such as interactions, dosage, history, recent prescription changes, side effects or not taking medications as prescribed
- history of psychiatric illness
- sight and hearing function as a decline in these can cause information to be misinterpreted
- general health concerns including blood tests, urine tests and/or cognitive assessment as needed
- whether surgery may be an option for Jack’s cataracts as this could be contributing to his misinterpretation of his surroundings; followed up with a referral to an eye surgeon in Darwin for assessment

- other medical conditions affecting Jack's eyes which could be contributing to his distressing sensations
- whether antipsychotic medication is indicated for Jack's symptoms.

Other potentially contributing factors have been considered:

- any change to Jack's routine, unfamiliar people and/ or, reduced time spent with family and community
- lack of attention to culturally- and/or spiritually-relevant needs
- changes to Jack's immediate surroundings or unfamiliar aspects of the physical environment
- Jack's reduced ability to cope with stress due to his advancing dementia
- some of the respite centre staff lack experience with clients who present with delusions or hallucinations which means that they are frightened of Jack, and this further isolates him.

English is not Jack's first language and he has had little opportunity for formal education so communication with respite centre staff and other attendees is limited; this further increases the potential for Jack's misinterpretation of their intentions.

A health professional has suggested the following strategies:

- Observe for triggers in situations that put Jack at risk such as attempting to leave the respite centre on his own; consider strategies to reduce/avoid these situations where possible.

- Ask respite centre staff if they are aware of triggers that may contribute to Jack’s symptoms.
- Gather additional information on Jack’s life story to try to identify historically/culturally relevant factors which may be contributing to his symptoms.
- Encourage Jack to express his concerns and distress as far as he is able.
- Be aware of signs such as facial expressions and body movements that suggest Jack’s agitation is escalating; try to divert his attention to something of interest before his distress increases.
- Provide appropriate activities related to Jack’s past interests to help keep him engaged.
- Picture aids developed with assistance of community members familiar with Jack’s first language could be used to support communication.
- Consider education for respite centre staff in how delusions and hallucinations can present in people with dementia and the importance of trauma-informed care for clients with the lived experience of trauma.
- Offer carer education for family and community members to support a better understanding of underlying factors and possible strategies to reduce Jack’s symptoms and distress.

Some outcomes

- Jack’s medical assessment indicated a number of underlying medical issues which may be contributing to his symptoms; a decision was made to treat these before considering a trial of antipsychotic medication.

- Staff at the respite centre were provided with training in delusions, hallucinations and strategies to assist them to deal with Jack's symptoms as well as the ongoing impacts of trauma in people with dementia and the need for trauma-informed care.
- Discussion with the family revealed that Jack's background as a member of the stolen generation may be relevant to his fear of being taken away from *Country* and his community.
- Two community members attended the day respite centre with Jack for a short period to assist in his adjustment to the unfamiliar environment.
- The respite centre is located in different *Country* to Jack's, causing him distress when he forgets that he will be returning home later in the day; staff at the centre now provide regular reassurance.
- An older Aboriginal man who is a nearby neighbour to the respite centre was originally from the same community as Jack and had some knowledge of his first language; he was available and willing to regularly spend some time *yarning* with Jack when he was at the centre.
- With the family's input, staff at the centre now provide Jack with activities relevant to his interests.
- Those providing Jack's care felt better able to understand and manage his symptoms without fear.

Module 8: Depression

Key messages

- Symptoms of depression in a person living with dementia include feeling unhappy, crying, withdrawing from others, loss of interest, reduced activity, fatigue, change in appetite, sleep disturbance and/or sometimes, thoughts of suicide.
- If the person with dementia is severely depressed, expressing suicidal thoughts, experiencing delusions or hallucinations or refusing to eat and/or drink seek medical attention urgently.
- Depression is one of the most commonly occurring psychological symptoms and rates vary with different types of dementia.
- Depression can be a symptom of the changes that occur in the brain with dementia.
- A person living with dementia may experience depressive symptoms when they are no longer able to control or deal with upsetting memories.
- Suggested strategies:
  - Consider individually tailored activities that are meaningful and previously enjoyable to the person.
  - Discuss the potential benefits of cognitive behavioural therapy (CBT) with a health professional.
  - Modify aspects of the person’s surroundings to include items that previously gave them pleasure.
  - Attend carer education.
  - Seek occasional respite.

Depression

What is depression and what does it look like in a person with dementia?

When a person living with dementia is depressed, their mood has been continuously low for more than two weeks. It is important to keep in mind that depression is NOT a normal part of ageing. Seek urgent medical advice if the person has thoughts of self-harm and/or suicide.

Depression is one of the most commonly occurring psychological symptoms although rates vary with different types of dementia. It can occur at any stage of dementia but tends to occur less frequently in the later stages.

Depressive symptoms include:

- unhappiness, tearfulness, hopelessness, negativity, feelings of worthlessness and/or low self-esteem
- increased anxiety, agitation, restlessness, psychotic symptoms and/or aggression
- withdrawal from other people, loss of interest
- slowed movement and/or speech
- physical symptoms such as fatigue, change in appetite, weight loss and/or sleep disturbance
- unable to find pleasure in activities or the company of others that they previously enjoyed
- thoughts of self-harm and/or suicide.

Depression in dementia can be difficult to diagnose because symptoms of dementia, such as apathy, overlap with those of depression. It is important to confirm that the symptoms of low mood are different from the person's usual behaviour and not due to a medical condition or other symptoms of dementia. Depression varies in intensity, ranging from mild to moderate to severe and relapses often occur following improvement in symptoms.

IMPORTANT
If a person with depression in dementia is expressing suicidal thoughts, has stopped eating/drinking or is experiencing psychotic thoughts (out of touch with reality) and/or acting on delusions and hallucinations or in a way that may be dangerous, contact the psychiatric crisis team or arrange transport to the closest hospital emergency department urgently.

What causes depression? When is it more likely to occur?

Depression is a symptom of the physical and psychological changes that occur in the brain of a person with dementia due to altered brain chemicals and blood flow. Damage to certain brain structures may increase the likelihood of depression. A person living with dementia may experience depressive symptoms when they are unable to control or deal with upsetting memories.

People with lived experience of dementia have said that depressive symptoms can reflect feeling muted, vulnerable, frustrated and/or pessimistic.

A person with dementia's risk of developing depression increases if they:

- have experienced depression in the past
- are female
- have a close relative with a history of depression
- have poor general health
- have recently experienced a major loss
- developed dementia at a younger age.

