

A Guide for Family Carers

*Dealing with Behaviours in People
with Dementia*



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Dealing with Behaviours in People with Dementia

A Guide for Family Carers

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Disclaimer

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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 family carers providing care to a person 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 the management of behavioural and psychological symptoms of dementia.

This Guide incorporates information from recent literature. 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 DCRC 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 *Guide to Good Practice (2012)* was prepared after an extensive review of the literature, review by an expert advisory committee and broad consultation, the authors do not bear any clinical responsibility for the practical application of the information contained in this Guide.

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The information contained in this *Guide* is a summary of the document *Behaviour Management - A Guide to Good Practice, Managing Behavioural and Psychological Symptoms of Dementia (2012)* which was developed after broad consultation with many experts in the field with co-authors Ranmalie Jayasinha and Ruby Tsang. We thank the members of the Alzheimer's Australia Consumer Dementia Research Network and Val Wotton for their critical reading of the manuscript and helpful suggestions. We also thank Wayne Rosenberg of Vertifix Printing for his assistance with design, artwork, printing and distribution.

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Purpose of this Guide for Family Carers

This *Guide* is for family carers providing care for a person with dementia. It includes practical information about how to deal with the behavioural and psychological symptoms of dementia (BPSD). The evidence supporting the content of this document is included as *Appendix 8* of the unabridged *Guide to Good Practice*. An electronic version with all appendices is accessible via the DCRC website www.dementiaresearch.org.au*.

Each module of this family carer *Guide* relates to a specific behaviour or psychological symptom and includes:

- A description of the behaviour or psychological symptom and what it looks like in dementia
- Potential causes and when it is most likely to occur
- How it affects the person with dementia and others
- What can be done to help manage it
- An example of a family's experience with BPSD

Additional considerations may be necessary for those with dementia from Aboriginal and Torres Strait Islander and CALD communities. Examples are included as family carer scenarios within the module.

As a family carer, you will likely know the person behind the dementia better than the health professionals involved. As such, your contribution to managing BPSD and improving the quality of life of the person with dementia is invaluable.

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

*To access: select the large 'project search' button on the right hand panel, and in the 'project title/description' section search for 'BPSD'

Module 1: Overview of behaviours in dementia

Key messages

- Structural and chemical changes that occur in the brain during the course of dementia can lead to behavioural and psychological symptoms
- Behaviours and psychological symptoms can vary with the type of dementia
- Behavioural symptoms are typically not deliberate and can be an attempt at communication when people with dementia have difficulty expressing their needs
- Consider the possibility that the person with dementia may be unwell, hungry, thirsty, tired and/or in pain and this could be prompting the BPSD
- The causes of BPSD are often complex and strategies to manage them are not 'one size fits all'; an intervention may help in one situation for a particular behaviour and not another
- Keeping a record of the situations which ultimately result in problematic behaviours can assist with identifying possible triggers and developing strategies to manage them
- Ensure you have access to the best level of support available when caring for a person with dementia

Overview of behaviours in dementia

What are behavioural and psychological symptoms of dementia (BPSD)?

The structural and chemical changes that occur in the brain during the course of dementia can lead to behavioural and psychological symptoms. BPSD include aggression, agitation, anxiety, apathy, calling out, depression, hallucinations and delusions, socially inappropriate behaviours, sleep pattern changes and wandering.

BPSD can vary according to the particular stage or type of dementia, specific circumstances, environmental conditions, interaction with others and time of day as well as the person with dementia's previous personality and history. People with dementia may not show any of these BPSD. Where they do occur, the person will display only some of these BPSD, and only some of the time. BPSD may also overlap.

Although BPSD can be challenging, they are typically not deliberate and it is important not to take them personally. BPSD can be an attempt at communication when people with dementia can no longer verbally convey their needs. Strategies targeting their unmet needs may be effective in reducing the BPSD.

General points to consider in managing BPSD

- Exclude the possibility that the person with dementia has an acute physical illness and may be unable to describe the symptoms; see GP for assessment.
- Relieve hunger and/or thirst; the person with dementia may no longer be able to express these needs in words.
- Ensure the person with dementia is getting sufficient rest and is not in pain.
- Support appropriate expression of feelings such as anger, grief, frustration and/or helplessness.
- Remove or reduce perceived threats to the person with dementia's space, dignity, privacy and/or safety.
- Minimise sensory losses with glasses and hearing aids; keep prescriptions for both current.
- Add orienting cues to the home environment, e.g. night lights, signs 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 with dementia. For example, think about the person's occupation before retirement, their hobbies or interests and tailor activities around these.

See the checklist (Appendix 2) at the end of this *Guide* for further suggestions of potential factors that may underlie and/or contribute to BPSD.

Additional information to consider

- Be aware of the person's diagnosis as BPSD can vary with the type of dementia.
- The person with dementia may relive past experiences or traumas. For example a history of displacement, war trauma or deprivation may activate fear of uniforms, being watched, queuing, hunger, being cold, identity tags, corridors and 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 problematic behaviours.
- People with dementia who originally migrated from elsewhere may have learnt English as their second language. As dementia progresses they can 'forget' how to speak English and hence, revert to their mother tongue. This can lead to difficulties with communication and increased frustration which can exacerbate behaviours. If the person's second language has been lost, seek resources to enable communication via their first language.

Interventions that can help

- Ask dementia support services about access to occasional respite care so that you can 'recharge your

batteries'; the person with dementia will also benefit if you are rested.

- Modifying the person's environment can make living areas more suitable, e.g. avoid harsh lighting and reduce noise levels to have a calming effect.
- Cognitive-behavioural therapies, especially where the therapist, the person with dementia and the carer work together, can help to reduce challenging behaviours.
- It may be helpful for you and others to collect the life story of the person with dementia, perhaps via a 'Life Story' book or a 'Talking Photo Album':
 - Use of life story book in a continuing care setting
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2682386/>
 - Dementia UK: Life Story Work
<http://www.dementiauk.org/information-support/life-story-work/>
 - A guide to creating a life story for Care-giving
<http://www.interiorhealth.ca/YourCare/ChronicConditionDisease/Dementia/Documents/GuideLifeStoryTools.pdf>
 - Talking Photo Album Project
<http://www.youtube.com/watch?v=r0nx1g4Dtr4>
- Reminiscence-based activities can include looking back on past events, family and friends using DVDs and/or life storybooks.
- Preferred music, movement, singing and/or listening to CDs/DVDs can help to keep the person with dementia meaningfully occupied.

- Recreational and/or occupational activities also assist the person with dementia to remain more functional. Examples include cooking, gardening, watering the garden or social events.
- Exercise activities such as walking and movement, help to maintain balance and the ability to move around safely as well as focusing the person's energy.
- Appropriate, supervised interaction with pets can enable a positive experience for a person with dementia who is an animal lover.
- Sensory stimulation such as aromatherapy can be calming.
- Gentle massage therapies can promote relaxation.
- Attend education sessions to learn new strategies and meet other carers who can provide understanding and friendship. Sessions may also involve activities and/or care for the person with dementia.
- An intervention may assist in a set of circumstances for one particular behaviour and not another. The causes of BPSD are often complex and strategies to manage them are not 'one size fits all'.

Do you have the best available support?

It is very important to have the best level of support available while you are caring for a person with dementia. Keep in regular contact with your doctor and/or health care professional. You can provide them with information about behaviours in the person with dementia as well as

discuss a workable routine, day-to-day strategies and ongoing review. The more accurate the information you provide, the more effective the individual strategies can be for you and the person with dementia.

Keeping a record of the situations which ultimately result in problematic behaviours can assist with developing strategies to manage 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 'swears at strangers', 'hides food' or 'talks to his deceased mother'. Likewise, it is important to note the frequency and severity of the behaviour and/or psychological symptom.

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

- relevant personal history, previous trauma, mother tongue, cultural background, personality, likes and dislikes, type of dementia, current medications and whether medications have been helpful
- information about behaviour that links it to specific people, situations, places and times of day; collect information over a week
- situations and interactions that work well and are manageable for both you and the person with

dementia; equally details of the strategies you attempted without success may be important

- circumstances that are becoming increasingly problematic
- usual weekly routine for you as the carer and the person with dementia
- occasions when problematic behaviours DO NOT occur

It is particularly important that you feel comfortable with your doctor as your doctor is essential to the best possible management of behaviours in dementia. The following questions may help you to decide whether you are comfortable with your present doctor or whether you may need to consider a change:

- Did the doctor suggest or initiate the process for the dementia diagnosis?
- Was the diagnosis explained in a way that you could understand?
- Did you have an opportunity to ask questions?
- Have you been able to discuss how the diagnosis affected you?
- Did you get the answers you needed?
- Do you feel you were given enough time?
- Do you feel that you can go back with your questions if you need to?

If you can answer 'yes' to these questions you have probably found a doctor who is right for you. A caring

doctor, who has knowledge of your situation, will be of great assistance to you and to the person with dementia.

To get the most from a visit to the doctor, write down your questions beforehand, choose a time of day when the doctor is less busy, book a double appointment if needed and take your journal so that you have an accurate record and history with you. Take brief notes or ask the doctor to write down important points, especially about medications.

