

A Clinician's Field Guide to Good Practice

*Managing Behavioural and Psychological
Symptoms of Dementia*



A PARTNERSHIP LED BY **HammondCare**

Terms and abbreviations

Term	Abbreviation
Alzheimer's disease	AD
Atypical antipsychotics are also known as second generation antipsychotics	
Behavioural and psychological symptoms of dementia	BPSD
Cholinesterase inhibitors	ChEIs
Culturally and Linguistically Diverse	CALD
Dementia Behaviour Management Advisory Service	DBMAS
Dementia Support Australia	DSA
Lewy body dementia; also known as dementia with Lewy bodies or Lewy body disease	DLB
Frontotemporal dementia	FTD
Neuropsychiatric Inventory	NPI
Neuropsychiatric Inventory – Clinician	NPI-C
Selective serotonin reuptake inhibitors	SSRIs
Typical or traditional antipsychotics are also known as first generation antipsychotics	

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**Managing Behavioural and
Psychological Symptoms of
Dementia (BPSD)**

***A Clinician's Field Guide to
Good Practice***

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Disclaimer

This Clinician's Field Guide was funded by the Australian Government and developed by the DCRC-ABC. The information contained in this Field Guide is a modified summary of the document *Behaviour Management - A Guide to Good Practice, Managing Behavioural and Psychological Symptoms of Dementia* (2012) which was developed as a resource for the Dementia Behaviour Management Advisory Services (DBMAS). It is recommended that clinicians consult the original *Guide to Good Practice* for more detailed information. This Field 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.

This Field Guide incorporates information from recent literature and other sources. Every effort has been made to ensure the accuracy and reliability of the information in this field guide 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 responsibility for clinical decisions rests with and is borne by the clinician; the authors do not bear any clinical responsibility for the practical application of the information contained in this Clinician's Field Guide.

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- UNSW

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Introduction

Aim

The aim of this field guide is to provide initial points for consideration for clinicians in their role of assisting residential aged care facility staff, community care staff and family members caring for persons living with dementia, who present with behavioural and psychological symptoms of dementia (BPSD).

A comprehensive evidence and practice-based overview of BPSD management principles is provided in the unabridged version of this document with practical strategies and interventions for managing behaviours in dementia. The evidence supporting the content of the *Guide to Good Practice* is included in a comprehensive reference list (Appendix 8). The *Guide* and appendices can be accessed via the DCRC website www.dementiaresearch.org.au*.

How to use this Field Guide

This clinician's field guide has been designed as a set of module summaries in order to facilitate ease of use and provide behaviour specific information. Each module begins with key messages, to enable quick reference to the most pertinent information of that module. *Module 1: Behaviour management process* provides a guiding framework for the process of managing BPSD; outlining the stages of risk assessment, comprehensive assessment and the implementation and evaluation of behavioural management strategies.

Modules include specific information relevant to the following aspects of the BPSD:

- A description of the behaviour or psychological symptom and how it presents in dementia
- Potential causes of the BPSD
- Differential diagnosis
- Measuring the BPSD
- Prevalence of the BPSD
- Effects of the BPSD on the person with dementia and others living with them or involved in providing care
- Management strategies for the BPSD including:
 - *Psychosocial and environmental interventions*
 - *Biological interventions*
- Conclusions, recommendations and limitations of the evidence presented

In order to illustrate the information included in each module, a brief clinical scenario encompassing BPSD presentation, assessment and strategies/outcomes is presented. It is anticipated that the evidence summarised in this clinician's field guide, in combination with clinical expertise may assist in achieving improved outcomes for those with dementia.

The unabridged *Guide to Good Practice* provides details of intervention studies and the strength of the evidence for the findings reported. Details are included in electronic Appendices 3 and 4 via <http://dementiaresearch.com.au>*.

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

Terminology

In this guide, the term BPSD will be used to refer to dementia related behavioural and psychological symptoms, unless otherwise specified. The term *Aboriginal and/or Torres Strait Islander peoples* will be used throughout and the abbreviation CALD will be used to refer to people from Culturally and Linguistically Diverse backgrounds. Additional considerations relevant to Aboriginal and Torres Strait Islander peoples and those from CALD communities have been included as a series of text boxes.

Managing BPSD - general principles

In providing assistance, clinicians need to be mindful of the rights of persons with dementia and the obligations of service providers toward persons with dementia. Persons with dementia must give informed consent for treatments or if this is not possible, proxy consent should be obtained.

The following broad principles should apply to all efforts in managing dementia related behaviour:

- The rights of persons with BPSD are recognised and protected
- Treatment or management has a goal of maximising quality of life and safety within the least restrictive environment for each individual
- The behaviour of persons with dementia is recognised as a form of communication
- The impact of BPSD on the person with dementia, families and staff who provide care is recognised

- Collaboration with all people affected is the preferred approach to managing BPSD

Cultural Competency

Cultural competency involves the recognition and respect of the aspects that make the person with dementia and/or their family and community diverse, understanding how these factors contribute to their interpretation of and ability to access appropriate and timely care, and incorporating these considerations in clinical practice. This includes an acknowledgement of the person's country of origin, family and cultural background, preferred language, education, religion, belief system and socio-political outlook and an appreciation of how these aspects influence care.

The following considerations are important for culturally competent and sensitive service provision:

Knowledge of local context: People from similar cultural and/or religious backgrounds should not be regarded as a homogenous group. It is important to avoid stereotypical assumptions about the person with dementia.

Communication: Communication not only encompasses language but also recognition of the various culturally appropriate methods of communication, i.e. preferred ways of addressing Elders, body language and other cultural cues.

Assessment tools: Culturally appropriate instruments, where available and appropriate, should be used for the assessment of possible cognitive impairment in those from

Aboriginal and Torres Strait Islander or CALD backgrounds, where indicated.

Aboriginal and Torres Strait Islander peoples are made up of many diverse communities and language groups within Australia. Variations in cultural norms are relative to multiple factors which include size of the community, geography, climate, urbanisation, language as well as traditional, historical, political and social influences.

Likewise, when working with CALD communities it is important to recognise the myriad of differing perceptions of wellbeing, health, illness, mental health and dementia, knowledge of service availability and pathways to access. These factors will vary widely and affect the way people interpret their situation and react to care and treatment.

Clinicians' usual approach to assessment and management may not be culturally appropriate or relevant for Aboriginal and/or Torres Strait Islander peoples or CALD communities. Culturally competent care and clinical practice is vital for comprehensive and appropriate assessment as well as management of BPSD within these populations.

The unabridged *Guide to Good Practice* and electronic *Appendices 5 and 6* outline additional resources specific to Aboriginal and/or Torres Strait Islander peoples and people from CALD backgrounds which may aid in developing cultural competence.

Module 1: Behaviour management process

Key Messages

- It is important to build rapport with the person making the referral from the outset
- Risk assessment should be undertaken promptly to determine whether the person with dementia or others are at risk of likely harm without an immediate response
- Risk assessment should consider medical and mental health as well as environmental areas of risk and potential for physical harm
- Effective communication with the person with dementia is a critical factor in the assessment and management of BPSD
- A thorough and detailed assessment of the person with BPSD, in combination with the interpersonal and physical environment, is essential to generate potential strategies and interventions
- Family members and care staff can be valuable sources of information on the person with dementia, his or her history, premorbid personality and/or preferences
- A management plan, based on analysis of the assessment, should be prepared in partnership with carers to ensure their cooperation and understanding

Module 1: Behaviour management process

The flow diagram (*Figure 1.1*) illustrates the standard process involved in responding to a request for assistance with managing BPSD. Key considerations in each step of the process are outlined in the following sections.

The referral

It is important to establish a rapport with the person making the referral from the outset. It can be difficult for carers to reveal BPSD in a loved one.

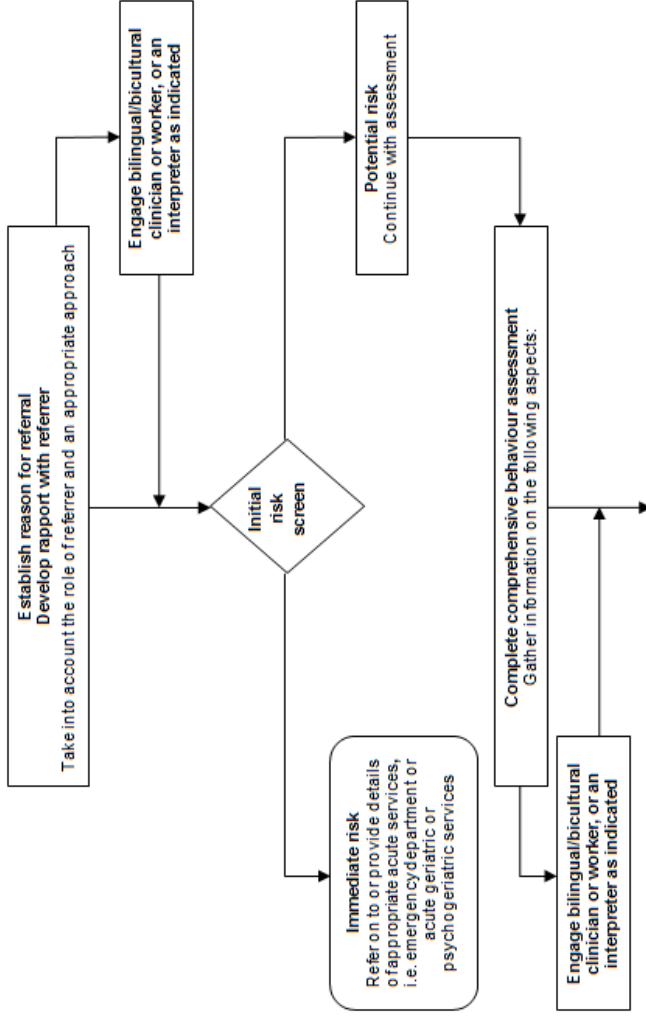
Risk assessment

The purpose of a risk assessment is to determine whether, without an immediate or prompt response, likely harm will come to the person with dementia or others. The degree of risk should be assessed without delay:

- *Immediate risk* of medical, mental health, physical and/or environmental risk to the person with dementia and/or others.
- *Potential risk* (i.e. no immediate risk) to the person with dementia or others. Strategies to prevent future risk should be integrated into the care plan.

When determining the degree of risk the following aspects should be taken into account:

- nature and severity of the presenting behaviour
- context of the behaviour
- resources available to manage the situation



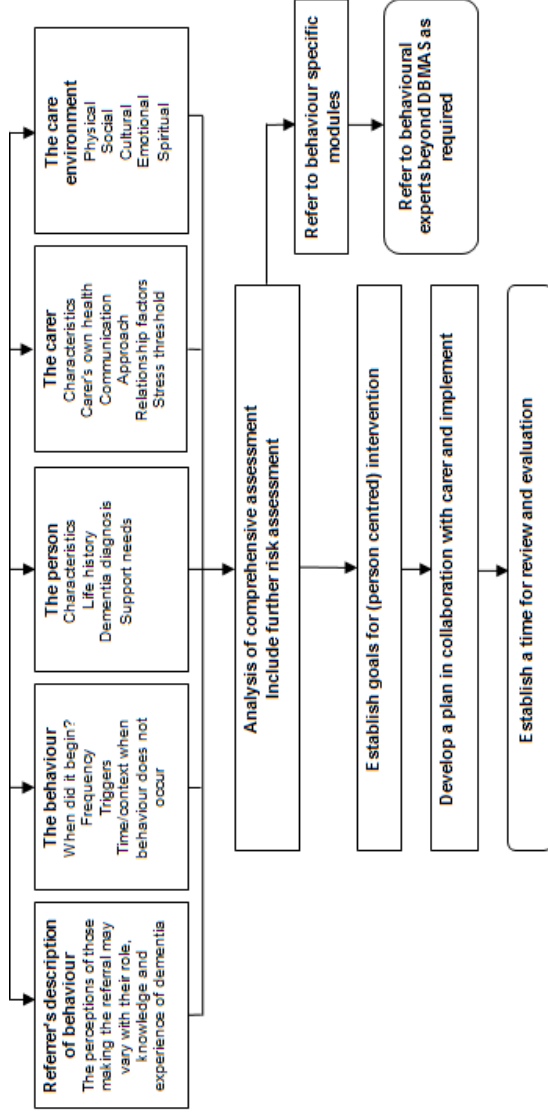


Figure 1.1: General behaviour management process

Areas of risk

When conducting a risk assessment the medical and mental health, physical and environmental areas of risk should be considered.

Medical and mental health risks

The person with dementia may be at risk from untreated, underlying medical conditions that may progress rapidly without urgent treatment.

Medical areas of risk:

- delirium
- urinary infection
- silent infection
- constipation
- inability to recognise or report pain and/or other symptoms
- reduced appetite, food and/or fluid intake resulting in dehydration, malnourishment and/or electrolyte imbalance
- atypical disease presentation, i.e. lack of common features
- polypharmacy
- medication noncompliance, overdose or toxicity
- co-morbid mental illness
- presence of other chronic diseases
- alcohol abuse

Mental health issues/co-morbidity areas of potential risk:

- depression
- suicidal ideation
- psychosis
- psychiatric history
- post traumatic stress disorder (PTSD)

Physical risks

Dangerous situations involving physical risk must be approached with caution. Advise the referrer to avoid escalating the situation and protect all involved.