How does depression affect the person with dementia and others?

- Unhappiness, tearfulness and negativity discourages others from attempting contact and/or interaction potentially leading to social isolation for the person living with dementia and their carers.
- Loss of interest and withdrawal makes it difficult to engage the person in previously pleasurable activities.
- Fatigue can prevent the person from attempting to engage with others and further reduce motivation.
- Sleep and appetite disturbance are disruptive to routines and make it more difficult for the person and the carer to engage in pleasurable activities with others.
- Low self-esteem and a sense of hopelessness require constant and exhausting reassurance from others.
- Thoughts of suicide require watchfulness around the clock and significantly increases the burden of responsibility for others.
- Other illnesses and/or medical conditions occur more frequently in those with depression.

What can be done to address depression?

Ask the doctor:

- to assess symptom severity and the risk of the person with dementia harming themself
- to check for other conditions which may overlap with the symptoms of depression e.g. apathy may be misdiagnosed as depression
- to check if the person has pain that they are unable to describe as those with chronic pain are more at risk of depression
- to check for potentially untreated physical symptoms

such as infection, illness and/or constipation

- to check for physical conditions e.g. low thyroid, high calcium or low blood count
- if treatment with medication or other therapies is indicated, how long after starting medication is an improvement in depressive symptoms likely to be evident.

Strategies to try:

- Unless the person is at risk of harm e.g. suicidal, not eating or drinking, or experiencing delusions or hallucinations, non-drug interventions are recommended as the first strategy for reducing depression.
- Provide activities that are tailored to the person's interests and current strengths which support them to feel some sense of achievement.
- Research provides evidence that reminiscence, music and education for carers can help to reduce depressive symptoms in people living with dementia.
- Modify aspects of their surroundings to include items that previously gave them pleasure.
- Ask a health professional about psychological therapies with carer participation.
- Depression can be frustrating for those around the person but it is important to avoid confrontation.
- Attend carer education to increase your understanding of depression and what it means for the person.
- Spend time with other carers to facilitate friendship and mutual support.
- Seek occasional respite care.

Stefan’s story

Stefan is a 65-year-old man who was born in Poland. After migrating to Australia, he married, raised three children with his wife, Olga and ran his own business until he retired. Olga describes him as determined and of strong character. The couple live in their own home and their children visit regularly to provide support.

Olga is finding it increasingly difficult to persuade her husband to attend family events and the dementia day centre. Staff at the centre have told Olga that Stefan can become verbally aggressive when they attempt to include him in activities he previously enjoyed.

Olga reports that she finds it stressful when her husband refuses to go to the day centre as she misses the break this provides. She then finds it more difficult to tolerate Stefan’s low mood and remain patient with him. Olga also reports that Stefan has become increasingly sad and tearful over recent months which is out of character for him. On occasion he has told her that she should “put him away” because he is too much trouble for the family.

Stefan reportedly experienced the harshness of wartime Europe as a teenager. He has rarely spoken of these experiences, but it is known that his parents and siblings did not survive the war. With the progression of dementia, Stefan has become more focused on the unpleasant memories of his past traumatic experiences. He has recently expressed feelings of guilt around his survival.

The following have been checked:

- pain, discomfort, illness, infection and/or constipation that may impact on Stefan’s mood

- medication effects such as interactions, dosage, recent prescription changes, side effects
- possible hypoactive delirium
- history of previous depression
- general health concerns including blood tests, urine tests and/or cognitive assessment as needed
- whether antidepressant medication is indicated for Stefan's symptoms.

Other potentially contributing factors have been considered:

- stress from any unfamiliar or changed aspects of Stefan's surroundings and/or routine
- Stefan's reduced ability to cope with stress due to his advancing dementia
- whether too much is expected of him for his current level of dementia
- lack of attention to culturally and historically relevant needs at the day centre.

A health professional has suggested the following strategies:

- Look for factors that may contribute to Stefan's low mood so these situations can be modified wherever possible.
- Ask day centre staff if they have identified specific situations that cause Stefan distress when he is there.
- Consider education for day centre staff to raise awareness of trauma-informed care. Stefan is not their only client with lived experience of trauma.

- Encourage Stefan to express his thoughts and concerns as far as he is able; he is having some difficulty expressing himself so allow him extra time to communicate.
- Stefan's family could seek carer education to learn the most effective ways of supporting him and meet other carers for friendship/support.
- Consider activities related to Stefan's past interests and culturally significant occasions that could be incorporated into his visits to the day centre.

Referrals were also made for the following:

- psychogeriatric assessment to assist in treatment of Stefan's post-traumatic stress and depressive symptoms
- community services to provide in-home respite
- the Multicultural Aged Care Service in their area for further suggestions and resources.

Some outcomes

- Medical assessment confirmed a diagnosis of depression, and a trial of antidepressant medication was recommended; Olga was told that potential benefits may not be evident for two or more weeks.
- A bilingual/bicultural staff member from the day centre was transporting a lady who could not travel on the bus; arrangements were made for her to also collect Stefan and he responded well to the culturally relevant attention she provided.
- Each of Stefan's children arranged to spend a few hours with him on different days at the day centre

to help him re-engage with the other attendees and activities at the centre; Stefan was proud and pleased to have his children there.

- Day centre staff received training in supporting people with depression and post-traumatic stress in dementia as well as providing trauma-informed care.
- In time Olga was aware of Stefan's mood lifting; she was pleased when he was willing to once again be involved in family events.

Module 9: Sleep pattern changes

Key messages

- The loss of regular or previous sleep patterns is common in people living with dementia; health professionals may call this nocturnal disruption.
- Disruptive changes to sleep patterns tend to increase with dementia severity.
- These can occur in response to physical factors, a change in surroundings, disruption to night-time environment, insufficient daylight exposure and/or medication side effects.
- Suggested strategies:
  - Identify triggers, frustrations and stressors which can be avoided or reduced before bedtime.
  - Identify and treat potential discomfort which may contribute to nighttime symptoms.
  - Learn to recognise cues that indicate distress and intervene early where possible.
  - Modify the home/bedroom environment and routine to promote restful sleep.
  - Ensure adequate natural light exposure and appropriate physical exercise during the day.
  - Adjust routines and adopt familiar evening activities to provide the person with cues that the time for sleep is approaching.
  - Try traditional methods to promote sleep, for example warm milk or gentle massage.
  - Attend carer education.
  - Seek occasional respite care.

Sleep pattern changes

What are sleep pattern changes and what do they look like in a person with dementia?