Confidentiality

Doctors are unable to talk about their patients without their consent so if you wish to be included in discussions about the person with dementia's medical issues, you should attend the appointment together. It is usual for the doctor to ask the family to choose one spokesperson who can then explain what has been said to the rest of the family.

Table 1.1 Generic and common trade names for medications relevant to BPSD

Generic name	Common trade name(s)
Anticonvulsants	
Carbamazepine	Tegretol, Teril
Gabapentin	Gabaran, Gabatine, Gantin, Neurontin, Nupentin, Pendine
Oxcarbazepine	Trileptal
Sodium valproate	Epilim, Valprease, Valpro

Antidepressants	
Agomelatin	Valdoxan
Citalopram	Celapram, Celica, Ciazil, Cipramil, Citalo, Citalobell, Talam
Clomipramine	Anafranil, Placil
Duloxetine	Cymbalta
Fluoxetine	Auscap, Fluohexal, Fluoxebell, Lovan, Prozac, Zactin
Mirtazapine	Avanza, Axit, Aurozapine, Milivin, Mirtazon, Remeron
Paroxetine	Aropax, Extine, Paxtine, Roxet
Sertraline	Concorz, Eleva, Sertra, Sertracor, Setrona, Xydep, Zoloft
Venlafaxine	Altven, Efexor, Elaxine, Enlafax, Venla, Venlexor
Antihistamines	
Cetirizine	Alzene, Zilarex, Zodac, Zyrtec
Cyproheptadine	Periactin
Dexchlorpheniramine	Polaramine
Ketotifen	Zaditen
Levocetirizine	Xyzal
Promethazine	Phenergan, Sandoz Fenezal
Trimeprazine tartrate	Vallergan
Antipsychotics - atypical (neuroleptics)	
Amisulpride	Solian, Sulprix
Aripiprazole	Abilify
Clozapine	Clopine, CloSyn, Clozaril
Olanzapine	Lanzek, Ozin, Zylap, Zypine, Zyprexa
Quetiapine	Delucon, Quipine, Sequase, Seronia, Seroquel, Syquet
Risperidone	Ozidal, Resdone, Rispa, Risperdal, Rispericor, Rixadone

Generic name	Common trade name(s)
Antipsychotics – typical (neuroleptics)	
Haloperidol	Serenace
Analgesics	
Aspirin	Aspro Clear, Disprin
Aspirin & codeine	Aspalgin, Codral
Ibuprofen	Brufen, Nurofen
Ibuprofen & codeine	Nurofen Plus
Paracetamol	Dymadon, Panadol, Panamax
Paracetamol & codeine	Panadeine Forte, Panamax Co
Paracetamol, codeine & doxylamine	Mersyndol, Mersyndol Forte, Panalgesic
Morphine	MS Mono, MS Contin, Momex SR, APOTEX-Morphine MR, Kapanol, Anamorph, Sevredol
Cholinesterase inhibitors/ Memantine	
Donepezil	Arazil, Aricept, Aridon
Galantamine	Galantyl, Gamine, Reminyl
Memantine	Ebixa, Memanxa
Rivastigmine	Exelon
Hypnotics	
Flunitrozepam	Rohypnol
Nitrozepam	Mopodon
Temazepam	Mosmson, Temaze
Zolpodem	Halcion, Stilnox
Zopiclone,	Imovane
Psychostimulants	
Methylphenidate	Concerta, Ritalin
Sympatholytics	
Prazosin	Minipress
Propranolol	Deralin, Inderal
Other	
Cimetidine	Magicul, Tagamet
Melatonin	Circadin

Table 1.2 Side effects of neuroleptics or antipsychotic medications

Drug	Extra-pyramidal side effects	Prolactin	Anti-cholinergic effects	Seizure risk	Orthostasis	Weight gain	Sedation	Haematological effects	Elevated blood sugar levels	Elevated cholesterol
Clozapine	0	0	+++	+++	+++	+++	+++	+++	+	+
Risperidone	0/++	0/++	+	+	++	+	+	0	0	0
Olanzapine	0/+	0	++	+	++	++	++	0	+	+
Quetiapine	0/+	0	+	+	+	+	++	0	+	+
Sertindole	0/+	0	+	+	++	+	+	0	+	0
Ziprasidone	0/+	0/+	+	+	+	?	+	0	+	+
Aripiprazole	0/+	0	+	+	+	+	+	0	+	+
Amisulpride	0/+	0	+	0	+	+	+	0	0	0
Haloperidol	+++	+	0/+	+	+	+	+/++	+	+	0

Key

- 0 no effect
- +
- ++ present and major side effect
- +++ present and very important side effects
- ? unknown

Module 2: Aggression

Key messages

- Aggression in a person with dementia includes physically and/or verbally threatening behaviours
- Aggressive behaviours in a person with dementia may be a response to experiences, such as feeling frustrated, uncomfortable, threatened, stressed, bored, agitated and/or lonely
- Ask your doctor for help or contact your closest hospital if you feel that you or others are at risk of harm
- Suggested strategies:
 - Identify potential triggers, frustrations and stresses
 - Don't argue or attempt to reason
 - Use gentle touch and non-threatening movement
 - Modify/simplify the person's environment and routines
 - Consider management with medication but only if necessary for the safety of the person with dementia and/or others
 - Avoid attempting to restrain the person with dementia; it can exacerbate the behaviour
 - Seek advice from health professionals and attend carer education
 - Seek occasional respite care

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.
- Aggressive behaviours may increase as dementia progresses and decrease during the very late stages.

Types of aggressive behaviours include:

- verbal: shouting, screaming, saying insulting things and using offensive language
- physical: hitting, punching, kicking, pushing and throwing objects
- sexual: repeated and sometimes threatening demands for sex from partners or other people

What causes aggression and when is it most likely to occur?

Aggression is a symptom of the physical and psychological changes that happen in a person with dementia. It may result from altered brain chemicals and structures or from the interaction of persons with dementia with their environment and other people. Changes to the frontal areas of the brain can make it

difficult for the person to exercise control over their emotions.

People with dementia may react with aggressive behaviours because they are:

- frustrated if they can't convey a physical need such as hunger or pain
- physically uncomfortable, constipated or dehydrated
- feeling threatened such as during personal care tasks where physical contact may be perceived as too close, particularly if the person with dementia does not recognise the person assisting them
- frightened and feeling the need to defend themselves
- stressed due to misunderstandings with carers
- bored, agitated or lonely

How does aggression affect the person with dementia and others?

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

What can be done to manage aggression?

Ask your doctor:

- to check if the person with dementia has symptoms of

an underlying depression, psychosis, physical illness or infection which could increase their irritability

- for help, if you feel that you or others are at risk of harm; there are assessment tools to measure the severity of aggression
- about medications to reduce physical aggression if it is necessary for the safety of the person with dementia and others

NB: Medication often provides limited benefit in the management of aggression and should only be trialled where necessary for safety and non-drug approaches have been unsuccessful. The risk of side effects limits the use of these medications.

Strategies you can try:

- Identify triggers, frustrations and stresses for the person with dementia so these can be minimised and/or avoided.
- Recognise cues that indicate increasing upset and 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 calm the situation.
- Speak clearly (without shouting) and calmly in a matter-of-fact way while reassuring the person; don't argue or attempt to reason.

- Use non-threatening posture and movement; consider gentle touch where appropriate.
- Modify/simplify the person's living environment and routines to avoid upsetting situations.
- Seek advice from health professionals about interventions such as light massage, individualised behavioural therapies and/or structured activities.
- Attend carer education and training courses to increase your skills, meet with other carers for friendship and support
- Seek occasional respite care.
- Avoid attempting to restrain the person with dementia; it can exacerbate the behaviour.

A family's experience of dealing with aggressive behaviours:

Mr B, an 89 year old man who migrated from Italy 60 years ago, now lives with his 85 year old wife in their Sydney home. Their large extended family is involved and attentive but his wife has been his primary carer since Mr B's diagnosis of dementia two years ago. Mr B is unable to read or write English and is increasingly reverting to his first language of Italian. His children are unable to speak Italian, although some elderly relatives remain fluent. Mr B's increasing frustration with being unable to communicate with his family and friends has resulted in episodes of verbal abuse and physical aggression.

Mr B resists care and, when displeased uses his walking stick as a machine gun, attempting to 'shoot' at others. He is verbally abusive in Italian. At times he appears threatening as though he might hit out. When Mrs B attempts to reason with him, Mr B becomes more frustrated. The couple is becoming increasingly isolated.