Areas of potential physical harm:

- lack of awareness of exposure to danger
- injury as a result of physical aggression directed at others or inanimate objects
- wandering from care setting unaccompanied
- changes in perception
- misinterpretation of environment, including other people
- increased risk of falls
- extreme carer stress leading to assault
- neglect or abuse, i.e. physical, financial, sexual
- self-destructive behaviours
- impulsive behaviours

Potential physical harm to others:

- physical aggression
- sexual disinhibition
- response to delusions or hallucinations
- situation exacerbated by alcohol or other drugs
- physical abuse

Environmental risks

Potential loss of accommodation as a result of the person with dementia's behaviour:

- transfer from current accommodation
- transfer to more restrictive care setting
- transfer resulting in increased confusion and distress

An unsafe physical environment can be associated with high risk.

Unsafe environment:

- safety hazards in care environment
- carer's capacity and/or tolerance compromised due to illness or lack of support
- avoidable transfer to hospital resulting in increased confusion and/or disorientation
- change to physical environment
- leaving the home unsecured
- allowing strangers into the home

Communication

Effective communication with the person with dementia is a critical factor in the assessment and management of BPSD. This is particularly important when aiming to provide culturally competent services to persons with dementia and their families from Aboriginal and Torres Strait Islander or CALD backgrounds.

An Aboriginal or Torres Strait Islander Health worker or a bilingual/bicultural clinician or worker should be included where the person with dementia, family and/or staff are not fluent or comfortable speaking in English. Where these options are unavailable, an interpreter may be required. Prior to engaging an interpreter:

- Determine the English language proficiency of the person with dementia, family carers and/or care staff.
- Establish the appropriateness of the interpreter for the assessment and brief them on the purpose of the consultation prior to the assessment.

- Where possible, avoid relying on family and/or friends to act as interpreters during a specialist assessment.

Aboriginal and Torres Strait Islander considerations

Communication

- Culturally appropriate language and communication may vary considerably within and across Aboriginal and Torres Strait Islander communities throughout Australia
- An appropriate spokesperson may be nominated to act as an interpreter and/or support person
- In some situations younger family members (under 18 years) may be nominated by an Elder or older Aboriginal or Torres Strait Islander person to interpret. Clinicians may need to rely on pre-existing partnerships with organisations and/or communities to determine if this is appropriate
- Assessment and diagnosis should ideally involve a relevant Aboriginal or Torres Strait Islander person. An Aboriginal and/or Torres Strait Islander cultural translator or health worker could assist in the assessment process. Consent to access a cultural broker must, of course, be obtained beforehand
- Consider the separation of 'Men's business' and 'Women's business' when appropriate

Use of interpreters

- Ask appropriate questions to determine whether the person with dementia requires an interpreter
- Where the family/spokesperson states that an interpreter is not required, consider the potential benefit for the person with dementia if an interpreter is present
- While the use of interpreters in the conventional sense for assessment is recommended, practical limitations exist

Culturally and linguistically diverse considerations

Communication

- Where possible, efforts should be made to work with bilingual/bicultural clinicians (as a first preference) and bilingual/bicultural workers (as a second preference) for ensuring culturally appropriate assessment and management of dementia
- Bilingual or bicultural clinicians are those registered health professionals who would typically provide assessment of dementia and/or BPSD
- Where the person with dementia's preferred language is *not* English it is important for the clinician or worker to have competency in both languages (bilingual)
- Bilingual workers can act as a communication facilitator, however, in some instance they cannot act as interpreters (due to confidentiality issue etc). In this situation an interpreter may be required

Use of interpreters

- Confidentiality issues can arise in CALD communities. The person with dementia, interpreter and/or family may be known to each other. A telephone interpreter who is external to the person's community, possibly from interstate may be preferred
- Be sensitive to the interpreter's country of birth and cultural background
- Seek guidance where appropriate from relevant ethnic community groups on these issues and identify suitable interpreters or cultural links

Comprehensive Assessment

Comprehensive assessment requires gathering information to assist in the description and investigation of the behaviour.

The following may influence the behaviour, and the development and implementation of a management plan:

- Description of the **behaviour**.
- Characteristics of the **person** with dementia.
- Characteristics of the **carer and the care relationship**.
- **Care environment** including the physical, social and cultural dimensions of the immediate and extended environment.

Description of the behaviour

It is essential to gather a detailed description of the behaviour and the context in which it occurs to establish an appropriate behavioural management plan.

- Family carers and staff of aged care facilities are important sources of information.
- When obtaining a description of the behaviour from the carer(s) be aware that their perception of BPSD may vary with their knowledge and experience of dementia.
- Collect information about the behaviour in a format designed to identify people, places and times of day associated with the behaviour.

The behaviour

Assessment of the behaviour will investigate the following:

- frequency, duration and intensity of the behaviour
- clarification of events which lead to the behaviour
- locations where the behaviour occurs
- other people present when the behaviour occurs
- consequences of, and responses to, the behaviour by other people
- circumstances that prevail when the behaviour is NOT occurring
- extent of discomfort that the behaviour causes the person with dementia
- extent of concern for the well-being of the person with dementia and others in the environment

The person with dementia

Discover as much as possible about the person with dementia and the aspects of their health and life experiences which may contribute to the behaviour.

- *Type of dementia:* Determine if a formal diagnosis has been made, length of time since diagnosis as well as associated cognitive and functional losses.
- *Aspects of the person's life story:* Develop a comprehensive picture of the person via a social history. Establish a sense of their life story through details of the person's interests, routines, social networks, social roles, cultural background, spirituality, sexuality and significant life events.
- *Physical and mental health:* Co-morbid physical and/or mental health issues, including depression or delirium,

may contribute to BPSD (see *Risk Assessment section*). It is important to check that the physical needs of the person have been addressed, including pain or discomfort.

Aboriginal and Torres Strait Islander considerations

The person with dementia and behaviour

Holistic perspective of wellbeing

- Aboriginal and Torres Strait Islander communities traditionally view health holistically
- The wellbeing of community members is maintained when the interconnected elements of spiritual, physical, emotional, social and cultural life are balanced
- Management of dementia and BPSD in this group requires an understanding of ill health from a cultural perspective, including approaches to wellness

Cultural and historical factors

- Many factors may affect dementia and BPSD within Aboriginal and Torres Strait Islander communities, linked to the unique cultural and historical background of these communities in Australia.
- Be aware of the local history of the place, family and community
- Understand possible cultural losses and trauma experienced by the person with dementia
- Appreciate the strengths and resilience that have developed within families and communities
- Recognise and acknowledge sources of strength for the person with dementia and their family in managing BPSD

Culturally and linguistically diverse considerations

The person with dementia and behaviour

Holistic perspective of health

- Depending on their cultural and spiritual perspectives, persons with dementia from CALD backgrounds and their families may view health holistically
- The physical, social, spiritual and emotional dimensions of health are interconnected aspects that can impact on BPSD and quality of life

Historical and cultural considerations

- Be aware of the influence culture and migration experiences can have on the course of dementia and BPSD
- Gather as much information about the older CALD person's life history, not only their cultural background but also their migrant and settlement experiences as these aspects can impact on BPSD
- Ascertain carers' and service providers' understanding of above as they may inadvertently exacerbate BPSD
- It is important to distinguish between PTSD and BPSD as they may occur independently or in combination
- Older migrants may be labelled as resisting care, uncooperative or exhibiting BPSD, when in fact they may be struggling to communicate due to language barriers.
- *Post traumatic stress disorder (PTSD)* can occur as a result of a refugee, refugee-like or a war survivor's history and impact on changing behaviours in later life

The carer and carer relationship

The effect of other people on the person with dementia and the way the behaviour of the person with dementia affects others will, in turn influence behaviour.

Factors relating to the carer's ability to interact with the person with dementia include the carer's:

- knowledge and understanding of dementia
- Aboriginal and Torres Strait Islander or CALD background
- knowledge of the person with dementia
- history with the person with dementia
- general emotional and physical health
- level of informal and formal support as well as services received
- skills, experience and level of training in managing dementia
- attitude and empathy
- communication and approach toward the person with dementia
- stress levels
- other demands on carer
- the nature and quality of their relationship with the person with dementia

Aboriginal and Torres Strait Islander considerations

Family, community and care roles

- Family and community structures, as well as social connectedness, are often extremely strong within Aboriginal and Torres Strait Islander communities.
- The 'decision-maker' for the person with dementia may not be a blood relative or geographically close.
- The concept of family is not restricted to westernised bloodlines and the *community* is typically not limited to family/blood connections but may include wider kinship.

Aboriginal and Torres Strait Islander considerations

- Home visits to an Aboriginal or Torres Strait Islander person with dementia may include many family members but the key person(s) to supply information need to be identified.
- The leadership responsibilities of older Aboriginal and Torres Strait Islander people can come with a heavy workload.
- Aboriginal and Torres Strait Islander older people are often carers for the extended family and hence, greater flexibility in approaches to care is required.
- Aboriginal and Torres Strait Islander people with dementia are typically younger at age of onset, hence issues for their children and/or grandchildren may also be relevant.
- An Aboriginal or Torres Strait Islander person with dementia may present across multiple services in different areas when care is shared between many family members.

Culturally and linguistically diverse considerations

CALD carers and families

- The care of persons with dementia varies across CALD communities and families, in terms of the roles of different family members and the importance placed on the care of the elderly.
- There can often be multiple carers for CALD persons with dementia, with the entire family sometimes being involved. However, the decision-making role may not necessarily be undertaken by a primary carer.
- It is important to understand the 'multiplicity' of carers and decision-makers when dealing with a CALD person with dementia as this will influence the information gathered and the care relationship.

Culturally and linguistically diverse considerations

- When making home visits, many family members may be present. The key person or persons to supply information need to be identified.
- As in all communities, denial can occur within the family around the symptoms of dementia. It is thus important to work with CALD families when undertaking assessment of behaviour by keeping them involved throughout the process.
- At times carers may unintentionally trigger behaviours, unaware of the effect on the person with dementia. It is important to educate carers about behavioural triggers.

The care environment

- The care environment includes the physical, social and cultural dimensions of the environment in which care is provided.
- Obtain a holistic understanding of the care environment as these factors are interconnected and can impact on BPSD.

Physical factors contributing to BPSD

- The physical and sensory environments.
- Environmental elements; indoor and outdoor including noise, access to outdoors, safety, security, glare, physical layout, size, furnishings, space for wandering, number of people, traffic through the area and/or time of day.
- Under or overstimulation.

Social and cultural factors contributing to BPSD

- The social and cultural dimension of the care environment comprises all people who come into contact and interact with the person with dementia and the shared values and practices of the group(s) in the person's immediate environment.
- A lack of bilingual or culturally competent staff where required, cultural and spiritual needs not integrated into care and dislocation from family, community and/or *Country*.

Aboriginal and Torres Strait Islander considerations

Care environment

- All service providers need to ensure care for Aboriginal and Torres Strait Islander peoples is delivered in a culturally competent manner.
- Person-centred care for those with dementia in needs to be 'family-centred' and 'community-centred'.
- Separation from *Country*, family and community can precipitate BPSD. Many Aboriginal and Torres Strait Islander peoples do not live on their Land.
- Hospitals, and by association RACFs, have historically been seen as places to die.
- Emotional and spiritual aspects of the care environment warrant careful consideration.
- Enabling physical and/or visual access to the outdoors can be important.
- In some cases, stereotypical and/or racist labels, attitudes or behaviours may be subtle but can, nonetheless, reinforce stigma and pose a major barrier to providing care.
- Separate 'Men's business' and 'Women's business' may impact on staff rostering.

Culturally and linguistically diverse considerations

Care environment

- Where residential care is indicated for a CALD person with dementia, attempt to arrange admission to an ethno-specific RACF before accepting a place in a mainstream facility.
- As this is often not possible, mainstream RACF staff members need to have a basic awareness of the potential antecedents that could make the CALD person with dementia uncomfortable and/or possibly trigger BPSD.
- Bilingual and/or bicultural clinicians or workers should be engaged in the provision of care in community and residential care settings wherever possible
- This can assist with building trust, promoting self-care for carers and recognising the significance of culture in care.
- It can be useful to identify whether a RACF has bilingual staff and other residents who speak the same language (and dialect) as the person with dementia.
- It is important to be aware of the potential for racism from the person with dementia directed toward workers and vice versa in RACFs and community care settings. The possible implications of this for care and for BPSD are significant.

Analysis of the comprehensive assessment

Analysis of the information from the comprehensive assessment should result in the identification of factors which separately or collectively suggest the cause of the behaviour and provide a basis for possible interventions.

Management Plan

A management plan, based on analysis of the assessment, should be prepared in partnership with carers to ensure their cooperation and understanding. Include the following elements:

- a problem statement which identifies specific problems, possible precipitating factors and incorporates clinical judgement
- baseline measurement of frequency and severity of BPSD
- elements of care, treatment, changes to daily routine, environment, carer relationships etc., that are to be provided as part of the care
- resources, steps, strategies and changes that are needed to implement the care plan
- timetable and milestones in the plan
- scheme for monitoring behaviour
- date for a review of the plan

Planning and communicating the intervention

- Tailor interventions to the individual
- Note strengths and limitations of the care environment
- Consider what combination of psychosocial, environmental and/or biological interventions will best suit this person
- Involve care staff and family in developing the intervention as well as determining clear goals and outcomes

Review and evaluation

- Schedule follow-ups, reviews and evaluations of the effectiveness of the intervention with the person, staff and/or family
- Maintain contact with the RACF and/or family to monitor the situation so interventions can be adjusted as needed

Before you move on, have the following been done?