Changes to sleep patterns or the person’s circadian rhythm commonly occur in those living with dementia. Symptoms may vary according to dementia type. This loss of regular or previous sleep patterns is also known as nocturnal disruption or sleep disturbance.

Sleep pattern changes include:

- taking longer to fall asleep at night, followed by interrupted sleep
- decreased total sleep time, shallower and less refreshing sleep
- reversed or disrupted day-night patterns
- excessive sleepiness during the day and/or increase in daytime naps
- increased confusion at night.

What causes sleep pattern changes? When are they more likely to occur?

Our 24-hour sleep-wake cycle is regulated by the brain and by the nightly secretion of a hormone called melatonin. Changed sleep patterns are symptoms of the physical and psychological changes that happen in a person with dementia due to altered brain chemicals and structures. Disruption to previous sleep patterns tend to increase with dementia severity.

Changes to sleep patterns can be caused by:

- physical factors such as hunger, thirst, discomfort, constipation, pain or just feeling generally unwell
- a change in surroundings e.g. holiday accommodation
- insufficient exposure to natural daylight

- disruption to their night-time environment e.g. noise, too much light, loss of their usual sleeping partner
- reliving or remembering previous or ongoing experiences of trauma
- unable to recognise signs that it is nighttime and hence, unaware that it is the usual time for sleep
- side effects of medication.

People with lived experience of dementia report that waking at night in dim light/darkness can be frustrating, frightening, confusing, isolating and lonely.

How do sleep pattern changes affect the person with dementia and others?

Changes in sleep patterns are associated with significant carer burden and reduced quality of life for the person living with dementia and others in their environment. Family carers can also experience poor quality sleep, significant distress and depressive symptoms as a result. These changes can prompt earlier admission to residential care.

The person with dementia may experience increased confusion, disorientation and/or changed behaviours at night due to disturbed sleep patterns e.g. restlessness, hallucinations, wandering, calling out.

What can be done to address sleep pattern changes?

Ask the doctor:

- to check for, and treat, underlying depression, anxiety, delusions or hallucinations where indicated
- if the person living with dementia has symptoms of an underlying physical and/or psychiatric illness, delirium or infection
- to check if the person has pain that they may be unable to describe as research indicates some evidence

for improved sleep pattern changes with better pain management

- to rule out a medication reaction/side effects or substance misuse as potential contributing factors as some medications for dementia (cholinesterase inhibitors) can cause sleep disturbance and nightmares
- to exclude other sleep disorders such as restless legs syndrome, sleepwalking, leg cramps or sleep apnoea
- about sleep questionnaires and technical instruments to assist in diagnosis
- for information about trialling short-term medication to encourage more regular sleep patterns, if necessary.

Good evidence for medication to improve sleep pattern changes is lacking, unless treating other medical conditions which may be contributing to changes in the person's sleep pattern.

Strategies to try:

- Limit caffeine intake.
- Know and consider the person's story, their previous night-time routines and winding down activities to help establish a routine and promote good sleep habits e.g. favourite (relaxing) evening TV show, usual bedtime, reading before lights out.
- Modify the home and bedroom environment as well as routines to avoid frustrating situations where possible, particularly before bedtime.
- Ensure adequate natural light exposure and appropriate physical exercise during the day.
- Identify and reduce triggers, frustrations and stressors for the person e.g. bright lights outside their window and

avoid these where possible.

- Keep the person active in the morning and encourage a short, early afternoon rest (30 mins) soon after lunch.
- Adopt familiar, early evening activities to provide cues as to the time of day, such as relaxing pre-dinner drinks (low/non-alcoholic and caffeine-free), assisting with preparing dinner, setting the table, feeding the pets, closing the curtains or blinds.
- Avoid bathing or a shower in the evening if this is likely to increase agitation or alternatively, arrange a warm bath before bed for people who find it calming.
- If changing into pyjamas leads to confrontation, consider allowing the person to change into comfortable clothing e.g. tracksuit earlier in the day and encouraging them to sleep in these.
- Consider possible causes of disrupted sleep such as hunger, thirst and/or the need to urinate; manage evening fluid intake to minimise the need for the person to empty their bladder overnight.
- Recognise cues that indicate increasing distress and intervene promptly to de-escalate or change the situation; don’t argue or attempt to reason.
- Use non-threatening posture and movement in your approach; consider gentle touch if appropriate.
- Try traditional sleep promotion methods such as warm milk, chamomile tea, reassuring human contact, gentle massage, aromatherapy and/or soothing, preferred music before bed.
- Seek professional advice as to how to build routines to promote good sleep habits and to set up the sleep environment e.g. cues to provide direction back to bed

from the toilet, appropriate night lighting.

- Attend carer education and training courses to increase your skills and meet other carers.
- Seek occasional respite care.

George's story

George has been recently widowed. His family has been increasingly supporting him in his own home since his diagnosis of dementia some years ago. Since their mother's death, George's four daughters have taken turns in staying with him overnight and community care services are visiting three mornings each week.

George's sleeping patterns have become very irregular. He is frequently awake at night and walks from room to room, turning on the lights, radio and/or television. When his daughters attempt to settle him back to bed they find that their father is very confused and can become agitated. George's family is determined to keep him at home as long as they can, however the disrupted nights mean that his daughters are exhausted the next day when they must meet their work and family commitments.

George's bedroom is close to a busy road where obvious traffic noise and headlights continue throughout much of the night; prior to his wife's death he would have rolled over and gone back to sleep if disturbed by these.

In the mornings George tends to sleep late and finds it difficult to get out of bed for his breakfast and shower when the care workers visit to assist. The community service provider has already rescheduled George's visits to happen as late as possible.

The following have been checked:

- pain, discomfort, illness, infection and/or constipation that may disrupt George's sleep
- medication effects such as interactions, dosage, recent prescription changes, side effects
- delirium and primary sleep disorders e.g. restless legs syndrome, sleepwalking, sleep apnoea
- general health concerns including blood tests, urine tests and/or cognitive assessment as needed.

Other potentially contributing factors have been considered:

- disturbances at night from noise, people and/or activities in or around George's home
- unsettling changes to George's routine
- George's declining ability to effectively communicate his needs/concerns to the family, particularly during the night
- whether too much is expected of him for his current level of dementia
- George's reduced ability for coping with stress due to his advancing dementia
- George's recent loss and ongoing grief in the context of his dementia; at times he forgets why his wife is not in the bed next to him when he stirs at night.