The GP has checked for the following:

- Pain/discomfort/illness/infection/constipation
- Medication effects: interactions, dosage, recently prescribed, adverse effects
- Underlying symptoms of depression or psychosis

Other possible sources of irritation for Mr B have been considered:

- Overstimulation from noise, people and/or activities in his environment
- Mr B's diminishing capacity to communicate with others
- Whether he is being overextended because too much is expected of him
- General routines, changes to routines and interaction with family members
- Strain arising from any unfamiliar or altered aspects of Mr B's physical environment
- Mr B's reduced threshold for coping with stress due to his advancing dementia

A health professional has suggested the following strategies for the family to try:

- Observe for triggers for Mr B's behaviours so that these situations/people can be avoided or minimised wherever possible
- Encourage/support Mr B to express his needs as far as he is able; allow him time and, if possible, access to other Italian speakers
- Record significant aspects of Mr B's life history so that visitors and family may share in some of his past experiences; consider photos, preferred music, films and/or family videos
- Tell Mr B in advance of any changes or new events, as he becomes anxious and resistant when he does not know what is about to happen
- Attend carer training to learn the most effective ways of helping Mr B to express his needs
- Contact extended family members who speak his preferred dialect to identify how and when they might interact with him
- Be mindful of Mr B's nonverbal signs of increasing anxiety or frustration so situations may be de-escalated before his behaviour becomes aggressive
- Reduce Mr and Mrs B's growing isolation by assisting them with planning social activities and visits with preferred people and to preferred places
- Offer activities related to Mr B's past interests such as Italian television programs, opera and radio as well as playing cards and gardening
- Incorporate culturally significant occasions and traditional foods where appropriate

Referrals were also made for the following:

- To engage a bilingual/bicultural health worker
- Access to the Multicultural Aged Care Service for further suggestions and resources such as Italian audio and videotapes
- A physiotherapist to assess whether Mr B's walking stick was the most suitable mobility aid for him. A change in aid could reduce the potential for inappropriate use and risk to others.

Adapted from the DBMAS Best Practice Guidelines for People with Dementia from a Culturally and Linguistically Diverse (CALD) Background who have Changing Behaviours (2007).

Module 3: Agitation

Key messages

- Agitation in a person with dementia presents as restless and repetitive behaviour that causes distress and appears purposeless
- Agitation may worsen during the late afternoon or early evening; this is known as sundowning
- People with dementia may react with agitated behaviours for many reasons, such as feeling frustrated, disturbed, tired, confused, bored, lonely and/or isolated
- Suggested strategies:
 - Identify triggers, frustrations and stresses so these can be minimised and/or avoided
 - Recognise cues that indicate increasing distress
 - Acknowledge the person'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 an individually meaningful activity 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 with dementia presents as very restless and repetitive behaviour that causes distress and appears purposeless. It is typically 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
- restlessness and/or pacing
- excessive fidgeting or hand wringing
- distressed calling out

What causes agitation and when is it most 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 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 or pain
- disturbed by a situation in their environment, their surroundings and/or particular people
- 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
- reacting to food intolerances
- physically uncomfortable, unwell or constipated

How does agitation affect the person with dementia and others?

Agitation is often viewed as one of the most challenging and persistent behaviours of dementia. Agitated behaviours are associated with significant carer burden and reduced quality of life for the person with dementia and the carer. Agitation can also prompt earlier admission to residential care and increased use of psychotropic medications in attempt to control the behaviour.

What can be done to manage agitation?

Ask your doctor:

- to check if the person with dementia has symptoms of an underlying physical and/or psychiatric illness, pain or infection

- to ensure that the person with dementia is not experiencing an acute delirium which has been misdiagnosed as agitation; in the case of delirium it is important to seek urgent medical attention
- to rule out medication side effects as a potential contributing factor

NB: Medication often provides limited benefit in the management of agitation and should only be trialled when non-drug approaches have been unsuccessful. The risk of side effects limits the use of these medications.

Strategies you can try:

- Identify triggers, frustrations and stresses for the person with dementia so these can be minimised and/or avoided
- Recognise cues that indicate increasing distress and intervene to de-escalate or change the situation where possible
- Validate the person's concerns (i.e. by being empathetic and allaying 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

- Seek advice from health professionals about calming interventions relevant to the person with dementia's interests such as preferred music, hand massage, aromatherapy or gardening
- Attend carer education and training courses to increase your skills, and meet with other carers for friendship and support
- Seek occasional respite care

A family's experience of dealing with agitation:

Mrs W is 76-year-old woman who lives at home with her husband, daughter and two teenage grandchildren. She was diagnosed with dementia five years ago and in the past year has become increasingly agitated. At times her agitated behaviours escalate to the point where she becomes aggressive. Mrs W walks from room to room of the home repeatedly moving and/or collecting objects. She gathers items of clothing and uses these to wipe the walls, frequently upsetting family members.

When she is locked out of a room, Mrs W becomes increasingly agitated. If her husband or a family member approaches Mrs W at this point, she can become aggressive. The grandchildren are particularly frustrated by their lack of privacy at home. At the end of the day, following the return of her daughter and grandchildren the home is busier and noisier with activity. Mrs W becomes more restless and agitated as the evening progresses. The family have difficulty settling Mrs W at the table to eat dinner and preparing her for bed.

The GP has checked for the following:

- Pain/discomfort/illness/infection/constipation
- Medication effects: interactions, dosage, recently prescribed, adverse effects
- Possible diagnosis of hyper- or overactive delirium

Other possible sources of irritation for Mrs W have been considered:

- Overstimulation from noise, people and/or activities in her environment
- Mrs W's diminishing capacity to communicate effectively with the family
- Whether she is being overextended or too much is expected of her
- General routines, changes to routines and interaction with family members
- Strain arising from any unfamiliar or altered aspects of Mrs W's physical environment
- Mrs W's reduced threshold to cope with stress due to her advancing dementia
- Tension because Mrs W is stopped from doing what she perceives as necessary tasks

A health professional has suggested the following strategies for the family to try:

- Observe for triggers for Mrs W's behaviours so that these situations/people can be avoided or managed wherever possible
- Encourage Mrs W to express her needs as far as she is able; allow her sufficient time to do so

- Be mindful of Mrs W's nonverbal signs of increasing distress or frustration so situations can be de-escalated before her behaviour becomes problematic
- Offer activities related to Mrs W's past interests, particularly art
- Record significant aspects of Mrs W's life history so that visitors and family may share in some of her past experiences; consider photos, preferred music, films and/or family videos
- Attend education and training courses to increase your skills as well as meet with other carers for friendship and support
- Seek occasional respite care

Outcomes:

- Family reported that at one time Mrs W had communicated that she was trying to finish her paintings in readiness for an art exhibition
- On occasion, showing Mrs W pictures hung on the walls in various rooms of the house appeared to reassure her that her paintings were ready and in place for the exhibition
- With assistance and safe materials Mrs W was able to be engaged with producing some new art
- Mrs W's new artwork was hung around her room; friends and family praised her efforts and Mrs W responded positively to being asked to show her art to others

- Library books with prominent pictures provided a varied and useful distraction at times
- Family members were more aware of the need to reschedule some of their evening activities to provide Mrs W with more individual attention at this time of greater need

Module 4: Anxiety

Key messages

- Anxiety in a person with dementia can present as tearfulness, excessive worrying, fear of abandonment, repeated questioning, distractibility and/or over-concern
- Dementia reduces a person's capacity to make sense of their environment which may cause anxiety and distress
- Suggested strategies:
 - Identify triggers, frustrations and stresses so these can be minimised or avoided
 - Recognise signs of increasing anxiety and intervene where appropriate
 - Speak slowly and reassuringly, don't argue or persist with attempts to reason with the person
 - Use reassuring, non-threatening posture and movement in your approach
 - 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 with dementia. It can present as tearfulness, fear of abandonment, repeated questioning, distractibility, excessive worrying about their health and/or over-concern. Agitated behaviours can be a visible response to anxiety.

Signs of anxiety include:

- facial expressions 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, shortness of breath, headaches, sleeplessness and/or heart palpitations
- behaviours such as constant watchfulness, avoiding specific situations or people, hand wringing, pacing, restlessness and/or repeatedly asking for help
- searching for a carer or family member when they are out of sight
- not wanting to be alone and/or 'shadowing' the carer

What causes anxiety and when is it most likely to occur?

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 are associated with altered ability to regulate emotions. 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.

Anxiety in a person with dementia may increase with:

- changes to their familiar routine or environment
- separation from a primary carer
- unrealistic deadlines or feeling rushed
- overstimulation
- fatigue
- 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 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. They may be concerned about making errors and/or failing at previously simple tasks. With advancing dementia, increased dependence in the form of 'shadowing' behaviours or constantly seeking reassurance can be very stressful for the carer.

What can be done to manage anxiety?