1. A **risk assessment** to identify any immediate risks to the person with dementia or others within the care environment
2. A **comprehensive assessment** that is person centred and considers the following key aspects:
 - Referrer's description of behaviour
 - The behaviour
 - The person
 - The carer
 - The care environment
3. Any reversible causes of the behaviour(s) excluded and/or treated

Module 2: General BPSD

Key messages

- BPSD can be conceptualised as a response to deficits in care (unmet needs), as a reaction to lowered stress thresholds (due to dementia), as a manifestation of brain pathology or changes in brain chemistry and/or a reaction to biological factors
- BPSD impact on the person with dementia, carers, family, care staff and other residents
- A person centred approach that reflects this diverse range of causative factors is likely to be the most effective way of managing BPSD
- Interventions which focus on addressing the underlying contributing factors rather than the behaviour itself are likely to be more effective
- Effective strategies may target carer and/or staff approaches, communication, burden or knowledge in relation to BPSD
- Psychosocial, environmental and biological interventions are not mutually exclusive
- Ethical considerations, in particular the wellbeing of the individual, should be a primary consideration in the implementation of interventions
- Monitoring and evaluating the impact of an intervention is an integral part of the process

General BPSD

What are general BPSD and what do they look like in dementia?

- Symptoms of disturbed perception, thought content, mood and/or behaviour frequently occurring in dementia.
- Commonly referred to as behaviours of concern, challenging behaviours and non-cognitive or neuropsychiatric symptoms of dementia.
- Occur at different levels of severity with the stages of disease progression.

Prevalence

- BPSD can occur in both community and RACFs, however they tend to occur more frequently in RACFs.
- Reported prevalence rates of BPSD range between 56% and 90%.
- Most frequently occurring are apathy, depression and anxiety.
- Individual BPSD fluctuate over time, with many behaviours occurring episodically.

Effects of BPSD

- Impacts on person with dementia and their carer(s).
- Reduced quality of life of the person with dementia.
- BPSD may interfere with the identification of underlying, potentially treatable conditions such as depression, pain, infection and/or constipation which can mimic or contribute to the BPSD.

- Stress and burn-out of residential care staff, particularly where support from management is lacking.
- Degree of carer burden can impact significantly on the carer's ability to manage BPSD.

Differential diagnosis

- Delirium can be identified by an abrupt onset of behaviour out of character for the person with dementia.
- Clinical features may include aggression, restlessness, hallucinations, clouding of consciousness, misinterpretation of events, disorganised thinking and sleep disturbance.
- Attempting to control the behaviours with medication can delay diagnosis and lead to poorer outcomes.
- The Confusion Assessment Method (CAM) is a scale used to detect delirium in those with or without dementia.

The potential impact of pain on BPSD

- Pain and other unmet physical and/or psychosocial needs may provoke BPSD.
- Pain frequently occurs with comorbid conditions in the older person with dementia.
- Those with dementia are at risk of unrecognised and undiagnosed pain and the risk increases with dementia severity as the capacity for self-report diminishes.
- Poorly controlled pain can impact on the person with dementia's quality of life and contribute to BPSD. Pain can also be misdiagnosed and mistreated as BPSD.
- Specific instruments for the assessment of pain in those with dementia include: Pain Assessment in Advanced

Dementia Scale (PAINAD), Pain Assessment Checklist for seniors with Limited Ability to Communicate (PACSLAC) and the Abbey Pain Scale.

Measuring BPSD

- Tools for measuring BPSD globally include the Behavioural Pathology in Alzheimer's Disease (BEHAVE-AD) as well as the Neuropsychiatric Inventory (NPI) and other versions; NPI-Clinician, NPI-Nursing Home and NPI-Questionnaire.
- Ensure culturally appropriate assessments are undertaken with people with possible cognitive impairment from Aboriginal and Torres Strait Islander or CALD backgrounds.
- The Kimberley Indigenous Cognitive Assessment (KICA-Cog) is the only validated dementia assessment tool for Aboriginal and Torres Strait Islander peoples.
- The Rowland Universal Dementia Assessment Scale (RUDAS), the Modified Mini Mental Exam (3MS) and the General Practitioner Assessment of Cognition (GPCOG) are suitable tools for most people from CALD backgrounds.
- Recommended tools for the assessment of cognition and BPSD can be accessed via the Dementia Outcomes Management Suite (DOMS)

<http://www.dementia-assessment.com.au/cognitive/index.html>

General guidelines for managing BPSD

1. Comprehensive assessment, including co-morbidities, concomitant medication and differentiation from depression. Address potential underlying causes.
2. Unless the person is very distressed or at risk of harm to themselves or others, introduce psychosocial methods **first** and attend to environmental contributors to the BPSD.
3. Educate carers; involve them in the management plan.
4. Individually tailor interventions to the person. Identify the person behind the behaviour in order to design the most appropriate psychosocial intervention.
5. Monitor symptoms and review for a suitable period **before** considering pharmacological therapy, as symptoms may resolve spontaneously or in response to psychosocial interventions.
6. Where pharmacological therapy is indicated, informed consent must first be obtained from the person or the person's legal proxy.
7. Dosage should start low and go slow. Trial dose reduction after an appropriate period, e.g. three months.
8. Monitor for adverse events, as these can also present as BPSD.
9. Review and reassess BPSD symptoms and therapy regularly.

Table 2.1 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
Trimепразине tartrate	Vallergan
Antipsychotics – typical (neuroleptics)	
Haloperidol	Serenace

Generic name	Common trade name(s)
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
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

Generic name	Common trade name(s)
Psychostimulants	
Methylphenidate	Concerta, Ritalin
Sympatholytics	
Prazosin	Minipress
Propranolol	Deralin, Inderal
Other	
Cimetidine	Magicul, Tagamet
Melatonin	Circadin

Physical and Chemical Restraint

- Restraint involves any aversive practice, device or action that restricts a person's free movement and/or hinders their ability to make decisions.
- This includes chemical restraint with medication.
- Alternatives to the use of restraint should always be considered and implemented **first**.
- Expected benefits need to be weighed against the potential harm of any form of restraint and appropriate consent obtained prior to implementation.
- Where the use of restraint is deemed necessary after thorough assessment, the following **must** be observed:
 - continuously and closely monitor physical health via skin colour, movement of extremities, sensation, etc
 - ensure personal needs such as safety, pain relief, toileting, warmth, comfort, hunger and thirst are met
 - protect privacy and dignity as far as possible
 - remove restraint at regular intervals
 - regular reassessment of ongoing need for restraint and serious consideration of alternatives

Table 2.2 Side effects of neuroleptics or antipsychotics

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
+++ present and major side effect
+++ present and very important side effects
? unknown

Limitations

- Many studies have methodological issues such as a wide range of definitions for the various BPSD which impact on the outcomes and/or potentially limit the generalisability of results.
- Limited psychosocial intervention studies are available in the scientific literature and many report little benefit or conflicting results.
- Psychosocial intervention studies tend to report on clusters of symptoms which include the individual BPSD. Where an individual BPSD is not one of the primary outcomes of a study, generalisability of findings is limited.
- Much of the available research is based on small sample sizes and/or case studies; evidence for such interventions cannot be considered robust.
- Few studies examine the long-term maintenance of benefits after interventions ceased.

Conclusions/recommendations

- Research findings suggest that pharmacological and psychosocial interventions have a modest effect when applied as a generic treatment for BPSD.
- This can largely be attributed to the diverse aetiology of BPSD; an intervention may be effective in one set of circumstances and not in another.
- Overall, there is a lack of sound research to guide clinicians and carers in the management of BPSD.

- Psychosocial and environmental intervention research has largely been conducted in residential settings.
 - Person- and behaviour-specific interventions that are tailored to individual situations tend to be the most effective and are recommended.
 - Thorough assessment of BPSD and the person (including physical health) as well as the interpersonal and physical environment are essential to uncover the factors that may be contributing to BPSD.
 - Potential drug side-effects and interactions need to be carefully weighed against benefits **before** considering pharmacological interventions.
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Module 3: Aggression

Key messages

- Aggression in dementia is characterised by physically and/or verbally threatening behaviours
- Aggression can arise from underlying depression, psychotic symptoms and/or unmet needs
- It is important for the clinician to understand what is underlying the aggression for the individual in an attempt to address the cause
- Although not common, harm to the person with dementia or others can be a serious consequence of aggression
- Where necessary, e.g. for safety, 2005 expert consensus guidelines recommend atypical antipsychotics as a first-line approach for physical aggression
- Individualised psychosocial interventions are otherwise recommended
- Support has been demonstrated for light massage, individual behavioural therapy and *Montessori* based, individually meaningful activities
- Where pharmacological management is indicated, some evidence is provided for cholinesterase inhibitors (ChEIs) in Alzheimer's disease (AD), memantine in AD and Lewy body dementia (LBD) and atypical antipsychotics
- Although the adverse effects of antipsychotics raise concerns, it is acknowledged that situations may arise which require an urgent response

Aggression

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

Aggression in dementia is characterised by physically and/or verbally threatening behaviours directed at people, objects or self. It is often quantified by specific acts which can include:

- verbal insults, shouting, screaming
- obscene language
- hitting, punching, kicking
- pushing, throwing objects
- sexual aggression

Causes of aggression

- Aggression can be a purposive and overt response to a violation of personal space or a perceived threat.
- It often occurs during personal care tasks involving close carer-/staff-resident contact.
- Aggression can also arise from underlying depression, psychotic symptoms, environmental stressors and/or unmet needs.

Differential diagnosis

Aggression can present independently or as a consequence of agitation. Aggressive behaviours are also strongly associated with depression and psychosis.

Measuring aggression

The following scales are widely used:

- The Rating scale for Aggressive behaviour in the Elderly (RAGE)
- The Overt Aggression Scale (OAS)
- The physically aggressive subscale of the Cohen-Mansfield Agitation Inventory (CMAI)
- The agitation/aggression subscale of the Neuropsychiatric Inventory (NPI) and the aggression subscale of the NPI-Clinician (NPI-C)

Prevalence of aggression

Aggression reportedly ranges from 20% to 30% of people with dementia living in the community and from 6% to 95% of those in RACFs.

Effects of aggression

- Aggressive behaviours are associated with considerable carer burden and stress, reduced quality of life and earlier admission to RACFs.
- Although not common, harm to the person with dementia or others can be a serious consequence, as can the use of physical or chemical restraint.

Management of aggression

- The crucial task for the clinician is to attempt to understand what is underlying the aggressive behaviour for the individual with dementia.
- Where underlying depression or psychotic symptoms are prompting aggressive behaviour, treatment of these BPSD may reduce the aggressive behaviours. Interventions targeting the cause will likely assist in reducing the behaviour.

Psychosocial and environmental interventions

- The greatest number of studies reported involves music interventions and a diverse range of touch therapies.
- Support has been demonstrated for light massage, *Montessori* based, individually meaningful activities and individual behavioural therapy, particularly where the carer is involved.
- Psychosocial and environmental interventions are recommended as part of an individualised care plan.
- Strategies can include adapting the living environment, structured activities for persons with dementia as well as providing training and support to family and paid carers
- The lack of scientific evidence for psychosocial interventions should not prevent clinicians considering these interventions on a case-by-case basis.

Biological interventions

- Although the adverse effects of pharmacological interventions raise concerns, particularly with antipsychotics, situations can arise which place the person with dementia and/or others around them at risk, requiring an urgent response.
- Where physical aggression presents a safety risk, 2005 expert consensus guidelines recommend short-term use of atypical antipsychotics although evidence to support their use is limited in the recent literature.
- Biological intervention studies largely focused on examining the efficacy of atypical antipsychotics, ChEIs (in AD) and memantine (in AD and LBD) and some support for reduced aggression is reported.

- While memantine is generally well-tolerated, some persons with dementia, including those with Lewy body pathology, may be susceptible to developing adverse effects.
- No good evidence is available for use of anticonvulsants, the antiandrogen cyproterone, the alpha-blocker prazosin, or the traditional Asian herbal formulation Yokukansan (Yi-Gan San).

Conclusions/recommendations

- Expert consensus guidelines recommend the use of multidisciplinary, individualised and multifaceted care including psychosocial interventions and short-term pharmacological treatment only when necessary.
- Expert consensus guidelines recommend short term use of atypical antipsychotics as first-line approach where necessary for safety.
- Individualised psychosocial interventions are otherwise recommended and sensory interventions provide the best evidence for these.
- Where pharmacological management is indicated, some evidence is provided for atypical antipsychotics, ChEIs (in AD) and memantine (in AD or LBD).

Presentation

Mr B, an 89 year old widowed gentleman who migrated from Italy 60 years ago, had served in the Italian army for 5 years and become widowed 28 years ago. He has a large extended family including two daughters who were his primary carers for the three years prior to his admission to an RACF and continue to visit frequently.