A health professional has suggested the following strategies:

- Observe for triggers that indicate when George is becoming unsettled during the evening prior to bedtime so these situations can be avoided or reduced wherever possible.

- Develop a plan for dealing with George’s disturbed nights so all his daughters can adopt a consistent routine for preparing him for sleep and approach to the nighttime disruptions.
- Encourage George to express his needs as far as he is able; allow him sufficient time to communicate.
- George’s daughters may decide to seek carer education to learn the most effective ways of supporting him as well as meet other carers for friendship/support.
- Seek occasional respite care.

Some outcomes

- George was persuaded to move into a quieter, darker back bedroom; as it faced east, it also received the first morning light which encouraged him to wake earlier.
- A small night light in his bedroom and in the bathroom assisted George with orientation when he needed to use the bathroom at night.
- During discussion to develop a behaviour support plan, George’s daughters realised that a television program that had previously been their father’s favourite was now difficult for him to follow and sometimes caused him great frustration; more relaxing activities were offered during the evening.
- Consistent nighttime routines (sleep hygiene) were put in place across George’s week; in time a regular bedtime and sleeping pattern were established.

- While George was still awake at times during the night, the situation was more manageable and less disruptive to both his, and his daughter's daytime activities.

Module 10: Socially inappropriate behaviours

Key messages

- Socially inappropriate or disinhibited behaviours occur when a person living with dementia is unable to control their impulses or follow everyday social cues that guide behaviour around others.
- Socially inappropriate behaviours include insensitivity, loss of insight, reduced awareness and inappropriate or offensive acts, sometimes sexual in nature.
- Events or factors in the person's environment can prompt some socially inappropriate behaviours.
- Disinhibition of a sexual nature is amongst the most challenging of changed behaviours for carers, staff and families.
- Suggested strategies:
  - Try to identify individual prompts for the person's inappropriate behaviours; always note details with the aim of reducing or avoiding these.
  - Recognise cues that indicate early signs of disinhibition and intervene where possible.
  - Use gentle but firm communication when a presenting behaviour is inappropriate; do not shame the person.
  - Provide activities to occupy the person's hands.
  - Attempts to restrict the person's actions can exacerbate disinhibition and may lead to aggression.
  - Attend carer education.
  - Seek occasional respite care.

Socially inappropriate behaviours

What are socially inappropriate behaviours and what do they look like in a person with dementia?

Socially inappropriate or disinhibited behaviours are common in people living with dementia, but it is less common for these behaviours to become problematic. Disinhibition occurs when the person with dementia is unable to restrain their immediate responses to a situation or follow everyday social cues. Social cues typically prompt us to behave in a particular manner in specific situations. Socially inappropriate behaviours in people with dementia tend to occur when they act on impulse without the ability to edit their behaviour or exercise judgement. Such behaviour is sometimes referred to as the person living with dementia “losing their social filter”.

A person with dementia may make increased sexual demands on their partner. Where this is out of character for the person it can be due to lack of impulse control, in combination with memory loss and an inability to recognise the impact of their actions on others. While additional signs of affection may be welcome, such extra and insistent demands can be particularly challenging for an exhausted carer.

People with lived experience of dementia have said that disinhibition may reflect feeling impulsive, irritated, intolerant and/or trying to maintain control.

Socially inappropriate behaviours include:

- tactlessness and insensitivity to social norms, expectations and/or rules e.g. commenting loudly on a stranger’s appearance in a public space
- loss of insight into their behaviour and its potential effect on others
- reduced awareness of others and the environment

- inappropriate and/or offensive behaviours, language or humour
- impulsiveness or lack of control
- poor assessment of risk due to impaired judgement
- poor self-care and personal hygiene due to lack of awareness and/or impaired judgement
- inability to restrain instinctual drives such as sexual responses.

Examples of socially inappropriate behaviours include:

- demanding undue attention
- taking items from others
- lacking awareness that some behaviours, language or humour may be acceptable in some situations and/or company but inappropriate in others
- talking about personal or private matters in public
- making insulting or hurtful comments about others
- overstepping social boundaries e.g. behaving in an overfamiliar manner with strangers or acquaintances
- finding humour where others do not; laughing inappropriately at another's misfortune
- uncontrolled eating.

Examples of sexually inappropriate behaviours include:

- unwelcome hand-holding, kissing, fondling, cuddling or touching
- undressing in public or removing items of others' clothing
- sexually related comments, use of offensive language or propositioning others, making unreasonable and/or insistent sexual demands of others

- eroticism, exhibitionism and masturbating or other sexual acts in communal spaces.

What causes socially inappropriate behaviours? When are they more likely to occur?

Socially inappropriate or disinhibited behaviours are symptoms of the physical and psychological changes that occur in a person with dementia. These changes are due to altered brain chemicals and structures, for example changes in the frontal areas of the brain can make it difficult to exercise control.

Some socially inappropriate behaviours can be triggered by events or factors in the environment, for example:

- confusion may lead to making sexual advances to a stranger whom they mistakenly believe is their spouse
- discomfort could result in undressing in public because clothes are too hot or tight
- memory problems or misidentification might lead to urination in a place that is not the toilet e.g. rubbish bin
- disorientation could result in the person undressing to prepare for bed in a communal space when it is mid-morning
- misinterpreting the intent when assistance with personal care is offered, especially if the helper is not familiar to them
- anger and aggression can arise from uncontrolled responses to frustration around a task which is unfamiliar or too complex for their current level of dementia.

How do socially inappropriate behaviours affect the person with dementia and others?

Disinhibition can affect all aspects of behaviour: thoughts, feelings, movement, basic drives and how the person living with dementia interprets their surroundings. Socially inappropriate behaviours of a sexual nature are particularly challenging for carers. A dilemma arises in attempts to allow sexual expression while protecting the safety, rights and dignity of all.

Lack of privacy and separation from a usual sexual partner can contribute to sexual disinhibition. The person with dementia may forget or fail to recognise that their spouse has died or that they now live in residential care. Spaces appropriate for privacy and intimacy as well as awareness of sexual health issues are important following admission to residential aged care services.

What can be done to address socially inappropriate behaviours?

Ask the doctor:

- for urgent help, if you feel that the person living with dementia, you and/or others are at risk of harm
- to check if the person has symptoms of an underlying medical or psychiatric condition, brain injury, urinary tract infection, fever, delirium or the potential effects of drug or alcohol
- to check for side effects or a reaction to medication
- to determine if the socially inappropriate behaviours are associated with agitation, hallucinations or delusions
- to check if the person may have suffered a significant brain event such as a stroke or seizure, if the behaviour has occurred suddenly
- if short-term medication could help reduce sexually inappropriate behaviours, if necessary for safety only.