Ask your doctor:

- to check for other conditions which may overlap with the symptoms of anxiety such as depression, panic attacks or phobias
- about potentially untreated physical symptoms, such as infection, constipation and/or chronic pain
- to assess for possible medication reactions, side effects or interactions which may contribute to the symptoms
- about measuring the severity of the anxiety symptoms
- if treatment with anti-anxiety medication is indicated
- where medication is in the best interest of the person, medications prescribed for dementia (cholinesterase inhibitors) provide the best evidence where the dementia is due to Alzheimer's disease; short term use of anti-anxiety or antidepressants may also be of benefit

Strategies you can try:

- 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 with dementia and intervene to de-escalate or change the situation where appropriate
- Simplify the environment and avoid overstimulation to reduce distress
- Speak slowly and reassuringly; use non-threatening posture and movement; consider gentle touch where appropriate
- Provide structure and routine in the person's day; reduce the need for them to make decisions
- Provide opportunities for safe walking if this eases anxiety
- Try activities which support the person's cognitive losses and build on their remaining skills such as preferred music, individually meaningful and structured activities and/or exercise
- Try cognitive behavioural therapy (CBT) and/or other psychological therapies which may be of benefit, especially if a carer is also involved
- Attend carer education and training courses to increase your skills, meet with other carers for friendship and support
- Seek occasional respite care

A family's experience of dealing with anxiety:

Mrs Y is an 86-year-old Vietnamese lady who lives at home with three generations of her family. When she migrated to Australia the family noticed that Mrs Y had difficulties with her memory which 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. Mrs Y does not speak, read or write English. Mrs Y's daughter is her primary carer and she has become concerned about her mother's increasing anxiety levels. Mrs Y reportedly has strong spiritual beliefs but since she started wandering during church services, she no longer attends with her family.

A culturally specific, in-home service has recently been cancelled and the family has largely become isolated from the local Vietnamese community. The granddaughter reports that many of those in the community lack an understanding of dementia. The family is concerned that others will think their mother is 'crazy'.

The GP has checked for the following:

- Pain/discomfort/illness/infection which may increase Mrs Y's anxiety
- Medication effects: interactions, dosage, recently prescribed, adverse effects
- Underlying depression

Other potentially contributing factors have been considered:

- Lack of attention to Mrs Y's culturally-relevant needs
- Unfamiliar or altered physical environment increasing her anxiety
- Unrealistic expectations causing Mrs Y to fear failure
- Mrs Y's doctor was informed that she was not taking the prescribed medication because family members are unfamiliar with western medical practices and they were reluctant to assist her to take it

A health professional has suggested the following strategies:

- Observe triggers for Mrs Y's anxiety so these situations/interactions can be avoided or better managed
- Encourage Mrs Y to report her concerns and fears as far as she is able
- Ask staff from the recently ceased community service if they have observed situations which may have provoked Mrs Y's anxiety
- As Mrs Y's granddaughter is the only fluent English speaker in the home, access to an interpreter who speaks the same dialect is important for assessment purposes whenever possible
- Reduce Mrs Y's increasing isolation by planning social activities and outings for her

- Strong community expectations that family must care for their aged relatives without assistance from 'outsiders' must be acknowledged; enlist the assistance of appropriate CALD aged care services to introduce assistance with sensitivity
- Record aspects of Mrs Y's life history so that visitors and family can share past experiences with her and provide distraction from her anxious thoughts when they visit; consider photos, preferred music, films and/or family videos
- Attend carer training to learn the most effective ways of assisting Mrs Y and minimising her anxiety
- Seek occasional respite care

Some outcomes:

- Information about dementia and changed behaviours was provided in Vietnamese in written and DVD format so this could be shared with extended family, friends and neighbours as appropriate
- It was discovered that family cancelled the community services because they feared Mrs Y might be removed from the family home by officials; information and reassurance was provided to encourage acceptance of the assistance available
- Mrs Y's family was provided with strategies to avoid triggering her anxiety and to help ease her symptoms during acute periods of escalation
- Family members were able to suggest activities such as those that Mrs Y previously found pleasurable and/or related to her spiritual beliefs

- The family was provided with further information around the purpose of the medication and how long Mrs Y needs to take it before her symptoms may reduce
- Extended family members were willing to assist when made aware of the situation and Mrs Y was able to resume attendance for part of the church service with others helping to supervise her

Referrals were also made for the following:

- A family conference with the Aged Care Assessment Team (ACAT) provided information about further changes anticipated with the progression of Mrs Y's dementia and possible ways of dealing with these
- Additional community services to provide a care worker who can encourage and assist Mrs Y to participate in her activities of daily living and household tasks as far as she is able
- To enrol Mrs Y in a day respite program that offers activities and outings for people with dementia including others from a Vietnamese background
- Assessments of Mrs P's hearing and vision as these had not been attended for some time

Module 5: Apathy

Key messages

- Apathy in a person with dementia is a mental state marked by a lack of interest, reaction and/or distress in response to their environment and/or others
- 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 and/or sensory impairment
- It is important to distinguish apathy from depression; anti-depressants are not effective for apathy
- Suggested strategies:
 - Encourage activities that are tailored to the person's abilities, do not require initiative and can be shared with others
 - Ensure activities are individually meaningful and reflect the person's previous interests
 - Seek advice from health professionals on possible strategies
 - Attend carer education
 - Seek occasional respite

Apathy

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

People with dementia may become passive and inactive. This is known as apathy which is a mental state marked by lack of interest, reaction and/or distress.

Symptoms of apathy include:

- diminished emotional reactivity or expression (i.e. blunted affect)
- indifference to their surroundings
- absence of willpower and drive
- low energy and lack of motivation (amotivation)
- reduced spontaneity and ability to self-start everyday activities
- 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 disinterested
- 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 and when is it most likely to occur?

Apathy 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 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 with dementia's physical and/or social environment as well as sensory impairment due to poor hearing or vision.

How does apathy affect the person with dementia and others?

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 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 manage apathy?

Ask your doctor:

- to check for other conditions which may overlap with the symptoms of apathy such as underlying depression or reaction to grief
- about potentially untreated physical symptoms, such as infection, constipation and/or chronic pain
- to assess for possible medication reactions, side effects or interactions
- if recent medication non compliance due to apathy could further affect the person with dementia's well being

A number of medication treatments have been trialled in the management of apathy in dementia and most have demonstrated little benefit. For those with Alzheimer's disease a group of dementia drugs known as Cholinesterase Inhibitors provide the best evidence. Those that did show benefit on these medications improved in their thinking as well as their apathy levels.

Strategies you can 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 they are unable to get started or continue independently
- Choose therapeutic activities that are tailored to the person's abilities and hence, not too difficult for them to feel some sense of achievement
- Ensure activities reflect the person with dementia's previous interests
- Use a structured routine; it may help by providing a framework for activities to engage the person
- Try music, cooking activities, exercise and/or pet therapy as these may help to reduce apathy
- Attend carer education and training courses to increase your skills, meet with other carers for friendship and support
- Seek occasional respite care

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

A family's experience of dealing with apathy:

Mrs P has been an efficient homemaker and loving mother of four. After her husband died, it became evident that he had been compensating for Mrs P's functional losses. One year since their father's death, her son and three daughters have so far managed to support Mrs P to live alone in the family home with minimal assistance from community services.

Her family report that Mrs P is a lovely lady who has been 'no trouble'. They have noticed that when they bring her groceries they often find her sitting alone and unoccupied in her lounge room. Items of interest that they previously left for her remained untouched and food uncooked. Mrs P reportedly no longer has any interest in her favourite television programs. The family suspect that Mrs P has stopped showering and taking her medications. When they visit she seems passive and uninterested. They are upset by her indifference to them and her self-neglect. Her children are concerned that Mrs P has become 'lazy' although they have noticed that she can still complete tasks quite well if they do them with her.

The GP has checked for the following:

- Pain/discomfort/illness/infection which may be demotivating Mrs P
- Medication effects: interactions, dosage, recently prescribed, adverse effects
- Underlying depression or grief reaction
- Untreated hearing or vision impairment

Other potentially contributing factors have been considered:

- Lack of environmental stimulation
- Reduced ability to initiate activities for herself
- Activities offered may not be of interest/unfamiliar /too difficult so Mrs P's response is to avoid them
- Previous personality and lifestyle; how active has Mrs P been in the past?

A health professional has suggested the following strategies:

- Work within the limits of Mrs P's amotivation as the family now understands that she has not become lazy and her symptoms are indicative of her advancing dementia
- Family members will more actively initiate interaction but still encourage Mrs P to express her interests as far as she is able
- Attend carer training to learn the most effective ways of assisting Mrs P
- Reduce Mrs P'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 Mrs P to participate in her activities of daily living and household tasks as far as she is able

- To enrol Mrs P in a weekly group that offers activities and outings for people with dementia
- Assessments of Mrs P's hearing and vision as these had not been attended for some time
- Mrs P's local pharmacy for a weekly prepacked medication system that could be supervised by community services and the family to improve medication compliance

Module 6: Calling out

Key messages

- When a person with dementia calls out or makes continuous or intermittent noises it is referred to as vocally disruptive behaviour
- These behaviours can occur in response to a change in environment and/or routine, unmet needs, social isolation, communication difficulties, hallucinations and/or delusions
- Repetitive questioning, commenting and/or actions can be irritating and exasperating for family carers
- Calling out behaviours may peak in the afternoon when associated with sundowning
- Suggested strategies:
 - Identify and relieve frustrations and irritants where possible
 - Recognise signs that indicate increasing upset and consider strategies to intervene
 - Monitor for fatigue and relieve with rest periods
 - 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 and calming activities
 - Attend carer education
 - Seek occasional respite care

Calling out behaviours

What are calling out behaviours and what do they look like in a person with dementia?

People 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 these as vocally disruptive behaviours (VDB).