Mr B is unable to read or write English and he is increasingly reverting to his first language of Italian. There are no other Italian speaking residents or staff in the facility. His increasing frustration with being unable to communicate with staff and other residents has resulted in physical aggression and verbal abuse. Mr B resists care and direction from staff. He uses his walking stick as a machine gun, attempting to 'shoot' staff and residents. He is verbally abusive in Italian; staff and other residents are frightened that Mr B will hit them. Strategies used by care staff have been unsuccessful and reactive to his behaviour. If Mr B's aggressive behaviour cannot be managed, he is at risk of losing his current accommodation.

Assessment

In order to reduce the presenting behaviours that are placing Mr B and others at risk, potentially contributing factors must be identified:

- Pain/discomfort/illness/infection/constipation
- Medication review: interactions, dosage, recently prescribed, adverse effects
- Overstimulation (noise, people, activities)
- Lack of attention to culturally-relevant and communication needs
- Overextending capabilities by expecting too much
- Altered routines, new staff, particular staff and/or family members
- Unfamiliar/altered/ deprived physical environment
- Reduced stress threshold
- Exclude underlying depressive & psychotic symptoms

Assessing the situation:

- Encourage Mr B to express his needs as far as he can
- Directly observe what may trigger the behaviour
- Ask staff who know Mr B quite well if they can assist in identifying his needs or reasons for his aggression
- Consult Mr B's life history as well as behaviour and clinical charts for further information with regard to triggers for the aggression
- Assess the immediate environment for triggers
- Consult close family members to identify possible triggers for the aggressive behaviours which are unknown to staff and not previously documented

Strategies/outcomes

- Mr B's frustration, related to his inability to express his needs in English, is contributing to his aggression.
- Some staff observed that Mr B can become anxious and resistant when he does not know what is about to happen.
- Staff have been relying on gestures and pointing to items in an attempt to communicate with Mr B. They were unaware of the range of language specific communication aids available to assist Mr B to express his needs. Training sessions were arranged regarding the effective use communication aids.
- Consultation with family members identified Mr B's preferred dialect and appropriate communication style. RACF staff was able to engage an interpreter or bilingual/bicultural health worker when conducting assessments or reviewing Mr B's care needs.

- Staff was made aware of the subtle signs in Mr B's nonverbal communication which may be indicators of his escalating anxiety or frustration. They were better able to deescalate situations before Mr B became aggressive.
- Since his admission to the RACF, staff and family members have noted that Mr B has become increasingly socially isolated. His children described Mr B as an outgoing man who previously had many friends and enjoyed the company of others.
- Mr B's inability to communicate effectively with others also results in his need for social contact not being met. An Italian gentleman, living in the self care units, was identified and he was willing to visit Mr B regularly.
- When visiting Mr B, the gentleman was able to share some points of conversation with staff, allowing some social interaction and rapport building to occur between Mr B and RACF staff.
- When asked, the family reported that Mr B enjoyed listening to Italian opera, Italian radio and television as well as gardening and playing cards. The family provided some of Mr B's favourite Italian music and the Multicultural Aged Care Service was contacted for an Italian radio program guide and audio and videotapes.
- Within the RACF, structured social activities were conducted in English and hence, Mr B had been largely excluded. The family identified special days which had always been culturally significant to Mr B and these were incorporated into the activity program.
- A mobility assessment was conducted to determine whether a walking stick was the most suitable mobility aid for Mr B and if a change was possible to reduce the inappropriate use of his current aid.

- Mr B was introduced to the RACF garden patch so he could continue his interest in vegetable gardening. While limited in what he could physically contribute, Mr B apparently enjoyed being in the garden.
- Mr B's aggressive behaviours were not eliminated, however follow up assessment indicated that instances were markedly reduced and staff was better able to manage episodes when they occurred.

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 4: Agitation

Key messages

- Agitated behaviours in dementia present as observable, non-specific, restless behaviours that are excessive, inappropriate, repetitive and are associated with distress
- In addition to the physical component of agitation in dementia, a psychological component involving strong and disabling emotions is proposed
- Symptoms of agitation can overlap with aggressive behaviours and delirium can be misdiagnosed as agitation
- Agitation is one of the most commonly occurring BPSD although not all presentations are clinically significant
- Individualised, psychosocial interventions are recommended as a first-line approach and short-term pharmacological intervention only when necessary
- Music interventions provide the best evidence for the psychosocial management of agitation
- The strongest evidence for pharmacological interventions is provided by trials of atypical antipsychotics, however these are not recommended due to safety concerns
- Where pharmacological management is required, there is evidence for cholinesterase inhibitors (ChEIs) in Alzheimer's disease (AD), memantine in AD and frontotemporal dementia (FTD) and antidepressants as possible alternatives to antipsychotics

Agitation

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

Agitation in dementia refers to observable, non-specific, restless behaviours that are excessive, inappropriate, and repetitive. Agitated behaviours are associated with distress and excess disability. Agitation may present as:

- irritability
- restlessness and/or pacing
- aberrant motor activities such as excessive fidgeting or hand wringing and/or
- disruptive vocalisations

Causes of agitation

- Decreased frontal or temporal lobe metabolism, increased neurofibrillary tangle burden in the frontal lobe, and altered activity in the neurotransmitter systems.
- Interaction between individual and environmental factors.

Differential diagnosis

- No standardised diagnostic criteria currently exist for agitation in dementia and symptoms can overlap with aggressive behaviours.
- Hyperactive delirium can be misdiagnosed as agitation.
- Comprehensive assessment is required to differentiate between these conditions and identify the underlying issues that may precipitate the behaviours.

Measuring agitation

Current guidelines recommend the use of:

- Cohen-Mansfield Agitation Inventory (CMAI)
- Pittsburgh Agitation Scale (PAS)
- Agitation/Aggression and Aberrant Motor Behaviour subscales of the Neuropsychiatric Inventory (NPI)

Other instruments include:

- Agitated Behaviour Mapping Instrument (ABMI)
- Brief Agitation Rating Scale (BARS)
- Excited Component of the Positive and Negative Syndrome Scale (PANSS-EC)

Prevalence of agitation

- Agitation is one of the most commonly occurring BPSD, with prevalence rates ranging from 9% to 96%. Not all cases are clinically significant.
- Prevalence rates also vary depending on the definition of agitation, the instrument used to measure agitation, the severity of the dementia and the population studied.
- More agitated behaviours have been reported in those with greater dementia severity, greater impairment of insight, faster rate of cognitive decline, poorer performance in activities of daily living and lower income.
- No difference in the prevalence rates of agitation have been reported for the different types of dementia.

Effects of agitation

Agitation is associated with:

- higher likelihood of psychiatric or medical comorbidity
- poorer health-related quality of life

- increased use of psychotropic medication
- increased use of physical restraint
- greater burden on family and RACF carers
- premature RACF placement

Management of agitation

- It is important for the clinician to attempt to determine the potential triggers behind the agitated behaviours for the individual with dementia.
- Episodes of agitation may be associated with underlying physical symptoms, pain, discomfort, medication effects or specific environmental stimuli.
- Where the person with dementia and/or others are not at risk and reversible causes have been eliminated, firstly consider psychosocial and/or environmental interventions.

Psychosocial and environmental interventions

- The majority of the studies fell within the music interventions category and these provided the best evidence. These included: group music therapy, music with hand massage, and individualised/preferred music.
- Moderate evidence was available for therapeutic recreation and touch therapies.
- Overall, interventions that attempt to address the unmet biopsychosocial needs of the person with dementia showed some beneficial effects.
- Individualised care based on psychosocial management is recommended.

- The lack of scientific evidence for psychosocial interventions should not prevent clinicians from considering these interventions on a case-by-case basis.

Biological interventions

- Pharmacological interventions should only be used as a second-line approach in the management of agitation.
- Although atypical antipsychotics provided the best evidence, current guidelines do not recommend their use due to safety concerns.
- Some positive results were reported for ChEIs in AD, memantine in AD and FTD and antidepressants (citalopram, mirtazapine), suggesting that they may be viable alternatives to atypical antipsychotics.
- Limited evidence for anticonvulsants, melatonin, cannabinoids, alpha- and beta-blockers and omega-3 are also reported.

Conclusions/recommendations

- A definitive diagnosis of agitation in dementia can be difficult due to overlapping symptoms of aggression, sundowning and other BPSD.
- Expert consensus guidelines recommend the use of multidisciplinary, individualised care including psychosocial interventions as a first-line approach in the management of agitation in dementia and short-term pharmacological intervention when necessary.
- Music interventions provide the best evidence for the psychosocial management of agitation.

- Where pharmacological management is required, ChEIs (for AD), memantine (in AD and FTD) and antidepressants may be considered as alternatives to atypical antipsychotics as these are not recommended due to safety concerns.

Presentation

Mrs W is considered by staff to be 'difficult', often agitated and sometimes aggressive. At times she is seen sitting at the dining table on her own for several hours at a time, continuously rubbing the table top with her fingertips. She flicks imaginary objects away with the back of her hand, while muttering to herself. RACF staff ignore this behaviour and leave her alone, except when she gets up and walks into other residents' rooms and touches items on their walls. The situation can become risky when other residents are angry with Mrs W for intruding into their rooms. Mrs W's reaction is to become increasingly agitated and verbally aggressive. If the resident approaches Mrs W at this point, she can become combative and the situation continues to escalate.

Clinical scenario adapted from Professor Lynn Chenoweth, with permission.

Assessment

In order to reduce the presenting behaviours that are placing Mrs W at risk, potentially contributing factors must be identified:

- Pain/discomfort/illness/infection
- Medication interactions, dosage
- Overstimulation (noise, people, activities)
- Lack of attention to culturally-relevant needs
- Overextending capabilities by expecting too much

- Stopped her from what she is doing or wanting to do
- Altered routines, new staff, particular staff or family
- Unfamiliar/altered/deprived physical environment
- Reduced stress threshold

Assessing the situation:

- Encourage Mrs W to express her needs as far she can
- Directly observe what may trigger the behaviour
- Ask staff who know Mrs W quite well if they can assist in identifying her needs, or possible reasons for her agitation
- Consult Mrs W's life history as well as behaviour and clinical charts for further information with regard to triggers for her agitation
- Assess the immediate environment for possible triggers
- Consult close family members to identify possible triggers for agitation unknown to staff and not previously documented.

Strategies/outcomes

- When asked, the family reported that when she was rubbing the table Mrs W had told them that she was trying to finish her paintings in time for the for the art exhibition.
- When she was touching items on the other residents' walls Mrs W was reportedly checking that her paintings had been hung, ready for the exhibition.
- Showing Mrs W the artwork in lounge and dining rooms as well as along the corridors of the RACF appeared to provide her with some reassurance that her paintings were ready for the exhibition.
- Mrs W responded positively to being given large sheets of paper and (safe) art materials to do new paintings.

- Staff hung Mrs W's new artwork around her room and the RACF
- Staff members praised her efforts to other residents and visitors, in her presence.
- These strategies provided staff with opportunities to interact positively and meaningfully with Mrs W as well as praise her work.
- Mrs W enjoyed being asked to show her art to others during planned art discussion activities.

Module 5: Anxiety

Key messages

- Anxiety in dementia presents with thoughts of worry, fearfulness as well as physical symptoms such as racing heart, hyperventilation, sweating and/or diarrhoea
- Anxiety is one of the most disabling and commonly occurring BPSD
- A multidisciplinary, individualised and multifaceted approach is important
- Multicomponent interventions, which target environmental, biological and psychosocial factors, provide the best evidence for psychosocial management
- Where anxiety is secondary to another psychological disturbance the primary problem should be treated
- Where pharmacological treatment is in the best interest of the person with Alzheimer's dementia, cholinesterase inhibitors (ChEIs) have the largest patient numbers treated in whom anxiety was a secondary measure, hence providing the best evidence of improvement in anxiety symptoms
- Short-term use of benzodiazepines and antidepressants may be of benefit
- For long-term management, selective serotonin reuptake inhibitors (SSRIs) are suggested
- Where required symptomatic pharmacological agents should be time limited, closely monitored and prescribed with appropriate psychosocial interventions

Anxiety

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

Anxiety in dementia can occur in isolation and this is often related to interpersonal situations or the environment. Anxiety in dementia can also occur in the context of depression or psychosis.

Anxiety can be described as an internal state defined by:

- thoughts of worry, anguish, apprehension and/or vigilance
- emotions such as fearfulness, unease or dread
- physical sensations of muscle tension, tremor, fatigue, nausea, hyperventilation/shortness of breath, headache, insomnia and/or palpitations associated with autonomic hyperactivity
- behaviours such as avoidance, hand wringing, pacing, requesting assistance or restlessness

Causes

- Higher rates of anxiety in those with dementia have been associated with unmet needs in RACFs.
- Anxiety can occur in response to the person's reduced capacity to make sense of their environment.
- Anxiety in the early stages of dementia can also arise from the diagnosis itself and subsequent fears.
- An exaggerated anxiety response may occur due to changes in the person's familiar routine or environment, separation from a primary carer, being rushed, overstimulation and/or fatigue.

Differential diagnosis

- Presentation of anxiety is not always typical in those with dementia and medical comorbidities.
- Differential diagnosis can be confounded by overlapping symptoms of anxiety and depression.

Measuring anxiety

The personal nature of the core symptoms of anxiety such as worry may mean that assessment based on behavioural observations or informant report alone may be inadequate.