Apart from some emergencies, medication is never the first strategy; medications have limited benefits and can cause side effects.

Strategies to try:

- Try to identify individual prompts for the person's socially/sexually inappropriate behaviours; always note frequency, severity and details of each incident with the aim of reducing or avoiding these.
- Recognise cues that indicate potential disinhibition and intervene promptly to de-escalate or change the situation beforehand where possible.
- Try to avoid overreaction which can induce shame, humiliation and/or aggression; remember it is the dementia prompting the socially inappropriate behaviours.
- Even when the person behaves in a way that offends, try to keep your communication respectful and be aware that what they say is not intended to be personal.
- Reorient the person living with if they are directing behaviour inappropriately toward a stranger due to misidentification.
- Use gentle but firm communication when a behaviour that is unacceptable occurs.
- Distract, or redirect the person to a private place if behaviours are inappropriate because they are happening in a communal space.
- Modify clothing, for example, trousers without zippers.
- Encourage socially appropriate activities that the person enjoys to occupy their hands.
- Increase time and opportunities for appropriate affectionate contact with loved ones, family and pets.
- Provide positive regard and appropriate reassuring contact, for example hugging.

- Where possible, eliminate alcohol and monitor the use of medications such as opiates for pain as these can increase disinhibited behaviours; a person living with dementia may be more sensitive to the effects of these substances.
- Consider the option of engaging the services of an appropriately skilled, sex therapist/worker where it is legal to do so and where acceptable in the context of the person's personal history, culture and spiritual beliefs.
- Do not attempt to restrain the person; this can exacerbate the behaviour and/or lead to aggression.
- Where a person living with dementia has experienced disinhibition, be mindful of the potential risks of leaving young children with them unsupervised.
- Ask a health professional about measuring the severity and frequency of the symptoms and suggestions for further, individualised strategies to discourage these.
- Attend education and training courses to increase your skills as well as meet with other carers for friendship and mutual support.
- Seek occasional respite care.

John's story

John and Mary lived together for 40 years until Mary died six months ago. Since then, the family has been supporting John in the family home with increasing assistance from community care services. Recently John has been behaving in a socially inappropriate manner. He makes loud and inappropriate comments about others when he goes out with the carers on shopping trips. At times John has been overly affectionate with female friends resulting in them feeling uncomfortable and preferring to avoid him.

John has also approached strangers and community care workers with sexual suggestions. At times, he has not recognised the need for privacy when masturbating and some care workers have complained to their manager and the family.

When others react to his behaviour John can become verbally aggressive and threatening. As these behaviours are very out of character for John, his family feel embarrassed, distressed and at a loss as to what to do. They cannot relate these behaviours to the perfect gentleman they have previously known as their father. They are also concerned that the community care services may not be able to continue under these circumstances.

The following have been checked:

- pain, discomfort, illness, infection and/or constipation that may contribute to John's agitation and/or confusion
- medication effects such as interactions, dosage, recent prescription changes, side effects
- underlying depression, psychosis and delirium
- general health concerns including blood tests, urine tests and/or cognitive assessment as needed.

Other potentially contributing factors have been considered:

- John's recent bereavement; he has lost his wife and long term sexual partner
- John's sexual history and previous patterns of sexual interest

- misunderstanding cues in his surroundings
- misinterpretation of others’ approach and intentions when providing assistance with personal care
- loss of awareness of personal and social boundaries due to his level of dementia.

The family report that John and Mary had been a close and affectionate couple until her death; John is likely missing the close companionship his wife provided.

A health professional has suggested the following strategies:

- Observe for triggers that prompt the inappropriate behaviours so that these situations can be avoided or reduced wherever possible.
- Ask community care staff about triggers for the behaviours that they may have identified during their visits and when attending specific tasks.
- Consider keeping a diary of times and situations that prompt the behaviours; this may provide further information around potential triggers or patterns in his behaviours and ways to avoid them.
- John’s family may decide to seek carer education to learn more effective ways of dealing with the situation as well as meet other carers for friendship/support.
- Reduce John’s growing isolation by providing distractions through appropriate social contact and increased family visits.
- Provide activities related to his past interests to help keep John occupied and reduce periods of boredom.

- Be mindful of the signs that John’s agitation or tension is increasing and try to divert his attention elsewhere; it may be possible to avoid or reduce behaviours before they escalate.

Some outcomes

- On occasion John has confused the intentions of female care workers during personal hygiene tasks and this has prompted a sexual response; changes to rostering enabled male staff members to cover John’s personal hygiene needs.
- Family members attended carer education to better understand potential causes of disinhibited behaviours, *normal* sexual expression in older people, lack of privacy issues and strategies to help deal with unwelcome sexual behaviours.
- John’s children also sought support for their emotional response to the changes in their father.
- After his family provided an explanation of the potential triggers for John’s disinhibition, female friends modified their approach to greeting him and avoided an unwelcome response.
- Family members understood that the behaviours were symptoms of their father’s dementia; they were more comfortable to spend time with him and help to keep him occupied with activities he previously enjoyed.
- The family was also relieved to learn that these behaviours will pass with the progression of their father’s dementia.

Module 11: Wandering

Key messages

- Wandering is defined as repetitive walking in a way that exposes the person living with dementia to risk of harm when boundaries and obstacles are not understood.
- People with dementia who wander are at risk of falls, injury, weight loss and death.
- The use of medication in an attempt to control wandering is known as chemical restraint; this is NOT justified or recommended.
- Suggested strategies:
    - Try to identify the cause of the wandering; always note frequency and details of each wandering incident; reduce and/or avoid where possible.
    - Recognise cues that suggest increasing upset and/or restlessness and intervene where possible.
    - Provide opportunities for independent, safe walking; be aware of potential risks.
    - Provide a regular activity e.g. someone to take the person for a walk just before the time of day they tend to wander.
    - Modify the person’s environment to support orientation; this can decrease wandering.
    - As a precaution, ensure the person living with dementia has identification on them and always keep a recent photograph of them on hand.
    - Attend carer education.
    - Seek occasional respite care.

Wandering

What is wandering and what does it look like in a person with dementia?

Wandering is one of the most commonly occurring changed behaviours although rates vary with different types of dementia. Wandering occurs when a person living with dementia repetitively walks in a way that exposes them to risk of harm, such as they may leave a safe environment or become lost when they are unaware of boundaries and obstacles. The person may follow others.