Calling out behaviours can include:

- cursing or verbal aggression
- screaming
- repetitious sentences/questions/actions
- complaining
- constant requests for attention
- groaning, sighing
- singing
- making odd noises

Calling out behaviours can be classified as one of the following:

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

What causes calling out behaviours and when are they most likely to occur?

Calling out or vocally disruptive behaviour 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 behaviours tend to occur more frequently. These behaviours may peak in the afternoon or early evening when associated with 'sundowning'. This is a period of increased confusion, restlessness and/or distress which tends to occur at the end of the day.

Calling out behaviours may occur in response to:

- a change in environment and/or routine
- unmet needs such as hunger, thirst, pain and/or constipation
- discomfort or pain during personal care activities such as bathing, feeding or toileting
- social isolation, boredom and/or communication difficulties
- forgetting information they have been told previously
- anxiety around what may be happening, planned and/or expected of them
- hallucinations or delusions

How do calling out behaviours affect the person with dementia and others?

Calling out behaviours tend to cause family carers

significant distress, frustration and stress, particularly where they are repetitious. Likewise, neighbours and visitors can be disrupted when the behaviours are loud. When the person with dementia is living in residential care, these behaviours can be problematic for other residents and care staff.

What can be done to manage calling out?

Ask your doctor:

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

Strategies you can try:

- Identify and relieve specific frustrations and irritants such as excess noise
- Provide orientating cues to the immediate environment to help reduce confusion and misinterpretation
- Recognise signs in the person with dementia which suggest increasing distress and intervene to de-escalate or change the situation where possible
- Facilitate more appropriate expression of feelings such as anger, grief, frustration and helplessness

- Relieve discomfort wherever possible; consider access to the toilet, adequate food and fluids, lighting as well as environmental temperature
- Monitor for fatigue and relieve with rest periods
- Positively reinforce appropriate, adaptive and quieter behaviours
- Minimise perceived threats to the person with dementia's space, dignity, privacy and/or safety
- Provide appropriate social contact
- Consider relaxation exercises, calming therapies, aromatherapy, preferred music and/or time spent outdoors
- Check that hearing and visual aids are as current and effective as possible
- Attend carer education and training courses to increase your skills, meet with other carers for friendship and support
- Seek occasional respite care

A family's experience of dealing with calling out behaviours:

Mrs T has been living with her youngest daughter for some years. With the progression of dementia, Mrs T has become largely unable to communicate her needs verbally but her calling out, for no obvious reason, has steadily increased. When her daughter attends her personal hygiene, Mrs T frequently screams loudly.

Mrs T's daughter reports significant stress and distress around her mother's chronic calling out behaviours. She feels a sense of dread and is avoiding or delaying attending to her mother's personal care needs whenever possible. On occasion, neighbours have made angry complaints to police, demanding investigation of possible maltreatment. Mrs T's previously attentive sister and nieces now visit infrequently because they are uncomfortable and embarrassed around her.

The GP has checked for the following:

- Acute illness/constipation/delusions/hallucinations
- Medication effects: interactions, dosage, recently prescribed, adverse effects
- Underlying depression
- Untreated hearing or vision impairment

Other potentially contributing factors have been considered:

- Possible overstimulation from excess noise or activities
- Mrs T's diminishing capacity to communicate
- Whether she is being overextended if too much is expected of her
- Additional strain from any unfamiliar or altered aspects of Mrs T's immediate environment
- Mrs T's reduced threshold for coping with stress due to her advancing dementia

A health professional has suggested the following strategies:

- A family conference with a consultant from the Dementia Services Australia (DSA) helped family members to understand the progression of Mrs T's dementia and potential triggers for her behaviours; they were unaware that pain can be a trigger for calling out
- Mrs T has chronic arthritis and investigation indicated that her pain relief was inadequate so medication was increased to better meet her needs
- A pain assessment indicated that Mrs T was experiencing pain during personal care, hence her frequent calling out during these activities
- Mrs T's daughter began showering her mother approximately half an hour after administering her pain relief medication to reduce her discomfort during the procedure
- Be mindful of Mrs T's nonverbal signs of increasing distress so situations may be de-escalated before her behaviour becomes disruptive
- Non-pharmacological pain relief interventions, such as gentle heat, were also implemented on a regular basis
- Observation indicated that that Mrs T responded positively to gentle touching and stroking and her daughter received training in how to provide this with good effect

- Mrs T's family members reported that they previously felt anxious about touching Mrs T, helpless to help her and distressed when they visited. Mrs T's daughter passed on her training and family were encouraged to gently touch or stroke Mrs T's hands and arms when they visited
- Willing family members subsequently developed an informal roster across the week and reported that they now felt their interaction with Mrs T was more purposeful and pleasant
- Mrs T's favourite music and aromatherapy were also trialled; these were sometimes soothing
- Attend carer training to learn the most effective ways of continuously assisting Mrs T
- Overall, Mrs T's calling out was substantially reduced and when she did call out, her family felt more confident to take steps that provided her with some comfort

Referrals were also made for the following:

- Aids to manage Mrs T's incontinence were reviewed and products trialled that reduced her need for frequent changes but still protected her skin
- Assessments of Mrs T's hearing and vision as these had not been attended for some time
- Community services to outline the help available to assist Mrs T's daughter if/when she would like some additional assistance in her challenging role as primary carer

Module 7: Delusions and hallucinations

Key messages

- People 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 not true and/or actually happening before seeking treatment, e.g. claims of theft may be true
- 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 and/or arguing to correct the person with dementia
 - Seek information and support as observing these symptoms may be distressing for those close to the person with dementia
 - Seek assistance from health professionals who can assist with tailoring individualised strategies for the person
 - 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 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
- *hallucinations* – false sensory experiences that occur without a physical stimulus; these can involve hearing, feeling, smell or touch
- *misidentification* – a mistaken perception of something real that becomes a fixed belief

The content of false beliefs and perceptions can include:

- delusions of theft, suspicion, abandonment, misidentification, danger, 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 and when are they most 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 are the most frequently reported of the psychotic symptoms, followed by hallucinations and then misidentifications. Hallucinations are more common in particular types of dementia. Delusions and hallucinations can arise from a delirium, underlying depression, substance use, some medications, infection and/or medical conditions.

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 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 manage 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 not true and/or actually happening to them before proceeding.

Ask your doctor:

- to check if the person with dementia has symptoms of an underlying medical condition, infection, delirium or the potential effects of drugs or alcohol
- to refer for assessment of sensory impairments and/or review of hearing aids and/or glasses
- about medication if the psychotic symptoms are placing the person with dementia and/or others at risk

NB: potential benefits must be balanced with the risk of side effects with the use of medication

Strategies you can try:

- Identify potential triggers for misidentification in the physical environment so these can be modified or eliminated; areas of shadow or patterned floor coverings and curtains can be misinterpreted

- 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
- Seek information and support: observing psychotic symptoms may be more distressing for you than for the person with dementia
- Consider trying preferred music and/or psychosocial interventions tailored to the individual person's interests and remaining abilities as research indicates that these may provide some relief from symptoms
- Attend carer education and training courses to increase your skills as well as meet with other carers for friendship and support
- Seek occasional respite care
- Ask a health professional about measuring the severity of the symptoms and suggestions for further, individualised strategies to manage these

A family's experience of dealing with delusions and hallucinations:

Mr H is a 70-year-old Aboriginal man from a remote community in the Northern Territory. He is dependent on his daughters for care, but they are currently unable to effectively meet his increasing needs due to Mr H's considerable demands and their other family responsibilities.

To ease the burden on the family, Mr H has recently started attending a day respite service. He is wary of care staff, particularly those who are from non-Aboriginal or Torres Strait Islander backgrounds, telling his family that they try to beat him and want to take him away from his community.

His family also report that Mr H has recently been distressed by seeing 'evil spirits' and feeling 'snakes coming out of his eyes'. At times Mr H has attempted to run away from staff at the day respite centre, which places him in considerable danger.

Adapted from Aboriginal and Torres Strait Islander considerations for DBMAS Best Practice Behaviour Guidelines (2007)

The GP has checked for the following:

- Sensory deprivation/impairment or inappropriate sensory stimulation
- Pain/discomfort/illness/infection/constipation
- Medication effects: interactions, dosage, recently prescribed, adverse effects or lack of compliance
- Exclude medical conditions potentially affecting his eyes which may contribute to Mr H's distressing sensations
- The feasibility of surgery for his bilateral cataracts which may be contributing to his misinterpretation of the environment

Other potentially contributing factors have been considered:

- Changes to routines, unfamiliar people and/or, reduced time spent with family and community
- Lack of attention to culturally- and/or spiritually-relevant needs
- Unfamiliar/ altered physical environment
- Reduced stress threshold due to progressive dementia
- English is not Mr H's first language and he has had no formal education so communication with respite centre staff and other attendees is limited and potentially open to misinterpretation

A health professional has suggested the following strategies:

- Observe for triggers for Mr H's behaviours so that these situations can be avoided or managed wherever possible
- Consult respite centre staff with regard to environmental triggers at the centre that they may or may not have identified
- Gather additional information on Mr H's life history to further search for historically relevant factors which may be contributing to the presence and/or content of his symptoms
- Be mindful of Mr H's nonverbal signs of increasing agitation or frustration so situations may be de-escalated before his behaviour becomes problematic

- Encourage Mr H to express his concerns and distress as far as he is able
- Provide appropriate activities related to his past interests to help keep Mr H occupied during periods of reduced environmental stimulation
- Visual resources and pictorial language aids developed and/or located with assistance of community members familiar with Mr H's first language could reduce potential for confusion around communication
- Attend carer training to better understand underlying factors and possible strategies to effectively avoid provoking and/or manage his symptoms

Some positive outcomes:

- Investigation revealed that Mr H's background as a member of the stolen generation may be relevant to his ongoing fear of being taken away from his community for day respite. Community members initially attended the day respite centre with Mr H to assist in his adjustment to the unfamiliar environment.
- An older Aboriginal man who is a nearby neighbour to the respite centre was originally from the same community and had some knowledge of Mr H's first language; he was available and willing to regularly spend some time 'yarning' with Mr H.
- Staff members at the respite centre had little knowledge or experience of psychotic symptoms in dementia and became fearful of Mr H after he spoke of his symptoms.