Scales employed to measure anxiety:

- Rating Anxiety in Dementia (RAID) scale
- Anxiety subscale of Neuropsychiatric Inventory (NPI) and NPI-Clinician (NPI-C)
- Anxieties & phobias subscale of Behavioral Pathology in Alzheimer's Disease Scale (BEHAVE-AD)
- Hamilton Anxiety Rating Scale (HAM-A)
- Geriatric Anxiety Inventory (GAI)

Prevalence of anxiety

- Anxiety is one of the most commonly occurring BPSD occurring as a symptom in 8% to 71% of persons with dementia and as a disorder in 5% to 31%.
- The incidence of clinically relevant anxiety is higher in those with frontotemporal dementia and vascular dementia than in those with AD.

Effects of Anxiety

- Anxiety is linked to earlier residential care placement, other BPSD, overestimation of dementia severity, impaired social function and poor quality of life.
- Anxiety can contribute to a higher carer burden due to increased dependence.

Management

- Do not purely manage symptoms; try to identify individual triggers when planning treatment
- Minimise and/or avoid triggers and frustrations where these can be identified
- Keep the environment uncomplicated
- Maintain structure and routine
- Reduce the need to make decisions
- Avoid overstimulation
- Provide opportunities to succeed and reinforce retained skills

Psychosocial and environmental interventions

- The music interventions group incorporated the greatest number of studies. This was followed by behavioural/cognitive-behavioural interventions.
- Multicomponent interventions provide the best evidence for the psychosocial management.
- This group includes a therapeutic day hospital program and the *Closing Group* intervention which targets environmental, biological and psychosocial factors contributing to anxiety and agitation.

- The need for a multidisciplinary, individualised and multifaceted approach to managing anxiety in dementia is emphasised.

Biological interventions

- Of the medications reviewed, ChEIs have the largest patient numbers treated in whom anxiety was a secondary measure, hence providing the best evidence of improvement in anxiety symptoms.
- ChEIs may reduce neuroleptic and benzodiazepine use in patients with AD and anxiety.
- Benzodiazepines may be of some benefit and evidence for antipsychotics is mixed, however expert consensus guidelines recommend against the long-term use of benzodiazepines or antipsychotics in this group.
- Antidepressants may have a potential part to play in anxiety in dementia but evidence is limited.
- In the case of mild-moderate dementia with prominent anxiety which is unresponsive to psychosocial interventions, SSRIs are suggested for long-term management.
- Limited evidence exists for traditional herbal medicine, Ginkgo biloba extract and sodium valproate.
- Where possible, the use of symptomatic, pharmacological agents, when required for treatment of anxiety should be time limited, closely monitored, reviewed, reduced and/or discontinued when indicated and prescribed with appropriate psychosocial interventions.

Conclusions/recommendations

- Diagnosis of anxiety in dementia may be difficult due to underlying symptoms of depression/agitation.
- Recognised expert guidelines are limited in the area of managing anxiety in dementia.
- Therapeutic activities, particularly those which are multicomponent provide the best evidence for psychosocial management. Environmental factors may also have a part in reducing anxiety symptoms.
- The need for a multidisciplinary, individualised and multifaceted approach is stressed.
- Studies of anxiolytic effects of ChEIs in dementia are restricted to those with AD.
- Where pharmacological treatment is in the best interest of the person with AD, ChEIs provide the best evidence, although short-term use of benzodiazepines and antidepressants may play a part in the treatment of anxiety in dementia.
- SSRIs are suggested for long-term management.

Presentation

Mrs Y is an 86 year old Vietnamese lady who lives with three generations of her family. She migrated to Australia under the Family Reunion Scheme. When she arrived in Australia, the family noticed that Mrs Y had some cognitive difficulties which ultimately led to a diagnosis of dementia, by the local doctor. Extended family members live in the same street and visit socially but they do not provide care. Mrs Y does not speak, read or write English.

Mrs Y's daughter is her primary carer and over past months she has become increasingly concerned about the degree of her mother's anxiety. 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 Vietnamese community. The granddaughter reports that many of those in the community lack an understanding of dementia and/or BPSD and the family is concerned that others will think their mother is 'crazy'.

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

Assessment

In order to reduce the presenting symptoms of anxiety, potentially contributing factors must be identified:

- Illness/infection/discomfort/pain
- Eliminate depression
- Medication review: interactions, dosage, recently prescribed, adverse effects
- Lack of attention to culturally-relevant needs
- Unfamiliar or altered physical environment
- Unrealistic expectations causing Mrs Y to overextend her capabilities

Assessing the situation:

- Encourage Mrs Y to report her concerns as far as she is able
- Directly observe for any environmental aspects that may contribute to the symptoms
- Consult close family members to identify possible triggers for the symptoms

- With the family's consent, communicate with staff from the recently ceased community service as to any incidents that provoked Mrs Y's anxiety
- Consult Mrs Y's family with regard to her life history and for further information around potentially relevant factors such as her war experiences

Strategies/outcomes

- Establish who is able to provide information on Mrs Y's behalf and who is the main decision maker within the family and liaise directly with them. Ensure that they are included in all discussions and/or decisions.
- The family was hesitant to provide information due to language barriers and fear of how the information will be used. They are concerned that they may be perceived as unable to cope which could result in Mrs Y being removed from the family home. The family was reassured that services are available to support them to continue to care for Mrs Y in the family home.
- Mrs Y's granddaughter is the only family member who speaks English. Access to an interpreter who speaks the same dialect as Mrs Y and her family was offered, where appropriate and possible.
- Mrs Y's family has been reluctant to accept formal services due to community expectations that they should care for their aged relatives. They do not want to be judged by members of the local community as unable to care for Mrs Y.
- Information about dementia and BPSD was provided in Vietnamese. The information in written or DVD format could be shared with the extended family and others.
- The family was linked with a Vietnamese agency that was able to provide further culturally safe support and information.

- The family has been reluctant to continue prescribed medication as they are unfamiliar with western medical practices. Mrs Y's doctor was informed that she was no longer taking the prescribed medication.
 - The family was provided with information around the purpose of medication and how long Mrs Y needs to take it before the anxiety symptoms may be reduced.
 - The family was able to suggest activities that could be encouraged, such as those that Mrs Y previously found pleasurable, engaging, comforting and/or related to her spiritual beliefs.
 - Mrs Y's family was provided with strategies to avoid triggering her anxiety and to help ease her symptoms during acute periods of escalation.
 - Extended family members were made aware of the situation they were willing to assist. Mrs Y was able to resume attendance for part of the church service with others helping to supervise her.
 - The possibility of Mrs Y attending a CALD day respite centre with others from a Vietnamese background was investigated.
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Module 6: Apathy

Key messages

- Apathy can be described as a state of lack of interest or behavioural inaction, typically without emotional distress
- Apathy is one of the most prevalent of the BPSD and the most frustrating for family carers
- It is a major clinical feature of dementia, especially those with subcortical and frontal pathology
- It is associated with increased disability and carer frustration as well as reduced quality of life, rehabilitation outcomes and survival after nursing home admission
- Despite a lack of methodological rigour, it is apparent that psychosocial interventions have the potential to reduce apathy
- Therapeutic recreation, particularly when provided individually, has the best available evidence for effectiveness in dementia
- The evidence for the efficacy of pharmacotherapy for apathy in dementia is limited and the research quality modest
- The best evidence was found for cholinesterase inhibitors (ChEIs) in Alzheimer's disease (AD)
- Some evidence exists for memantine (in AD); less for stimulants, calcium antagonists and antipsychotics
- No evidence was found to support the use of antidepressants or anticonvulsants

Apathy

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

- Apathy can describe an internal state of lack of interest or a state of behavioural inaction.
- The apathy spectrum includes reduced initiative, interest, motivation, spontaneity, affection, energy, enthusiasm, emotion and persistence as well as blunted affect.
- Apathy occurring in the course of dementia is frequently accompanied by one or more neuropsychiatric symptoms.
- Emotional distress is typically absent.
- Symptoms should cause clinically significant functional impairment not attributable to physical disabilities, motor disabilities or direct physiological effects of a substance.

Causes of apathy

- Apathy is a major clinical feature of dementia, especially those with subcortical and frontal pathology such as Lewy body dementia, vascular dementia, frontotemporal dementia and Huntington's disease.
- Apathy in AD has also been significantly related to older age and depression.

Differential diagnosis

- Apathy in dementia may be misdiagnosed as depression
- Apathy should be differentiated from medication effects
- Lack of motivation is evidenced by diminished goal-directed behaviour, goal-directed cognition and emotion, relative to previous functioning levels and not attributable

to intellectual impairment, emotional distress or diminished consciousness.

- Antipsychotic/neuroleptic and antidepressant medications can initiate, maintain or imitate apathetic behaviours.
- Selective serotonin reuptake inhibitors (SSRIs) have been reported to induce an amotivational or apathy syndrome and which is reversible when the dose is ceased or reduced.

Measuring apathy

Scales designed to specifically measure apathy:

- Apathy Evaluation Scale (AES)
- Apathy Inventory (AI)
- Neuropsychiatric Inventory (NPI) and NPI-Clinician (NPI-C) apathy subscale.

Prevalence of apathy

- Apathy occurs in up to 70% of persons with dementia.
- The highest prevalence has been reported in progressive supranuclear palsy, FTD and severe AD.
- Apathy tends to appear early in dementia, increases with dementia severity, typically persists and is consistently reported globally.

Effects of apathy

- Apathy is associated with increased disability and frustration, worsening functional impairment and poorer quality of life for both those with dementia and carers, with family life and relationships often disrupted.

- Families not recognising an apathetic state may become increasingly resentful as they misperceive the person with dementia as lazy.
- Morbidity and mortality may be indirectly related to apathy as residents in long-term care tend to be less noticed by care staff and receive fewer direct care hours.

Management of apathy

With regard to treating apathy in dementia the following indications should be considered:

- Excess disability of the person with dementia
- Potential for improvement in quality of life
- Burden to carers and/or family

Psychosocial and environmental interventions

- There is evidence for the benefit of therapeutic activities for apathy in dementia.
- Therapeutic activities include *question-asking reading* as well as small group, individual/tailored, *Montessori* based and kit-based activities.
- Some positive results were reported for music, exercise, multi-sensory stimulation, pet therapy and special care units.
- There is limited evidence of sustainability of effect once interventions cease.

Biological interventions

- ChEIs have demonstrated beneficial effects on non-cognitive symptoms such as apathy in AD. No one ChEI has been shown to be superior.

- Limited evidence exists for improvement in apathy with memantine (in AD) and no sound evidence of benefit was found for traditional antipsychotics.
- Atypical antipsychotics may have some beneficial effect although it is not possible to determine if improvement in apathy occurs independent of the effect on psychosis.
- Good evidence indicates that antidepressants do *not* significantly improve apathy in persons with dementia.
- Modest efficacy has been demonstrated for psychostimulants although side effects are a concern.

Conclusions/recommendations

- Psychosocial and environmental interventions are indicated in the management of apathy, particularly individually tailored therapeutic activities.
- Some positive results were reported for music, exercise, multi-sensory stimulation, pet therapy and special care units.
- Of all the pharmacological treatments reviewed, ChEIs provide the best evidence of improvement in those with AD, with most responders improving in cognition as well as in apathy levels.
- There is some evidence for the benefits of memantine (in AD) and mixed evidence for benefits of atypical antipsychotics although the latter are not recommended for the treatment of apathy in dementia due to potentially serious adverse effects

Presentation

Mrs P had been an efficient homemaker and loving mother of four. After her husband died, it became evident to the family that he had been significantly compensating for Mrs P's functional losses. Her son and three daughters managed to support Mrs P in the family home, with the assistance of community services, for a year following Mr P's death.

When she was admitted to a RACF Mrs P presented as physically well for her years with a MMSE score of 19/30. She responded positively to family visits and outings. Staff reported that Mrs P was a lovely lady who was 'no trouble'. Family visited regularly and would invariably find her sitting alone in her room. Items of interest that they left for her remained untouched and they repeatedly complained to staff that their mother 'does nothing' and speaks to no one between family visits. Staff did not know how to resolve the situation and so they did their best to stay out of the way of Mrs P's family members when they visited.

Assessment

In order to reduce the presenting behaviour, potentially contributing factors must be identified:

- Pain/discomfort/illness/infection
- Medication interactions, dosage
- Impaired hearing and/or eyesight
- Underlying depression, grief reaction
- Lack of stimulation
- Unfamiliar/altered/deprived physical environment
- Reduced ability to initiate activities for herself
- Activities offered not of interest/unfamiliar/too difficult
- Mrs P's premorbid personality; how readily did she join in group activities in the past?