Restlessness and agitation can overlap with wandering. Patterns of wandering can be lapping, circular, pacing back and forth, random without a direct path and/or direct to a destination. It tends to be more prevalent in men and in younger people with dementia.

People with lived experience of dementia have described wandering as “searching” which can occur after distraction or memory lapses interfere with reaching a desired destination.

What causes wandering? When is it more likely to occur?

Wandering is a symptom of the physical and psychological changes that happen in a person with dementia due to altered brain chemicals and structures. Wandering tends to increase in the earlier to moderate stages and then lessen in late-stage dementia. Wandering has different meanings and causes for each individual. It may be brought on by physical and/or emotional discomfort.

Wandering can be associated with:

- feeling alone/abandoned or searching for a loved one
- a usual or habitual pattern of activity
- escaping from a perceived threat
- distress due to barriers, alarms or surveillance devices

- confusion or anxiety around a lack of familiar people and/or surroundings e.g. unable to find a toilet or someone they recognise
- agitation and restlessness
- the idea of attempting to return to a familiar environment such as the person's home as they remember it from long ago, possibly even from their childhood.

How does wandering affect the person with dementia and others?

- The potentially severe consequences of wandering mean that addressing it is crucial.
- People living with dementia who wander are at risk of falls, injury and/or fractures, weight loss, exposure to the elements, social isolation and death.
- Wandering has been associated with high carer burden and anxiety around the associated safety risks.
- Wandering may result in earlier admission to residential aged care services.

What can be done to address wandering?

Ask the doctor:

- to check for other medical or psychological conditions which may underpin the wandering
- about possible reactions or side effects to medication that may prompt wandering
- to check for, and treat, underlying anxiety, depression, delusions or hallucinations where indicated
- about potentially untreated physical symptoms, such as infection, constipation and/or chronic pain that may increase restlessness and confusion which can prompt wandering

- for referral and/or advice on technological devices that help discourage wandering or keep the person safe when walking such as sensor monitors and GPS tracking.

The use of medication in an attempt to control wandering is known as chemical restraint; this can increase confusion and risk of falling and is NOT justified or recommended. Good evidence for medication to reduce wandering is lacking, unless treating other medical conditions which may be contributing to the person's wandering.

Strategies to try:

- First steps are to try to identify the cause of the wandering; always note frequency and details of each wandering incident.
- Identify frustrations and stressors for the person living with dementia so these can be minimised and/or avoided before they prompt wandering.
- Recognise cues in the person with dementia that suggest increasing upset/restlessness and intervene promptly to de-escalate or change the situation where possible.
- Reduce overstimulation around them or encourage the person to quieter spaces if this is prompting irritation.
- Avoid confrontation as this can exacerbate the situation; where possible try diversion with the person's preferred, individualised activities before restlessness or wandering occurs.
- Arrange opportunities for independent, safe walking but be aware of the potential for safety risks, dehydration, physical exhaustion and/or unreported pain or discomfort.
- Provide the company of others and positive social interaction or schedule a regular activity e.g. someone to

take the person for a walk just before the time of day they tend to wander.

- Research provides some evidence for decreased wandering by modifying the person's environment to support orientation.
- As a precaution, ensure the person with dementia is wearing a form of identification e.g. wallet, bracelet.
- Always keep a recent photograph which clearly represents the person to hand. This can help to quickly check with others who may have seen them. It will also be invaluable should the assistance of emergency services be required.
- Attend carer education and training to increase skills and meet other carers for friendship and mutual support.
- Seek occasional respite care.

Shirley's story

Shirley is a 68 year old Aboriginal woman who moved to Adelaide from a regional community when she was 16. She was widowed several years ago and it was around this time that family members noticed problems with Shirley's memory and thinking. Her GP later diagnosed dementia. While raising her five children, Shirley maintained strong links with her original Aboriginal community. Her connection to *Country* remains strong.

Family and community members have been supporting Shirley in her home with the assistance of an Aboriginal-specific home care service. This has been working quite well until recently.

On several occasions in the past month Shirley has been found after dark some distance from home, underdressed for the weather and distressed. On the most recent occasion a concerned passer-by alerted police after Shirley was unable to provide her address or contact details for her family. When police approached her Shirley was uncooperative and she became verbally aggressive. Local police ultimately located Shirley's daughter who picked her up from the police station.

Shirley's family understand that walking in her local community has been a lifelong pattern for Shirley. Her cognitive impairment due to dementia means Shirley is now less aware of the potential risks to her safety when she leaves her home. Shirley's daughters have been staying overnight to keep an eye on her. This can be stressful when they are unsure of how best to support their mother in these situations.

The following have been checked:

- pain, discomfort, illness, infection and/or constipation that may contribute to Shirley's restlessness
- medication effects such as interactions, dosage, recent prescription changes, side effects
- underlying symptoms of depression or delirium
- general health concerns including blood tests, urine tests and/or cognitive assessment as needed
- other medical conditions that can increase Shirley's risk of falling.

Other potentially contributing factors have been considered:

- possible triggers in Shirley's home environment that may prompt her to leave

- recent changes to Shirley's familiar carers, routines and/or surroundings
- Shirley may be searching for family members, her childhood home and/or Country
- boredom or lack of stimulation in her home environment.

Family report that Shirley's beloved dog died recently. At times Shirley forgets that the dog has died and becomes distressed when she can't find him and he doesn't respond to her calls.

A health professional has suggested the following strategies:

- Identify situations that trigger Shirley leaving her home, in a way that puts her at risk, so these can be modified where possible.
- Ask home care workers if they have noticed situations that may prompt Shirley's restlessness.
- Consider Shirley's life story for additional information that may be relevant to her wandering.
- Offer carer education to Shirley's family to assist them to learn more potentially effective ways of dealing with her wandering and meet other carers for friendship and/or support.
- Reduce Shirley's boredom and growing isolation by assisting her with planning activities and outings as she is no longer able to initiate or organise these for herself.
- Identify situations where Shirley does NOT attempt to wander and put these conditions in place, when and wherever possible.

Some outcomes

- Shirley's childhood history helped to explain her reaction to contact with the police; with the progression of dementia, traumatic experiences from her past have increased her fear of authority figures.
- Home care staff have noticed that Shirley is more restless after phone contact with her younger brother who lives near the town of their childhood home.
- Shirley's younger brother came to Adelaide to join a family meeting; he agreed that she may benefit from staying with him and his wife for a period.
- Shirley responded well to returning to Country and the company of the older community members who were able to interact with her in her traditional language.
- The additional support and company from family and community members meant that Shirley spent less time on her own and this significantly reduced her risk of wandering from a place of safety.
- Shirley was also able to enjoy the company of her brother's dogs, one of which was a sibling of Shirley's own beloved dog.