- Staff and the extended family were given information about dementia and its signs and symptoms and strategies to manage them.
- Staff at the centre now provide Mr H with activities relevant to his interests as well as regular reassurance that he will be returning home later in the day.
- While the above strategies did not eliminate Mr H's symptoms, those providing his care felt better able to understand, tolerate and manage his psychotic symptoms without fear.

Module 8: Depression

Key messages

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

Depression

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

Depression is one of the most commonly occurring BPSD 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 behaviours and symptoms include:

- unhappiness, tearfulness
- withdrawal from other people, loss of interest
- reduced activity
- physical symptoms such as fatigue, change in appetite and/or sleep disturbance
- low self-esteem
- feeling negative and/or hopeless
- thoughts of suicide

Depression in dementia can be difficult to diagnose because symptoms of dementia overlap with those of depression. Depression is diagnosed if symptoms have been present for more than two weeks and the person's behaviour is different from their usual 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. Depression may be

accompanied by increased irritability, agitation, aggression, anxiety and/or psychosis.

IMPORTANT

If a person with dementia is expressing psychotic thoughts (out of touch with reality) and/or acting on hallucinations or delusions in a way that may be dangerous, contact the psychiatric crisis team or arrange to transport them to your local hospital emergency department immediately.

What causes depression and when is it most 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 likelihood of depression. A person with dementia may experience depressive symptoms when they are unable to control or deal with upsetting memories.

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

- have experienced emotional problems or 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 both, the person with dementia and the carer
- Loss of interest and withdrawal makes it difficult to engage the person with dementia in previously pleasurable activities
- Fatigue can prevent the person with dementia 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 with dementia and the carer to engage in pleasurable activities with others
- Low self-esteem and a sense of hopelessness require constant & exhausting reassurance from others
- Thoughts of suicide require watchfulness around the clock and 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 manage depression?

Ask your doctor:

- to check for other conditions which may overlap with the symptoms of depression
- about potentially untreated physical symptoms, such as infection, constipation and/or chronic pain
- to assess depression severity and the risk of the person with dementia harming themselves
- if treatment with medication or other therapies is indicated

Strategies you can try:

- Try Life review and storybook programs as well as exercise programs and music interventions: they may be of benefit to the person with dementia and their carers
- Discuss referral with your doctor for cognitive behavioural therapy (CBT) involving the carer: it can encourage participation in pleasurable events, help carers with problem solving and identify ways to adapt the person's environment; discuss referral with your doctor
- Attend carer education and training courses to increase your understanding of depression and what it means for the person with dementia
- Spend time with other carers; it can facilitate friendship and support
- Seek occasional respite care

A family's experience of dealing with depression:

Mr L was born in Poland. After migrating to Australia, he married, had three children and ran his own business until he retired. Mr L's wife describes him as patriarchal, determined and of strong character. They live in their own home and their children visit regularly to provide support.

Recently Mrs L has been having increasing difficulty encouraging her husband to attend family events and the local dementia day centre. When he does attend day care, he can become aggressive when attempts are made to include him in activities. Mrs L reports that she feels more stressed when her husband refuses to go to the day centre as she then loses her respite hours. She increasingly finds it more difficult to stay patient and tolerant of his symptoms and behaviours. Mrs L also reports that her husband has become increasingly sad and tearful over recent months which is out of character for him.

Adapted from the DBMAS Best Practice Guidelines for People with Dementia from a Culturally and Linguistically Diverse (CALD) Background who have Changing Behaviours (2007).

The GP has checked for the following:

- Pain/discomfort/illness/infection/constipation which could impact on Mr L's mood
- Medication effects: interactions, dosage, recently prescribed, adverse effects
- Overlapping symptoms of other conditions

Other potentially contributing factors have been considered:

- Distress from excess noise, people and/or activities in his environment
- Whether he is being overextended or too much is expected of him
- General routines, changes to routines and interaction with family members
- Strain arising from any unfamiliar or altered aspects of Mr L's physical environment
- Mr L's diminishing capacity to communicate and reduced stress threshold due to his advancing dementia
- Lack of attention to Mr L's culturally and historically relevant needs
- Mr L reportedly experienced the harshness of wartime Europe as a teenager. He has rarely spoken of these experiences but it is known that his family of origin did not survive the war
- With the progression of dementia, Mr L has become more inclined to focus on unpleasant memories and express feelings of guilt and distress around the traumatic experiences of his youth

A health professional has suggested the following strategies:

- Observe what may exacerbate Mr L's depressive symptoms so that these situations can be avoided wherever possible
- Encourage Mr L to express his needs as far as he is able; allow him sufficient time to do so

- Access positive aspects of Mr L's life history so that visitors and family are encouraged to visit and share some of these past experiences with him; consider photos, preferred music, films and/or family videos
- Reduce Mr and Mrs L's growing isolation by assisting them with planning social activities and outings
- Training was provided to the day centre staff about the symptoms of dementia, depression and post-traumatic stress and potential management strategies.
- Day centre staff were asked to assist in identifying Mr L's needs or possible reasons for his low mood
- Consider activities related to Mr L's past interests, culturally significant occasions and traditional foods that may be incorporated into his visits to the day centre
- Further medical assessment indicated that Mr L may benefit from a trial of antidepressant medication. It was explained to the family that potential benefits might not be evident for two weeks but side effects may occur first. These would most likely diminish with time
- Attend carer training to learn the most effective ways of assisting Mr L
- A bilingual/bicultural staff member from the day centre was already transporting another lady. She was recruited to also collect Mr L on the same trip and he responded well to the additional culturally relevant attention provided by her

Referrals were also made for the following:

- Psychogeriatric assessment to assist in the management of Mr L's post-traumatic stress and depressive symptoms
- To engage a bilingual/bicultural care worker to provide in-home respite for Mrs L
- Access to the Multicultural Aged Care Service for further suggestions and resources

Module 9: Sleep pattern changes

Key messages

- The loss of regular or previous sleep patterns is known as sleep disturbance or nocturnal disruption
- 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 stresses which can be avoided or minimised before bedtime
 - Identify and treat potential discomfort which may contribute to the symptoms
 - Recognise cues that indicate distress and intervene early where possible
 - Modify the home and bedroom environment 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 cues as to the approaching time for sleep
 - Try traditional methods to promote sleep, e.g. 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 people 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 and when are they most 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, 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
- side effects of medication

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 with dementia and the carer. These changes can prompt earlier admission to residential care.

Family carers can also experience poor quality sleep, significant distress and depressive symptoms as a result. Changes to sleep patterns can lead to worsening behavioural changes in the person with dementia at night. These can include increased confusion, restlessness, hallucinations, wandering, calling out and/or disorientation.

What can be done to manage sleep pattern changes?

Ask your doctor:

- to check if the person with dementia has symptoms of an underlying physical and/or psychiatric illness, depression, pain or infection

- to rule out medication side effects or substance misuse as a potential contributing factor; cholinesterase inhibitor medications for dementia can cause sleep disturbance and nightmares
- to exclude other sleep disorders such as restless legs syndrome, sleepwalking, leg cramps, which can be side effect of medications prescribed for dementia (cholinesterase inhibitors) or sleep apnoea
- about sleep questionnaires and technical instruments to assist in diagnosis
- about medication that may be of assistance to regulate sleep patterns if necessary; there is limited evidence that complementary medicines such as melatonin may be helpful

Strategies you can try:

- 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 minimise triggers, frustrations and stresses for the person with dementia, particularly before bedtime; avoid where possible.
- Keep the person with dementia active in the morning and encourage an early afternoon rest soon after lunch.
- Limit caffeine intake

- Adopt familiar, early evening activities to provide cues as to the time of day, e.g. relaxing pre-dinner drinks (low/non alcoholic), assisting with preparing dinner, setting the table, feeding the pets, closing the curtains.
- Avoid bathing or a shower in the evening if this is likely to increase agitation; alternatively, others may be calmed by a warm bath before bed.
- If changing into pyjamas leads to confrontation, consider allowing the person with dementia to change into comfortable clothing, e.g. tracksuit earlier in the day and allowing 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 with dementia to empty their bladder overnight.
- Recognise cues that indicate increasing distress and intervene promptly to de-escalate or change the situation.
- When distress is evident, speak calmly, slowly and reassuringly; 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.
- Consider whether bright lights outside the window or noise from a television elsewhere in the house are

adding to the person's confusion and/or restlessness.