Assessing the situation:

- Encourage Mrs P to express interests as far as she can
- Directly observe and document Mrs P's response to items brought in by her family
- Ask staff who have become familiar with Mrs P if they have identified any activities that she appears to enjoy
- Consult Mrs P's life history, behaviour and clinical charts
- Consult family members to identify possible activities Mrs P was able to enjoy and achieve prior to admission which may be unknown to staff and not previously documented

Strategies/outcomes

- The family reported their distress at seeing Mrs P 'wasting away'. They feel she is often unnoticed by staff and receives less care than other residents.
- Family feel guilty as Mrs P's functioning and quality of life appear to be diminishing further since admission to RACF. Information about changes anticipated with the progression of dementia was provided.
- Staff report that they have tried to help Mrs P by escorting her to craft activities or weekly bingo games however, she 'refused' to join in.
- One member of staff found that Mrs P became quite animated when included in simple housekeeping tasks but other staff see this as exploiting her good nature.
- Some staff members have limited knowledge of dementia, believing that Mrs P chooses to isolate herself. Education was provided on BPSD and Mrs P's potentially retained skills as a homemaker.
- Staff encouraged Mrs P to talk about her family and the things that were important to her in the past. Family members understand they need to assist Mrs P to engage with items of interest they bring in.

Module 7: Depression

Key messages

- Depression in dementia presents as unhappiness, withdrawal, inactivity, fatigue, tearfulness and/or loss of interest
- Depression in dementia should be differentiated from apathy, anhedonia, sleep disturbance, delirium and symptoms of the underlying dementia
- Prevalence of depression in dementia clusters around 30%
- Depression can occur as a presenting feature of dementia and it is one of the most challenging BPSD to diagnose and treat
- Psychotic depression and suicidal depression require urgent psychogeriatric review
- Individualised psychosocial interventions are recommended as a first-line approach, or in combination with medication where indicated
- Support is demonstrated for selected psychosocial and environmental interventions, with exercise and behavioural approaches providing the best evidence
- Where medication is indicated, 2005 expert consensus guidelines recommend the use of antidepressants as a first-line approach for non-psychotic depression in dementia
- Combination therapy with cholinesterase inhibitors (ChEIs) is recommended as a second-line approach in Alzheimer's disease (AD)

Depression

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

- Depression in dementia can present as unhappiness, withdrawal, inactivity, fatigue, tearfulness and/or loss of interest.
- Other symptoms include negativity, hopelessness, low self-esteem, worthlessness, tearfulness, suicidal ideation, anxiety, delusions (e.g. paranoia, guilt) as well as sleep and appetite disturbances.

Causes of and risk factors for depression

- Degenerative changes in the brain associated with dementia
- Family history
- Past history of depression
- Psychosocial stressors eg bereavement, loss of home

Differential diagnosis

It is essential to differentiate depression in dementia from hypoactive delirium and apathy.

Measuring depression

Expert consensus recommends the use of the Cornell Scale for Depression in Dementia (CSDD) and (unless cognitive impairment is too severe) the Geriatric Depression Scale (GDS) to assess depression in dementia. Other rating scales used to assess depression include the Hamilton Depression Rating Scale (HAM-D), the depression/dysphoria subscale of the Neuropsychiatric

Inventory (NPI) and the dysphoria subscale of the NPI-Clinician (NPI-C).

Prevalence of depression

- Depression is one of the most commonly occurring BPSD, with prevalence rates clustering around 30% and a range of 9% to 96%.
- Variance in prevalence arises from differing definitions, diagnostic tools used and/or the populations assessed.
- Depressive symptoms in dementia tend to increase in prevalence as cognition declines and then decrease when cognitive functioning is severely impaired.
- Persons with vascular dementia tend to have higher rates of comorbid depression compared to other dementia subtypes.

Effects of depression

Depression in dementia is associated with increased carer burden, earlier admission to a residential aged care facility, increased mortality, medical comorbidity, social withdrawal and reduced quality of life.

Management of depression

- It is important for the clinician to identify potentially reversible factors that may be contributing to the depressive symptoms in the person with dementia.
- Untreated physical symptoms such as those related to infection, constipation and/or chronic pain may be exacerbating the low mood.
- Likewise delirium and apathy should be excluded.

Psychosocial and environmental interventions

- The exercise category incorporated the greatest number of intervention studies.
- Exercise and behavioural approaches provide the best evidence for the psychosocial management of depression in dementia.
- Cognitive behavioural therapy, which includes carer participation may be helpful.

Biological interventions

- Pharmacological intervention studies for the management of depression in dementia are limited in number and quality.
- 2005 expert consensus guidelines recommend the use of antidepressants as a first-line approach for non-psychotic depression in dementia, and combination therapy with ChEIs are recommended as a second-line approach for AD.
- Evidence for the efficacy of antidepressants is mixed with more recent large trials showing no benefit in group data.
- There is moderate evidence for the efficacy of ChEIs in alleviating depressive symptoms in AD.
- Combination therapy of an antidepressant and an antipsychotic is the recommended treatment for psychotic depression.
- There are case reports of successful use of Electroconvulsive Therapy (ECT) for severe or psychotic depression,
- Newer brain stimulation techniques for depression in dementia have not yet been adequately evaluated.

Conclusions/recommendations

- Depression in dementia has significant consequences.
- Exercise and behavioural approaches provide the best evidence for the psychosocial management of depression in dementia.
- An increasing number of psychosocial interventions have been reported as effective in managing depression in dementia.
- Positive findings are in line with expert consensus recommendations for the psychosocial management of depression in dementia.
- Antidepressants, and ChEIs (in AD), provide some evidence for the pharmacological management of depression in dementia.
- Individual outcomes vary and interventions may need to be trialled before results are evident.

Presentation

Mr L was born in Poland and was a Holocaust survivor. After he migrated 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. He currently lives with his wife in a retirement village and their children visit regularly and provide support. Mrs L is finding it increasingly difficult to encourage her husband to attend family events and the local dementia day centre.

When he does attend the day centre, Mr L can become aggressive with staff, volunteers and other attendees when attempts are made to include him in activities. Mrs L reports that her husband has become increasingly sad over recent months and even tearful at times which is out of character for him. When she mentioned her concerns to their doctor, he explained to her that Mr L's symptoms, particularly the apathetic behaviours, can occur with the progression of dementia and they should just monitor his symptoms for now.

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

Assessment

In order to reduce Mr L's presenting psychological symptoms, identify potentially contributing factors:

- Pain/discomfort/illness/infection
- Medication review: interactions, dosage, adverse effects, recently prescribed
- Overstimulation (noise, people, activities)
- Lack of attention to culturally-relevant needs and historical issues
- Overextending his capabilities by expecting too much of him
- Altered routines, new day centre staff, particular staff, other day centre attendees and/or family members
- Unfamiliar/altered/threatening physical environment
- Reduced stress threshold

Assessing the situation:

- Encourage Mr L to express his needs as far as he can

- Directly observe any situations that appear to exacerbate his depressive symptoms
- Consult close family members to identify potentially contributing factors
- Consult Mr L's life history for further information with regard to his symptoms
- Ask day centre staff who know Mr L quite well if they can assist in identifying his needs or possible reasons for his increasingly low mood
- Assess the immediate environment for possible factors contributing to Mr L's symptoms

Strategies/outcomes

- The family reported that Mr L experienced the harshness of wartime Europe as a teenager, prior to his migration to Australia.
- Mrs L is aware that after he migrated her husband applied to bring his parents and younger brother to Australia on compassionate grounds. This was not possible and the family 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 around the traumatic experiences of his youth.
- Mrs L reports that she is finding the situation increasingly stressful as she now becomes anxious when readying Mr L for the day centre, unsure of what his response will be when the bus arrives to collect him.
- She is also concerned that the loss of her limited respite hours, when Mr L refuses to go, is reducing her tolerance for his symptoms.

- Mr L underwent further medical assessment and a medication review. When his doctor was made aware of the full extent of his symptoms, Mr L was prescribed a trial of antidepressant medication.
- It was explained to the family that it may be two weeks before potential benefits of the medication are evident and he may initially experience side effects that will hopefully resolve.
- Mr L was referred to a psychogeriatrician for further assessment and management of his post traumatic stress symptoms.
- Staff reported that hostility towards others at the day centre was typically reserved for those from other European backgrounds.
- Mr L had also mistakenly identified some of the other men attending the centre as German. The group composition of attendees on other days of the week was examined and it was determined that it was possible to trial Mr L on a day when fewer men from European backgrounds and more women were present.
- Many of the day centre staff members have little knowledge of dementia, BPSD or post traumatic stress symptoms and/or their management. Training was provided to enable staff to develop strategies which may assist in managing and supporting Mr L.
- While the day centre is small, it tends to bustle with high levels of activity and noise which can cause Mr L additional distress.
- Opportunities were created for Mr L to spend some time in a quiet area where additional individual time was provided for activities he previously enjoyed such as listening to his favourite music.

- Additional information was provided to the day centre regarding Mr L's likes/dislikes, food preferences and daily routine as well as cultural and/or religious occasions that are important to him.
- Mr L has been apathetic with regard to outings and has been expressing increased anxiety around leaving his familiar home environment. A bilingual/bicultural staff member, who was already transporting another lady, was recruited to collect Mr L also and he responded well to her additional attention.

Module 8: Disinhibited behaviours

Key messages

- Disinhibited behaviours in dementia present as those behaviours associated with a reduced capacity to restrain or control immediate, impulsive responses
- Disinhibited behaviours can be caused by frontal lobe pathology, substance use or other underlying medical/psychiatric conditions
- Differential diagnosis requires establishing whether the manifested behaviours are inappropriate because of impaired impulse control or may be 'normal' premorbid behaviour for the individual
- Identification of potentially modifiable factors is necessary for the management of disinhibited behaviours
- Behavioural-based strategies for the person with dementia and psychoeducation/psychotherapy for carers should be considered
- Limited evidence for galantamine over placebo in BPSD, including disinhibition, was demonstrated in a post hoc analysis of 3 RCTs; effect size is very small and results may not be specific to galantamine
- Atypical antipsychotics may be of some benefit, but their use is not recommended due to safety concerns
- Where pharmacological intervention is indicated, cholinesterase inhibitors (ChEIs) in Alzheimer's disease (AD) and selective serotonin reuptake inhibitors (SSRIs) may be safer alternatives to antipsychotics

Disinhibited behaviours

What are disinhibited behaviours and what do they look like in dementia?

- Disinhibited behaviours in dementia typically occur with reduced capacity to control immediate impulsive responses.
- Behaviours include those associated with impaired judgement and reduced awareness of the environment as well as the impact on others around them.
- Sexual disinhibition in dementia is particularly problematic and can include simulating sexual acts, requesting unnecessary genital care, unwelcome attempts at intercourse, rape, sexual aggression, propositioning others, grabbing, groping, sexual remarks, masturbation in public, exhibitionism, unsolicited fondling, frotteurism and/or pursuing others for sexual purposes.

Causes of disinhibition

- Biological causes include frontal lobe pathology, misuse of drugs and/or alcohol, delirium, cerebral event or other psychiatric syndromes such as mania or psychosis.
- Social factors such as the lack of a usual sexual partner and lack of privacy in communal living can also contribute to sexual disinhibition.

Differential diagnosis

In the case of sexual disinhibition, it is important to determine if the presenting behaviour is actually 'normal' premorbid sexual behaviour for that individual which may

present inappropriately as impulse control, judgement and/or moral values become increasingly impaired.

Measuring disinhibited behaviours

- While no standardised measure of disinhibition in dementia exists, the Disinhibition Scale has been validated in dementia.
- The Neuropsychiatric Inventory (NPI) and the NPI-Clinician (NPI-C), the Behavioral Syndromes Scale for Dementia (BSSD), the Challenging Behaviour Scale (CBS) and the CERAD Behaviour Rating Scale for Dementia (BRSD) include relevant items.

Prevalence of disinhibited behaviours

- Clinically significant disinhibition is a relatively uncommon BPSD.
- Symptoms reportedly occur in 2% to 25% of persons with dementia, particularly in those with frontotemporal dementia.
- Reports are inconsistent with regard to prevalence ratios in males and females.

Effects of disinhibited behaviours

- Disinhibited behaviours can be associated with aggression, hallucinations, delusions, frustration, agitation and/or negative symptoms such as apathy.
- Disinhibited behaviours of a sexual nature can be a source of significant stress and distress for carers.
- Disinhibited behaviour may also provoke an aggressive response from others.

- Urinary tract infections, physical trauma and/or sexually transmitted infections are potential consequences.
- Within a RACF, staff may need to determine the capacity of residents with dementia to pursue a sexual relationship to avoid potential exploitation of vulnerable individuals. While formal guidelines are lacking in this area, the following are suggested.

Assessing a person with dementia's competency to participate in a sexual relationship

Person with dementia's awareness of the relationship:

- Is he/she aware of who is initiating sexual contact?
- Does he/she believe that the other person is his/her spouse/partner and thus acquiesces out of a mistaken belief or misidentification?
- Is he/she aware of the other person's intent?
- Can he/she state what level of sexual intimacy he/she would be comfortable with?

Person with dementia's ability to avoid exploitation:

- Is the behaviour consistent with formerly held beliefs and values?
- Does he/she have the capacity to say no to any uninvited sexual contact?

Management

- The initial challenge is to determine which of the underlying, individual factors driving the behaviour are potentially modifiable.
- Sexually inappropriate behaviours can be differentiated between those that are misplaced in a particular social

context (e.g. public versus private spaces) and those that would be considered inappropriate in most contexts.

- Consider the need to provide rooms/facilities appropriate for privacy and intimacy.
- Interventions reported in the literature are related to sexual disinhibition.