Appendices 1 and 2: Glossary and Checklist

Appendix 1: Glossary of terms

Appendix 2: Checklist of potential underlying factors that can contribute to changed behaviours and psychological symptoms in dementia

Appendix 1: Glossary of terms

Activities of Daily Living (ADLs): Activities necessary for everyday functioning and self-care. These include the ability to eat, drink, walk around, move onto/from a chair, bed and/or the toilet and dress as well as maintain continence, personal hygiene and grooming.

Acute: A condition which is of rapid onset and/or short duration.

Adverse effects: see Side Effects

Amotivation: Lack of drive to become involved with activities and/or other people.

Anticholinergic effects: Acetylcholine is a neurotransmitter in the nervous system which plays a role in attention, arousal and involuntary muscle function. Anticholinergic agents block the action of acetylcholine which can lead to anticholinergic effects such as dry mouth, constipation, blurred vision, increased heart rate as well as changes in concentration, confusion, attention and/or memory.

Antipsychotic medication: A class of medication primarily used to treat psychotic symptoms including delusions and hallucinations.

Aphasia: Language difficulties which can be caused by dementia. Those with aphasia can have difficulty talking, understanding others, reading, writing and/or using numbers.

Aromatherapy: The use of essential oils to improve physical and emotional well-being. Methods of delivery include massage, inhalations, baths and vapourisers.

Biological and pharmacological interventions: Physical treatments such a medication and electroconvulsive therapy (ECT) as opposed to psychosocial or environmental interventions.

Blunted affect: A reduced range and depth of emotional reaction.

Circadian rhythm: Also known as the *body clock*. A 24-hour cycle that regulates many of our bodies' physiological processes such as sleep. This internal body clock is affected by environmental cues, like sunlight and temperature.

Chronic: A medical condition which is persistent and long lasting in its effects, typically more than three months.

Cognition: Mental processes involved in thinking, knowledge, comprehension, problem-solving, memory and judgement.

Cognitive Behavioural Therapy (CBT): A technique used by health professionals to provide strategies and tools to help reduce negative thoughts.

Culturally and Linguistically Diverse (CALD): A broad concept which encompasses the differences that exist between people such as language, dress, traditions, food, societal structures, art, culture and religion.

Delirium: An acutely disturbed state of mind that comes on abruptly and requires prompt medical attention. Symptoms include increased confusion, disorientation and behaviour that is out of character for the person living with dementia. Delirium can occur in response to undiagnosed and/or untreated pain, infection, drug reaction and/or acute illness.

Dementia: There are many different causes of dementia, with varied symptoms and presentations, depending on the brain structures and processes involved. Common types of dementia include:

- Alzheimer's disease (AD)
- Vascular Dementia (VaD)
- Dementia with Lewy bodies (DLB); also referred to as Lewy body dementia or disease (LBD)

- Frontotemporal dementia (FTD); also referred to as Frontotemporal Lobar Degeneration
- Parkinson's disease dementia (PDD).

Dementia Behaviour Management Advisory Services (DBMAS): A Commonwealth Government funded service which provides support and advice to family members, residential aged care staff and community care staff looking after people living with dementia who present with changed behaviours and/or psychological symptoms. Contact via the Dementia Support Australia website.

Extrapyramidal symptoms (EPS): or extrapyramidal side-effects can occur as a result of taking antipsychotic medications. Symptoms may present as the inability to stay still (akathisia), the inability to initiate movement (akinesia) as well as unusual involuntary muscle contractions that can affect walking, movement and/or posture.

Folstein's Mini Mental State Examination (MMSE): A brief 30-item questionnaire test of thinking and memory, often used by health professionals to screen for cognitive impairment or dementia.

General Practitioner (GP): A medical doctor who provides primary care. A GP treats acute and chronic illnesses as well as provides preventive care and health education for all age groups.

Haematological effects: such as changes in the number of white blood cells (leukocytes) can occur during treatment with antipsychotic medications. Although these effects tend to be mild, a decrease in white blood cells increases the person's risk of infection.

Mild Cognitive Impairment (MCI): A syndrome characterised by mild impairment in brain function, particularly in memory and thinking. In some people it can be a precursor to the onset of dementia.

Nonverbal signs: Aspects of communication that do not involve verbal communication e.g. gestures, body language, facial expressions. These also include nonverbal aspects of speech such as tone and volume of voice as well as speed of talking.

Panic attack: An acute episode of anxiety which can cause a racing heart, dizziness, shortness of breath and/or headaches. The physical sensations can be severe such that the person may believe that they could die, have a stroke or are going “mad”.

Passivity: Lack of drive and initiative, where the individual is uninterested in what is happening around them. It is a key feature of apathy.

Perception: Perception is our sensory experience of the world around us. It involves recognition and interpretation of our environment via the five senses - touch, sight, taste smell and taste.

Pharmacological treatment: The use of medication to treat and/or assist in the management of an illness or condition.

Phobia: A persistent, irrational, intense fear of a specific object, activity or situation that is recognised as excessive. Phobias can be a source of significant distress and interfere with everyday functioning.

Prolactin: is a hormone produced by the pituitary gland in the brain. Some antipsychotic medications can increase prolactin levels in the blood which can impact on the health and/or sexual satisfaction in the person with dementia.

Psychogeriatric Service or Psychiatry of Old Age or Geriatric Psychiatry: Specialist mental health services for older people that provide support to those with conditions such as dementia, depression and/or changed behaviours or psychological symptoms in dementia, as well as psychological symptoms in their carers.

Psychotropic medication: Medications capable of affecting a person’s mind, emotions and/or behaviour e.g. antipsychotics, antidepressants, anxiolytics (anti-anxiety drugs). People living with dementia are particularly vulnerable to the side effects of these medications.

Residential aged care services (RACS): Services which offer low-level care in hostel style accommodation for people who are largely independent but require some support and/or high-level care for those who are physically frail or unable to look after themselves because of dementia and/or physical dependence.

Restrictive practices: Any physical or chemical device that prevents a person’s freedom of movement. Medication used to control an individual’s behaviour is known as chemical restraint. Federal and state laws prohibit residential aged care services from using restraint unless medically prescribed. Ethical concerns are important.