- 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.
- Look after yourself and get enough sleep; family carers experience poorer sleep quality, more depressive symptoms and increased burden because of the wakefulness of the person with dementia
- Attend carer education and training courses to increase your skills and meet other carers.
- Seek occasional respite care.

A family's experience of dealing with sleep pattern changes:

Mr C has been recently widowed. His family has maintained him in his own home since his diagnosis of dementia. His worsening symptoms have been managed by visits and overnight stays rostered between his four daughters and the assistance of community care services.

His sleeping patterns have become very irregular so he is frequently awake at night, wandering around the house and turning on lights, radio and/or television. When his daughters attempt to settle him back to bed he can become increasingly agitated. In the mornings he tends to sleep late and resists getting up for his shower and breakfast when the care workers visit to assist. The service provider has already rescheduled Mr C's visit as late as possible.

The GP has checked for the following:

- Pain/discomfort/illness/infection/constipation
- Medication effects: interactions, dosage, recently prescribed, adverse effects

Other potentially contributing factors have been considered:

- Overstimulation from noise, people and/or activities in Mr C's environment
- Mr C's reduced threshold for coping with stress due to his advancing dementia
- Unsettling changes to Mr C's routines
- Mr C's diminishing capacity to effectively communicate his needs to the family, particularly during the night
- Whether he is being overextended if too much is expected of him; he may become overtired

A health professional has suggested the following strategies:

- Observe for triggers for Mr C's behaviours so that these situations/people can be avoided, reduced or managed wherever possible
- Encourage Mr C to express his needs as far as he is able; allow him sufficient time to do so
- Develop a management plan for Mr C's symptoms so family members and community carers can adopt consistent routines and approaches

- Be mindful of Mr C's nonverbal signs of increasing distress or frustration so situations can be de-escalated before behaviours become problematic
- Attend education and training courses to increase your skills as well as meet with other carers for friendship and support
- Seek occasional respite care

Some positive outcomes:

- It became evident that Mr C was somewhat disrupted at night by traffic noise and car headlights on the busy road outside his bedroom.
- Mr C was persuaded to move into a quieter, darker back bedroom. As it faced east, it also received the first morning light.
- Better sleep routines (sleep hygiene) meant that the family planned around daytime naps and gradually established an earlier and regular bedtime for Mr C.
- A small night light in his bedroom and in the bathroom assisted Mr C with orientation when he needed the bathroom at night.
- While Mr C was still awake at times during the night, the situation was more manageable and less disruptive to other family members.

Module 10: Socially inappropriate behaviours

Key messages

- Socially inappropriate or disinhibited behaviours occur when the person with dementia is unable to restrain their reaction to a situation, fail to recognise social norms or follow social cues
- Socially inappropriate behaviours include insensitivity, loss of insight, reduced awareness, lack of control, and inappropriate or offensive acts, sometimes sexual
- Some socially inappropriate behaviours can be triggered by events or factors in the environment
- Disinhibited behaviours of a sexual nature are amongst the most challenging for family carers
- Suggested strategies:
 - Identify potential triggers, frustrations and stresses; minimise and/or avoid where possible
 - Recognise cues that indicate disinhibition and intervene where possible
 - Use gentle but firm communication when a particular behaviour is unacceptable
 - Encourage activities to occupy the person's hands
 - Attempts to restrain the person can exacerbate the behaviour and/or lead to aggression
 - Seek the assistance of health professionals who can help to develop individualised strategies
 - 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 which become problematic are relatively uncommon in people with dementia. These occur 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.

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.

Socially inappropriate behaviours include:

- tactlessness and insensitivity to social norms, expectations and/or rules
- loss of insight into behaviour and its effect on others
- reduced awareness of others and the environment

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

Examples of socially inappropriate behaviours include:

- demanding attention
- taking items from others
- using inappropriate language
- talking about personal or private matters in public
- commenting loudly about others around them
- finding humour where others do not
- 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, masturbating in communal spaces or sexual acts

What causes socially inappropriate behaviours and when are they most 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
- disorientation could result in the person getting ready for bed in a communal space when it is mid-morning
- anger and aggression can arise from unrestrained responses to frustration around a task which is too complex

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 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 RACF.

What can be done to manage socially inappropriate behaviours?

Ask your doctor:

- to check if the person with dementia has symptoms of an underlying medical or psychiatric condition, brain injury, urinary tract infection, delirium or the potential effects of drug or alcohol
- to determine if the behaviours are associated with agitation, hallucinations or delusions
- about medication which may provide some benefit, if behaviours are insistent and/or risky; the evidence for medication is limited but the doctor may consider prescribing antipsychotics, antidepressants or drugs which target dementia symptoms

NB: potential benefits must be balanced with the risk of side effects with the use of medication

Strategies you can try:

- Identify triggers, frustrations and stresses so they can be minimised and/or avoided.
- Avoid 'shaming' the person with dementia; they are not intentionally behaving in this manner.
- Recognise cues that indicate potential disinhibition and intervene promptly to de-escalate or change the situation where possible.
- Try to avoid overreaction which can induce shame, humiliation and/or aggression; remember it is the dementia prompting the behaviour.
- Reorient the person if they are directing behaviour inappropriately toward a stranger due to misidentification.
- Use gentle but firm communication when a particular behaviour is unacceptable.
- Distract, or lead the person to a private place if behaviours are inappropriate in a communal space.
- Modify clothing, for example, trousers without zippers.
- Encourage socially appropriate activities that the person enjoys to occupy their hands.
- Increase appropriate affectionate contact with family and pets.
- Provide positive regard and appropriate reassuring contact, e.g. hugging.
- Engaging the services of an appropriately skilled, sex therapist/worker has been reported.

- Attend education and training courses to increase your skills as well as meet with other carers for friendship and support.
- Seek occasional respite care.
- Do not attempt to restrain the person with dementia; it can exacerbate the behaviour and/or lead to aggression.
- Ask a health professional about measuring the severity and frequency of the symptoms and suggestions for further, individualised strategies to discourage these.

A family's experience of dealing with socially inappropriate behaviours:

Mr and Mrs A lived together for 40 years until Mrs A died unexpectedly six months ago. Since then the family has been maintaining Mr A in the family home with increasing assistance from community care services. Recently Mr A has been behaving in a socially inappropriate manner. He makes loud and inappropriate comments about others when he accompanies the carers on shopping trips. At times Mr A has been overly affectionate with female friends to the extent that they are uncomfortable and prefer to avoid him.

Mr A has also approached strangers and community careworkers with sexual suggestions. He appears to no longer recognise the need for privacy when masturbating and some careworkers have complained to their manager and the family.

When others react to his behaviour Mr A can become verbally aggressive and threatening. As these behaviours are very out of character for Mr A, his family is embarrassed, distressed and at a loss as to what to do. They are also concerned that the community care services may not be able to continue under these circumstances.

The GP has checked for the following:

- Pain/discomfort/illness/infection/constipation
- Medication effects: interactions, dosage, recently prescribed, adverse effects
- Underlying symptoms of depression or psychosis

Other potentially contributing factors have been considered:

- Sexual history and patterns of sexual interest
- Recent loss of his wife
- Misinterpretation of environmental cues
- Misinterpretation of others' approach and interaction
- Sensory impairments
- Loss of social and sexual controls with impaired understanding of personal boundaries due to progressive dementia

A health professional has suggested the following strategies:

- Observe for triggers for Mr A's behaviours so that these situations can be avoided or managed wherever possible

- Consider significant aspects of Mr A's life history for potential triggers
- Family report that Mr A and his wife had been a close and affectionate couple until her death; Mr A is likely missing the close contact but he has become increasingly less aware of appropriate boundaries
- Be mindful of Mr A's nonverbal signs of increasing agitation or frustration so situations may be de-escalated before his behaviour becomes problematic
- Consult community care staff with regard to environmental triggers they may have identified
- Consider keeping a diary of incidents for further information around potential triggers and ways to avoid them
- At times a sexual response has been provoked when Mr A misidentified the intentions of female careworkers during personal hygiene tasks; changes to rostering enabled two male staff members to cover Mr A's personal care needs
- Reduce Mr A's growing isolation by providing distractions through appropriate social contact and increased family visits
- Attend carer training to better understand causes of disinhibited behaviours, 'normal' sexual expression in older people, diminished privacy issues and strategies to effectively avoid provoking and/or manage unwanted sexual behaviours

Module 11: Wandering

Key messages

- Wandering is defined as 'repetitive locomotion' that exposes the person 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 social isolation
- The use of medication in an attempt to control wandering in a person with dementia is known as 'chemical restraint'; this is NOT justified or recommended
- Suggested strategies:
 - Identify potential triggers for wandering behaviours; minimise and/or avoid where possible
 - Recognise cues that suggest increasing upset and/or restlessness and intervene
 - Provide opportunities for independent, safe walking; be aware of potential risks
 - Consider trialling positive social interaction, ambient lighting and/or repetitive, slow tempo music as these have helped to reduce wandering
 - Try slow massage to reduce restlessness which can prompt wandering
 - As a precaution, ensure the person with dementia has identification on them and keep a recent photograph of them on hand at all times
 - 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 BPSD although rates vary with different types of dementia. Wandering is defined as 'repetitive locomotion' that exposes the person with dementia to risk of harm when boundaries and obstacles are not understood. The person may exit a safe environment and become lost. While restlessness and agitated behaviours can overlap with wandering behaviours, they are different. Wandering patterns 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.