Psychosocial and environmental interventions

Suggested interventions and strategies:

- supportive psychotherapy and/or education of family carers and RACF staff
- identify potential triggers, social cues and early indicators
- modify environmental aspects, clothing and RACF staff roles
- provide distraction, redirection and modified learning techniques
- activities to occupy the person's hands and increased, appropriate, positive contact with family
- avoid overreaction or knee-jerk responses that induce shame or humiliation
- provide private space for person to share intimate time with his or her partner if that is requested

Biological interventions

- Limited evidence for galantamine over placebo in BPSD, including disinhibition, was demonstrated in a post hoc analysis of 3 randomised controlled trials. While the effect size is significant, it is very small and results may

not be specific to galantamine but a class effect of ChEIs.

- Case studies and an open label trial provide limited evidence for the use of: anticonvulsants, hormonal agents (female hormones or anti-androgens), antipsychotics—atypical, antidepressants, ChEIs and an H₂-receptor antagonist.
- Hormonal therapy is controversial as it can be viewed as feminisation or chemical castration of males.
- Although antipsychotics may be of some benefit, expert consensus guidelines recommend against their long-term use; ChEIs (in AD) or SSRIs may provide a safer option.
- The potential benefits to the person with dementia and the safety of others must be weighed against the potential side effects of pharmacological treatments.
- It is crucial to obtain informed consent from the person or proxy and in some cases, from official bodies such as the Guardianship Tribunal (in NSW) or equivalent for the use of hormonal agents.

Conclusions/recommendations

- A major dilemma arises in attempts to allow the person with dementia's sexual expression while protecting the safety, rights and dignity of all.
- The limited evidence available suggests that individual situations must be managed on a case-by-case basis.
- Modifying environmental factors including allowing privacy with the person's partner may have a part in reducing symptoms.

- The need for a multidisciplinary, individualised and multifaceted approach is stressed.
- Where pharmacological treatment is necessary, the reported medications may have a role to play in managing disinhibited behaviours in dementia although sound evidence is lacking.
- Employment of an appropriately skilled sex therapist/worker has been reported. This would need to be considered in context of values of the person with dementia, family and facility.

Presentation

Not long after his admission to the RACF, Mr A approached several female staff members and a female resident with sexual suggestions. He was initially transferred to another part of the facility but Mr A soon resumed the behaviour which escalated to the point of inappropriately touching others and publicly masturbating in the dining room during meals. When staff intervened or asked him to return to his room he could become verbally aggressive and threatening.

Assessment

In order to reduce the presenting behaviours, identify contributing factors:

- sexual history and premorbid patterns of sexual interest
- pain/discomfort/illness/infection
- medication reactions, interactions, dosage, recently prescribed
- lack of usual sexual partner/privacy
- unfamiliar/altered/ deprived physical environment
- psychotic symptoms/misidentification
- loss of premorbid social controls

- altered routines, new staff, particular staff and/or family members
- misinterpretation of environmental cues
- sensory impairments

Assessing the situation:

- directly observe what may trigger the behaviour
- ask staff who know Mr A if they can assist in identifying possible triggers for the behaviour
- consult Mr A's life history as well as behaviour and clinical charts for further information with regard to triggers
- assess the immediate environment for possible triggers
- consult family members to identify possible triggers which may be unknown to staff and not previously documented

Strategies/outcomes

- Direct observation suggested possible triggers for the behaviour were related to the presence of specific female staff members and a very sociable female resident who was seated at Mr A's table in the dining room. The female resident was happy to change her seating to join a friend at another table.
- RACF staff reported that Mr A was possibly misidentifying their intentions during personal hygiene tasks as these also provoked a sexual response at times. Change in rosters enabled two male staff members to largely cover Mr A's personal care needs between them.
- A review of Mr A's current medication did not suggest any association with the behaviour.
- When asked, the family reported that Mr A and his wife had been openly affectionate and apparently a close couple until her death in the past year.

- Mr A has reportedly become increasingly less aware of social boundaries.
- Family members provided items of special interest from Mr A's home that helped to keep him occupied during periods of reduced environmental stimulation. They also increased their visits to provide him with additional appropriate human contact.
- Consultation with staff members indicated that some were shocked and repulsed by Mr A's disinhibited behaviours and were unaware that these BPSD can occur during the course of dementia.
- Staff education was provided around causes of disinhibition, 'normal' sexual expression in older people, diminished privacy issues, strategies to avoid provoking and/or manage unwanted sexual behaviours as well as potential consequences of overreaction and shaming the resident.
- Opportunities for staff to debrief and validate their personal reaction to Mr A's behaviour in a safe and enabling environment were provided.
- Increased staff awareness of the underlying issues increased staff confidence and ability to implement successful strategies for dealing with the behaviours.
- Close monitoring of Mr A's behaviour continued with a view to trialling pharmacological interventions if the safety of others was jeopardised.

Module 9: Nocturnal disruption

Key messages

- Symptoms of nocturnal disruption can present as part of a range of sleep related symptoms associated with night and daytime behaviours
- Nocturnal disruption can be caused by physical factors or be inherent to the type of dementia
- The impact on the health of person with dementia and their carer can be significant
- Management requires identifying the potentially treatable contributing factors
- The *NITE-AD* multicomponent intervention, provides the best evidence for psychosocial management
- Where pharmacological treatment is indicated, cholinesterase inhibitors (ChEIs; if Alzheimer's dementia) and atypical antipsychotics provide the best available evidence
- The use of antipsychotics is not recommended due to safety concerns
- In some cases the use of ChEIs may be problematic due to the potential adverse effects of sleep disturbance and nightmares
- Sleep disturbances can occur secondary to depression, anxiety, agitation and/or pain
- Pharmacotherapy for underlying, potentially causal conditions, good sleep hygiene and/or traditional measures may be helpful in reducing nocturnal disruption

Nocturnal disruption

What is nocturnal disruption and what does it look like in dementia?

Nocturnal disruption refers to circadian rhythm and sleep disturbances. Symptoms of nocturnal disruption vary with dementia subtypes, but may present as:

- increased early-morning awakenings
- nocturnal sleep fragmentation
- decreased total sleep time
- decreased sleep efficiency
- reverse day-night patterns
- decreased slow wave sleep
- excessive daytime sleepiness
- decreased rapid eye movement sleep
- nocturnal confusion
- increased daytime napping
- loss of normal sleep architecture
- increased sleep onset latency

Causes of nocturnal disruption

- Causes include physical factors such as pain or adverse effects of medication.
- It can also be inherent to the type of dementia e.g. tends to occur more frequently in DLB.
- Where sleep disruption occurs other BPSD may become exacerbated at night due to reduced environmental cues.

Differential diagnosis

- Delirium, comorbid medical and/or psychiatric conditions, substance abuse, physiological effects of medications, parasomnias and other primary sleep disorders can be misdiagnosed as nocturnal disruption in dementia.
- Comprehensive clinical assessment in combination with information from sleep questionnaires and/or polysomnography may assist diagnosis.

Measuring nocturnal disruption

- Current guidelines recommend the use of actigraphy and keeping a sleep log in the assessment of nocturnal disruption.
- Questionnaires such as the sleep disorders subscale of the 12-item Neuropsychiatric Inventory (NPI) or the NPI-Clinician (NPI-C), the Pittsburgh Sleep Quality Index (PSQI) and the Epworth Sleepiness Scale (ESS) may be useful.

Prevalence of nocturnal disruption

- Nocturnal disruption occurs in 20% to 82% of persons with dementia.
- The occurrence of nocturnal disruption in dementia increases with dementia severity, negative ApoE ϵ 4 allele status, anxiety, depression, reduced exposure to environmental cues and poor sleep hygiene.

Effects of nocturnal disruption

- Nocturnal disruption in dementia is associated with poor sleep quality, depressive symptoms, greater carer burden, earlier RACF placement, poorer cognitive

functioning, more rapid cognitive decline, greater functional impairment, poor quality of life and/or wandering behaviours in persons with dementia as well as a higher risk of mortality and distress to the family carer.

Management of nocturnal disruption

- It is important for the clinician to determine potentially treatable factors contributing to the nocturnal disruption.
- Management of underlying causes may require providing relief for pain, hunger, thirst and/or treating infection, acute illness or adverse drug reactions.
- Where nocturnal disruption prompts night wandering or exacerbates other BPSD, safety may be an issue.
- Carer education around sleep hygiene or assessing degree of night-time, environmental disturbance occurring close to the person with dementia may be helpful.
- Sleep hygiene includes establishing a regular night time routine, limiting caffeine, adequate hydration but decreased fluids in the hours before going to bed as well as minimising noise and light intrusion.

Psychosocial and environmental

- Most studies fell under the sensory or multicomponent categories.
- Evidence for light therapy is inconsistent.
- Positive results were found in two studies of moderate quality for therapeutic recreation interventions; an outdoor activity program and indoor gardening activity.

- A study which looked at residential respite reduced carer stress but exacerbated sleep disturbances in persons with dementia.
- The NITE-AD intervention, a multicomponent intervention which comprised carer sleep hygiene education, daily walking and increased daylight exposure reduced nocturnal disruptions, whereas other multicomponent interventions showed improvement on daytime measures only.
- Although scientific evidence is lacking, traditional interventions may nonetheless contribute to management and should not be overlooked. Consider warm milk, reassuring human/pet contact, gentle massage and/or soothing music as well as adequate day-time light exposure and physical activity to induce sleep.
- Adequate exercise and exposure to sunlight during the day

Biological interventions

- Limited high quality evidence is available for pharmacological management.
- Most studies examined the effects of ChEIs or atypical antipsychotics.
- Although some evidence is provided for atypical antipsychotics, current guidelines recommend against their use unless nocturnal disruption is secondary to psychosis.
- Limited evidence is reported for melatonin, Ginkgo biloba extract EGb 761 and Yi-Gan San.

- Mixed results were reported for light stimulation, electrical stimulation interventions.

Conclusions/recommendations

- The multicomponent *NITE-AD* intervention provides the best evidence for psychosocial management.
- Where pharmacological treatment is indicated, ChEIs (if AD) and atypical antipsychotics provide the best evidence, but the use of antipsychotics is not recommended due to safety concerns. Further, sleep disturbance and nightmares are well known potential adverse effects of ChEIs.
- Sleep disturbances can occur secondary to depression, anxiety, agitation and/or pain. Pharmacotherapy for the underlying condition may help.

Presentation

Mr C is a recent admission to the RACF from hospital, following a medical crisis. He lived a chaotic lifestyle at home with no real routine and was dishevelled and underweight on admission. He did not have a regular sleeping pattern so was often awake at night. RACF staff report that he has a disrupted sleep/wake cycle. When he is awake late into the night, Mr C wanders into other resident's rooms while they were sleeping and turns on the lights.

In the mornings, Mr C does not wish to be disturbed. He has become increasingly resistant to their encouragement to eat breakfast or have a shower. He can ill afford to lose weight at this time. Because staff are busy, Mr C frequently falls back to sleep until 11am.

Assessment

In order to reduce the presenting behaviours, potentially contributing factors must be identified:

- Pain/discomfort/illness/infection keeping Mr C from settling at night
- Medication interactions, dosage
- Unfamiliar physical environment
- Unfamiliar noise/disruption/light from night staff attending to needs of other residents close to Mr C
- Less flexibility with routine than Mr C had previously
- Staff have little awareness that Mr C's previous lifestyle factors may be contributing to the behaviour

Assessing the situation:

- Consult family members to identify possible strategies to assist in managing the behaviour
- Directly observe Mr C's pattern across a 24 hour period
- Monitor his food and fluid intake
- Contact the hospital for any additional information available with regard to Mr C's history

Strategies/outcomes

- After investigation via the hospital, Mr C's only surviving sibling was contacted. He reported that Mr C used to enjoy his garden and was very proud of his fig trees. Mr C would also spend time flicking through Greek newspapers and junk mail brochures.
- Mr C has had two recent relocations which will likely have increased his confusion. Providing familiar items may help him identify his space, making it more comfortable and appealing at night. Although Mr C's brother had not been close to him for some years, he was willing to bring some personal items to the RACF.

- It became evident that Mr C was further disrupted at night by activity around the nursing station and staff attending to the high level needs of the resident in the next room. He was moved to a quieter area.
- The relative inactivity and darkness within the RACF environment at night, provides reduced cues and a small night light assisted with orientation.
- Keeping Mr C's daily routine as predictable as possible, given his previous lifestyle, provided some structure and ultimately, familiarity.
- Supporting staff through Mr C's transition to RACF and providing education around the factors contributing to his night-time wandering improved tolerance of the behaviour.
- Staff members were able to chat to Mr C about his passion for gardening and source Greek newspapers for him to browse.
- A daily walk to RACF letterbox after multiple brochures (recycled by staff) were 'delivered' became a positive activity.
- Better sleep hygiene minimised opportunities for sleep during the day and gradually helped to establish a somewhat earlier and regular bedtime for Mr C.
- While he was still awake later than other residents in the facility, the situation was more manageable and less disruptive to others.