Self-esteem: Also known as self-worth or self-regard, it is related to how we generally view ourselves. If positive, we regard ourselves as worthwhile and valuable; if negative, as worthless and useless. Low self-esteem may be a symptom of depression and dementia.

Sensory impairment: Relates to an impairment or deficit in one or more of the senses i.e. sight, sound, touch, smell, spatial awareness and taste. Hearing and vision impairment are common, particularly in older people.

Severe Behaviour Response Team (SBRT): A Commonwealth Government funded service which provides tailored advice and strategies to family members, residential aged care staff and community care staff caring for people living with dementia who present with severe changed behaviours and/or psychological symptoms. Contact via the Dementia Support Australia website.

Side effects or adverse effects: Unintended effects, particularly those which are unpleasant or harmful, that can occur with the beneficial effects of a medication.

Signs: Signs are manifestations of an illness or disorder that are visible to others, such as observable memory loss or difficulty making decisions i.e. objective evidence.

Sleep hygiene: Habits adopted to aid a good night's sleep, for example avoiding caffeine later in the day, winding down, maintaining a regular bedtime routine or relaxing before bed.

Stressor: An event, interpersonal interaction or situation that causes a person stress, worry and/or anxiety.

Sundowning: Occurs when people living with dementia become more confused, anxious, restless, agitated or insecure late in the afternoon or early evening, especially after a change to their routine or familiar environment e.g. the start of daylight saving, introduction of a new staff member.

Symptoms: Evidence of an illness or disorder as perceived by the person themselves i.e. subjective evidence.

Syndrome: A group of symptoms, signs or behaviours that tend to cluster together and act as a marker for a disease or disorder.

Appendix 2: Checklist of potential underlying factors that can contribute to changed behaviours and psychological symptoms in dementia

Has a doctor or health professional checked the person with dementia for physical health problems?

☐ fever

☐ dental/mouth problems

☐ under-recognised and/or under-treated pain (including feet)

☐ urinary tract infection

☐ chest infection

☐ adverse effects of, or reaction to, medication

☐ poor or interrupted sleep

☐ constipation

☐ headache

☐ fatigue

☐ increased impairment in vision and/or hearing

☐ irritating itch

☐ other acute illness

Could the person with dementia be experiencing mental health and/or emotional difficulties?

☐ depression

☐ anxiety

☐ psychotic symptoms

☐ post-traumatic stress disorder

☐ other mental health issues

☐ unmet spiritual/religious needs

☐ loneliness, isolation and/or feeling disconnected from loved ones, family and/or significant others

Consider the significance of the person with dementia's individual history

☐ missing significant family, friends and/or pets

☐ preferred routines

☐ special treats

☐ nickname/s

☐ key events or anniversaries

☐ sexuality

☐ migrant or refugee experiences

☐ cultural traditions and events

☐ past trauma - Stolen Generations, war experiences, immigrant dislocation, intergenerational trauma

☐ significant losses - family, peers, home, place of origin, work, wealth, reputation, role, pets, sense of purpose

Consider difficulties with communication

A person with dementia can have difficulty when others:

☐ speak quickly or loudly

☐ are unaware of the tone of voice they are using

☐ are perceived as treating them in a condescending or childish manner

- ☐ use inappropriate, or avoid, eye contact; consider cultural aspects
- ☐ do not address the person by name
- ☐ do not use the correct form of address or pronouns e.g. Mr, Miss, They, Them
- ☐ argue with them
- ☐ correct mistakes, indicating failure
- ☐ inappropriately attempt to reason with them
- ☐ do not follow appropriate cultural protocols
- ☐ do not speak the person's preferred language

Without appropriate interaction the person with dementia can become lonely, isolated, withdrawn and/or frustrated.

Consider difficulties around meals

- ☐ inflexible meal times
- ☐ table setting too cluttered/confusing
- ☐ eating space not clearly defined; consider a placemat in a contrasting colour
- ☐ insufficient contrast between tablecloth and crockery
- ☐ more than one course presented at a time
- ☐ table companions provoking irritation, agitation, distress and/or confusion
- ☐ dental/mouth pain causing discomfort when eating
- ☐ food not to the person's liking or culturally inappropriate

Consider difficulties around personal hygiene

- ☐ bathroom environment uncomfortable, claustrophobic, cold and/or noisy
- ☐ rough or rushed approach
- ☐ conflicting gender roles
- ☐ no input into decisions around procedure, timing, etc
- ☐ too many different carers involved
- ☐ current personal/dental hygiene practices inconsistent with previous habits, choices and/or routine
- ☐ over/under expectations of the person’s abilities
- ☐ carers talking over the person during hygiene practices
- ☐ painful movement of limbs during care
- ☐ lack of effective communication and/or explanation before and during procedure
- ☐ cultural/spiritual preferences not considered

Consider aspects of the person’s indoor environment

- ☐ size of the overall space overwhelming or confusing
- ☐ no/limited cues to provide orientation or direction
- ☐ glare from lighting/sun
- ☐ cluttered or unsafe environment
- ☐ contrasting floor surfaces appear as steps or trip hazards prompting anxiety
- ☐ noisy environment
- ☐ too many other people or isolation within a group
- ☐ their personal space not personalised

☐ their space/room is difficult for them to find

☐ culturally/spiritually inappropriate or offensive objects

☐ lack of appropriate space for spiritual/religious activities

☐ lack of privacy

☐ outdoors rather than indoors more familiar/preferred

Consider aspects of the person's outdoor environment

☐ lack of points of interest or attraction

☐ insufficient shade in summer or shelter in winter

☐ physically unsafe

☐ lack of comfortable seating options

☐ does not encourage walking e.g. uneven pathways

☐ not readily visible/accessible from indoors

☐ paths lead to frustrating dead ends

Consider under- or over-stimulation

☐ dislocation from family, community, *Country*, peers, home and/or place of origin

☐ lack of support/opportunities to participate in physical activity during the day

☐ environment lacking stimulation or points of interest

☐ too much stimulation increasing the person's confusion or distress

☐ lack of company or opportunities for appropriate social interaction

☐ lack of opportunities to participate in activities that the person enjoys or can relate to

☐ lack of encouragement/prompting when the person lacks capacity to initiate participation for themselves

☐ changed behaviours result in others around them avoiding/excluding/fearing the person even when the behaviours are not occurring

☐ carers lacking time, energy, knowledge, confidence and/or motivation to engage the person living with dementia

☐ boredom and loneliness