What causes wandering and when is it most 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 behaviours tend to increase in the earlier to moderate stages and then lessen in late-stage dementia. Wandering has different meanings and causes for each individual. Wandering behaviours may be brought on by physical and/or emotional discomfort.

Wandering may be associated with:

- 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
- 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

How does wandering affect the person with dementia and others?

- The potentially severe consequences of wandering and becoming lost mean that appropriate management of wandering behaviours is crucial.
- People with dementia who wander are at risk of falls, injury and/or fractures, weight loss and social isolation.
- Wandering has been associated with high carer burden and anxiety around the associated safety risks.
- Wandering may result in earlier admission to a residential aged care facility.

What can be done to manage wandering?

Ask your doctor:

- to check for other medical or psychological conditions which may underpin the wandering behaviours
- about possible reactions to medication causing the behaviour

- about potentially untreated physical symptoms, such as infection, constipation and/or chronic pain which can increase restlessness and confusion
- for referral and/or advice on barriers and devices that help discourage wandering such as technological aids, sensor monitors and GPS monitoring

The use of medication in an attempt to control the person with dementia's wandering is known as 'chemical restraint'. This can increase their confusion and risk of falling and is NOT justified or recommended.

Strategies you can try:

- Identify frustrations and stressors for the person with dementia so these can be minimised and/or avoided before they prompt wandering behaviours.
- Recognise cues in the person with dementia that suggest increasing upset and intervene promptly to de-escalate or change the situation where possible.
- Arrange opportunities for independent, safe walking but be aware of the potential for safety risks, dehydration, physical exhaustion and/or unreported pain or discomfort.
- Consider comfortable, ambient lighting in the person's environment as research indicates that this can help to reduce wandering.
- Provide the company of others and positive social interaction as appropriate.

- Reduce restlessness which can lead to wandering; some evidence indicates that slow massage and the use of lemon balm and lavender oil have helped.
- Try aerobic, strength, balance and/or flexibility type exercises as well as repetitive, slow tempo music according to the person's individual abilities and preferences.
- As a precaution, ensure the person with dementia is wearing a form of identification, e.g. wallet, bracelet
- Keep a recent photograph which clearly represents the person to hand at all times. This can help to quickly check with others who may have seen them. It will also be invaluable should the assistance of emergency services ever be required.
- Attend carer education and training to increase your skills and meet other carers for friendship and support.
- Seek occasional respite care.

A family's experience of dealing with wandering:

Mr E is a 63-year-old Aboriginal man who moved to Adelaide from a regional community when he was 16. He lived with his wife until she died several years ago. While raising their five children, Mr E and his wife maintained strong links with Aboriginal friends and family in their original community. His connection with *Country* has always been very strong.

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

On several occasions in the past month Mr E 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 Mr E was unable to provide his address or contact details for family. When the police approached Mr E he became uncooperative and verbally aggressive. Police ultimately located Mr E's daughter, who picked him up from the police station.

The GP has checked for the following:

- Pain/discomfort/illness/infection/constipation
- Medication effects: interactions, dosage, recently prescribed, adverse effects
- Underlying depressive symptoms
- Other medical problems which increase concerns that Mr E may fall if he wanders from home

Other potentially contributing factors have been considered:

- Possible triggers in his immediate environment which may prompt him to leave
- Changes to Mr E's familiar routines and/or aspects of his physical environment

- Searching for family members or his childhood home environment and *Country*
- Family report that Mr E's beloved dog died recently; Mr E doesn't remember that the dog has died and becomes distressed when the dog doesn't respond to his calls
- Carers noticed that Mr E became more restless after phone contact with his younger brother, who still lives in the town near their childhood home
- Lack of stimulation or boredom
- Mr E's daughters are feeling the stress of providing care; they feel guilty when leaving their father alone but they must also meet the demands of their own families

A health professional has suggested the following strategies:

- Identify circumstances which provoke Mr E's wandering so that these situations can be avoided where possible
- Ask community service workers to assist in identifying potential triggers for Mr E's wandering
- Mr E is increasingly reverting to his traditional language, making it difficult for family and community workers to communicate with him; encourage Mr E to express his needs and wishes as far as he is able and allow him time to do so
- Identify circumstances where Mr E does NOT attempt to wander and promote these conditions wherever possible

- Consider Mr E's life history for additional information which may be relevant to his wandering behaviours
- Mr E's history helped to explain his reaction to contact with the police; with the progression of dementia, traumatic experiences from his past have exacerbated his fear of authority figures
- Reduce Mr E's growing isolation by assisting him with planning appropriate activities and outings
- Family and community care staff have little understanding of Mr E's dementia and his wandering behaviour; training was provided around BPSD and potential strategies

Outcomes from a family/community meeting:

- Mr E's younger brother travelled to join the meeting and agreed that Mr E may benefit from staying with him and his wife for a period
- Mr E responded well to returning to *Country* and the company of some of the older community members who were able to interact with him in his traditional language
- The additional support from community members meant that Mr E received more supervision

Appendices 1 and 2: Glossary and checklist

Appendix 1: Glossary of terms

Appendix 2: Checklist of potential underlying factors that can contribute to BPSD

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.

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 interventions: Physical treatments such as 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 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): CBT is a technique used by health professionals to provide strategies and 'tools' to help reduce the negative thoughts associated with depression.

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 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
- Frontotemporal dementia (FTD); also referred to as Frontotemporal Lobar Degeneration; and previously known as Pick's disease
- Parkinson's disease dementia (PDD)

Dementia Support Australia (DSA): DSA clinicians provide support and advice to family members, residential aged care staff and community care staff looking after people with dementia who present with BPSD (dementia.com.au).

Dementia Collaborative Research Centres (DCRC): DCRCs conduct research into many aspects of dementia to improve diagnosis and the lives of people living with dementia, their families and carers. Research findings are

translated into knowledge to support the care of people with dementia.

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

General Practitioner (GP): A general practitioner is 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. These effects tend to be mild although a decrease in white blood cells increases the person's risk of infection.

Mania: A state of heightened mood and energy which can include delusions and/or hallucinations.

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.

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.

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

Orthostasis: is also known as postural hypotension or a dizzy spell. This occurs when a person's blood pressure suddenly falls when they stand up from a sitting or lying position.

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 manage an illness or disorder.

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 reproductive 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 BPSD and their carers.

Psychotropic medication: Medication capable of affecting the mind, emotions and/or behaviour. People with dementia are particularly vulnerable to side effects of these medications.

Residential Aged Care Facility (RACF): RACFs offer low-level care in hostel style accommodation for people who are largely independent but require some support and/or high-level care in a nursing home environment for those who are physically frail or unable to look after themselves because of dementia.

Restraint: 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 nursing homes 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.

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, e.g. avoiding caffeine late in the day, 'winding down' or relaxing before bed.

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

Sundowning: Occurs when people with dementia become more confused, restless or insecure late in the afternoon or early evening, especially after a change to their routine or familiar environment.

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 BPSD

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

- ☐ fever
- ☐ dental/mouth problems
- ☐ unrecognised and/or untreated pain (including feet)
- ☐ urinary tract infection
- ☐ chest infection
- ☐ adverse effects of 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 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 Generation, war experiences, immigrant dislocation, intergenerational trauma
- ☐ significant losses – family members, peers, home, place of origin, wealth, pets

Consider difficulties with communication

A person with dementia can have difficulty when others:

- ☐ speak too quickly
- ☐ are not aware of their tone of voice
- ☐ are perceived as treating them in a condescending or childish manner
- ☐ avoid making eye contact
- ☐ do not address the person by name
- ☐ do not use the correct form of address, e.g. Mr, Miss
- ☐ argue with them
- ☐ correct mistakes, indicating failure
- ☐ attempt to reason with the person
- ☐ 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.

Difficulties around meals

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

Difficulties around assisting with 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
- ☐ 'talking over' the person during hygiene practices
- ☐ painful movement of limbs during care
- ☐ lack of effective communication and/or explanation during procedure
- ☐ cultural/spiritual preferences not considered

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 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

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

Under- or over-stimulation

- ☐ lack of physical activity during the day
- ☐ daytime tiredness
- ☐ not enough stimulation in their environment
- ☐ too much stimulation and/or noise
- ☐ lack of company or boredom
- ☐ dislocation from family, community, peers and/or place of origin