Module 10: Psychotic symptoms

Key messages

- Psychotic symptoms in dementia present as delusions or hallucinations indicative of a disturbance in the perception and/or appreciation of objective reality
- Psychosis of dementia needs to be differentiated from schizophrenia, other primary psychotic disorders and delirium
- Prevalence rates for psychotic symptoms in dementia range from 12.2% to 74.1%
- Delusions are the most prevalent psychotic symptom followed by hallucinations
- Individualised, psychosocial interventions are recommended initially unless the psychotic symptoms are causing significant agitation, distress or safety concerns
- Where pharmacological treatment is necessary, cholinesterase inhibitors (ChEIs) and memantine may provide a safer option than atypical antipsychotics for Alzheimer's dementia
- Where medications are indicated, concurrent psychosocial interventions may be of benefit
- The multifaceted dementia care program *GentleCare* provides the best evidence for the psychosocial management of psychotic symptoms

Psychotic symptoms

What are psychotic symptoms and what do they look like in dementia?

Psychotic symptoms in dementia are defined as a disturbance in the perception and/or appreciation of objective reality. Criteria for psychosis of dementia:

- delusions or hallucinations in the presence of dementia
- psychotic signs and symptoms which are present at least intermittently for at least one month and onset occurs after the onset of other dementia symptoms
- symptoms are severe enough to disrupt the person with dementia's functioning
- symptoms are not better accounted for by another psychotic disorder, medical condition, or effects of a drug and not occurring during the course of a delirium

Causes of psychotic symptoms

- Potentially reversible causes of psychotic symptoms include misinterpretation of reality, sensory deprivation or vision loss, inappropriate sensory stimulation and/or depression.
- Those with a history of intake of anticholinergic drugs or with extrapyramidal signs are also at a higher risk of experiencing psychotic symptoms.
- Psychotic symptoms can also arise from delirium, substance use and other medical conditions such as infection.

Differential diagnosis

- It is important to determine if the presenting psychotic symptoms can be attributed to schizophrenia, another primary psychotic disorder or delirium.
- Delusions and/or hallucinations may be mistakenly attributed to the person with dementia's religious/spiritual beliefs and/or cultural background rather than the dementia.
- 'Delusions' may be true, e.g. the person's valuables really are being stolen.

Measuring psychotic symptoms

Psychotic symptoms can be assessed using the delusions and hallucinations subscales of the Neuropsychiatric Inventory (NPI) and the NPI-Clinician (NPI-C), the Behavioural Pathology in Alzheimer's Disease scale (BEHAVE-AD), the CERAD Behavior Rating Scale for Dementia (BRSD) or the Columbia University Scale for Psychopathology in Alzheimer's Disease (CUSPAD).

Prevalence of psychotic symptoms

- Psychotic symptoms occur in 12.2% to 74.1% of persons with dementia.
- Delusions are the most frequently reported psychotic symptoms, followed by hallucinations and misidentifications.
- Hallucinations are more prevalent in Lewy body dementia (LBD) and Parkinson's disease dementia (PDD) and are rarely reported in frontotemporal dementia or vascular dementia.

Effects of psychotic symptoms

- Psychotic symptoms have been associated with more rapid cognitive decline, greater mortality, impaired 'real-world' functioning, lower quality of life, higher risk of comorbid BPSD, earlier residential care placement, higher healthcare costs and increased carer burden.

Management of psychotic symptoms

- It is important to rule out delirium or potentially reversible causes, and to confirm that the claims of the person with dementia are not actually occurring, e.g. their valuables may have actually been stolen.
- Dependent on the content, the presence of psychotic symptoms may be more distressing for the carers than for the person with dementia. Education and support for family and staff may be more relevant than treating the person with dementia symptoms.
- Those who experience more distressing symptoms, particularly in DLB or PDD, may require more active treatment.

Psychosocial and environmental interventions

- While all studies were of moderate quality, music interventions made up the largest group and these reported mixed results.
- The *GentleCare* protocol which comprised a non-pharmacological, supportive, prosthetic approach within a dementia unit provides the best evidence of psychosocial management.

- No benefits were found for therapeutic activities or aromatherapy.
- Individualised care based on psychosocial management is recommended.
- The lack of scientific evidence for psychosocial interventions should not prevent clinicians considering these interventions on a case-by-case basis.

Biological interventions

- Where psychotic symptoms are a significant concern or a safety risk, pharmacological interventions may be indicated as a first-line approach.
- The majority of intervention studies focused on atypical antipsychotics, ChEIs or memantine and citalopram.
- Positive results reported for ChEIs and memantine provide the best evidence for the pharmacological management of psychotic symptoms in AD.
- The findings for atypical antipsychotics and antidepressants were mixed. Three studies from one group reported benefits of citalopram for delusions.
- Little to no evidence of efficacy was reported for omega-3 supplements, traditional Asian herbal formulation or Ginkgo biloba extract.
- A small case series reported some positive results for electroconvulsive therapy (ECT) but results should be interpreted with caution.
- When psychotic symptoms occur with other BPSD, medication which may also address other symptoms

should be considered in an attempt to avoid polypharmacy.

Conclusions/recommendations

- Expert consensus guidelines recommend the use of individualised psychosocial interventions where they are effective in the management of psychotic symptoms in dementia.
- Special care programming provided the best evidence for the psychosocial management.
- Where distress or safety is an issue short-term pharmacological treatment may be indicated as a first line approach or concurrent with psychosocial interventions.
- Treatment outcomes reported in studies are generally dependent on the severity of psychotic symptoms at baseline, which may vary across dementia subtypes.
- Where pharmacological management is required, ChEIs and memantine (if AD) followed by citalopram may provide a safer option than atypical antipsychotics.
- The use of symptomatic, pharmacological agents, should be time-limited, closely monitored, reviewed, reduced and/or discontinued when indicated.

Presentation

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 physical 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 respite centre staff, particularly those who are from non-Aboriginal or Torres Strait Islander backgrounds. Mr H tells his family that staff try to beat him and want to take him away from the 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)

Assessment

In order to reduce the presenting behaviours, potentially contributing factors must be identified:

- Exclude potentially reversible causes of the psychotic symptoms
- Misinterpretation of reality and/or other's intentions
- Sensory deprivation/impairment or inappropriate sensory stimulation
- Illness/infection/delirium/depression Has a recent medical review has been attended?
- Pain/discomfort may not be well managed. An eye examination may exclude medical conditions which could account for the sensation of snakes.
- Medication review: interactions, dosage, recently prescribed, adverse effects, compliance.
- Is pharmacological intervention indicated, possible and/or practical for treatment of psychotic symptoms?
- Lack of attention to culturally-relevant needs. Altered routine, unfamiliar people, reduced time spent with family.

- Unfamiliar/ altered physical environment
- Reduced stress threshold

Assessing the situation:

- Consult family members to identify possible reversible causes for psychotic symptoms and/or underlying reasons for his distress
- Encourage Mr H to express his concerns as far as he can
- Directly observe what may trigger the behaviours
- Assess the immediate environment for possible triggers

Strategies/outcomes

- Any one of Mr H's numerous comorbid illnesses may be causing discomfort or pain. Limited access to health services and transport within the community can preclude regular medical treatment.
- A medical review was arranged with the assistance of male family members.
- Mr H suffers from visual impairment due to bilateral cataracts which could potentially contribute to his misinterpretation of items in the environment. The feasibility of cataract surgery was a matter for a family case conference.
- When family provided relevant details of Mr H's history, it became evident that his past experiences as a member of the stolen generation and his ongoing fear of institutions may provoke anxiety around being taken out of his community for day respite.
- Community members initially attended the day respite centre with Mr H, for part of the day, to assist in his adjustment to the unfamiliar environment.

- English is not Mr H's first language and he has had no opportunity for formal education so communication with respite centre staff and other attendees is limited.
- Visual resources and pictorial language aids were developed and/or found with assistance of community members familiar with Mr H's first language.
- A language appropriate telephone interpreter was located but attempts to use the service with Mr H were largely unsuccessful.
- 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 willing to assist with communication when he was available and regularly spend some time 'yarning' with Mr H.
- Some staff members at the respite centre with little knowledge of dementia and BPSD became fearful of Mr H after he spoke of his psychotic symptoms.
- Education was provided to increase awareness of BPSD and management of clients with dementia.
- The respite centre is located in different *Country* to Mr H's own, causing him distress when he forgets that he will be returning home later in the day.
- With a better understanding of the needs of clients with dementia, staff at the centre provided Mr H with regular reassurance.
- Limited experience and knowledge of dementia and BPSD within Mr H's extended family and community was increasing his daughters' stress and alienation. A visit to the community was attended to provide education and culturally appropriate information.
- Family assisted the respite centre staff to plan appropriate activities, relevant to Mr H's interests and background.

Module 11: Vocally disruptive behaviour

Key messages

- Vocally disruptive behaviour (VDB) can be described as any vocalisation that causes stress within the person's environment
- Differing definitions of VDB yield varying prevalence rates and research outcomes
- VDB causes significant distress within the RACF or home environment
- Potential causes of VDB for the individual may provide clues to an intervention to trial
- Discomfort or social isolation, operant learning and reduced stress thresholds are suggested as key areas for potential causes of VDB and targets for planning intervention strategies
- Therapeutic recreation interventions, where they are individually meaningful provide the best evidence for psychosocial management
- Where pharmacological agents are indicated, the best available evidence is for risperidone however, the use of atypical antipsychotics is not recommended
- Evidence for the benefit of cholinesterase inhibitors (ChEIs) in Alzheimer's dementia is limited
- A multidisciplinary, individualised and multifaceted approach to managing VDB is required

Vocally disruptive behaviour

What is vocally disruptive behaviour and what does it look like in dementia?

- Vocally disruptive behaviour (VDB) is also referred to as screaming and verbal agitation.
- VDB can be described as any vocalisation that causes stress within the person's environment.
- VDB can be intermittent or incessant and include vocalisations such as singing, screaming, abusive or verbally aggressive comments, perseveration, repetitive questioning, groaning and sighing.

Causes of vocally disruptive behaviour

- Theories propose that unmet needs, operant conditioning, environmental vulnerability and reduced stress-threshold contribute to VDB.
- Three key areas are suggested as potential causes for VDB and targets for intervention:
 - discomfort (physical and/or psychological/social isolation)
 - operant conditioning associated with the behaviour due to the increase in the attention it attracts
 - reduced-stress threshold secondary to cognitive impairment
- VDB can also occur in response to visual and/or auditory hallucinations.

Differential diagnosis

- Symptoms of VDB overlap with other agitated behaviours in dementia.

- VDB is disruptive whether or not the person with dementia has an awareness of their needs.
- The inclusion of 'disruptive' in the definition is based on the perception of others.
- The same behaviour may be disruptive in one context and not in another.

Measuring vocally disruptive behaviour

- The original Neuropsychiatric Inventory (NPI) did not include a subscale relevant to VDB, however the revised NPI-Clinician (NPI-C) includes an additional subscale for measuring aberrant vocalizations.
- The majority of scales measuring VDB include it as a subset of BPSD or agitation.
- The Cohen-Mansfield Agitation Inventory (CMAI) includes six items relevant to VDB.
- The Pittsburgh Agitation Scale (PAS) includes a category which measures aberrant vocalisation.

Prevalence of vocally disruptive behaviour

Different definitions of VDB yield varying prevalence rates based on how inclusive they are and the setting. The prevalence of common VDB in persons with dementia:

- cursing and/or verbal aggression from 10% to 48%
- repetitious sentences/questions from 3% to 31%
- screaming from 10% to 15%

Effects of vocally disruptive behaviour

VDB causes significant stress and/or distress within the RACF or home environment. It has been shown to cause

concern, frustration, anxiety, anger and/or complaints from care staff, visitors, other residents and neighbours.

Management of vocally disruptive behaviours

- The initial step for the clinician in managing VDB is to attempt to understand the underlying factors provoking the behaviour.
- Where this is not achievable, management may involve minimising distress to the person with dementia and those around them.

Psychosocial and environmental

- The potential causes of the VDB may provide clues to the appropriate intervention.
- The music interventions group included the greatest number of studies followed by behavioural/cognitive-behavioural interventions and models of care.
- Individually meaningful, therapeutic recreation interventions provide the best evidence for psychosocial management.
- Moderate support for attempts at promoting relaxation, e.g. aromatherapy and music therapy with and without hand massage.
- Moderate quality studies showed reduced VDB when pain was minimised, comfort increased, opportunities for social interaction increased and/or attention or stimulation provided.
- The need for a multidisciplinary, individualised and multifaceted approach is stressed.

Biological interventions

- The evidence for pharmacological treatments for VDB overall is limited.
- The best evidence is for risperidone, however, current guidelines recommend against the use of atypical antipsychotics in this group.
- Evidence for antidepressants is limited.
- ChEIs may play a role in the management of VDB in AD, although similar to other pharmacological treatments, the evidence is mixed.
- Wherever possible, the use of symptomatic, pharmacological agents, when required for treatment of VDB, should be time limited, closely monitored, reviewed, reduced and/or discontinued when indicated, and prescribed alongside appropriate psychosocial interventions.

Conclusions/recommendations

- If discomfort, reduced-stress thresholds and operant conditioning contribute to VDB, interventions focusing on these elements will likely be the most successful in reducing this disruptive behaviour.
- Recognised expert guidelines and reports on the outcomes of interventions are limited.
- Numerous definitions of VDB mean differing prevalence rates shape how VDB is measured and treated.
- Therapeutic recreation provides the best evidence for psychosocial management.
- The need for a multidisciplinary, individualised and multifaceted approach is stressed.

- Results for pharmacotherapy to treat VDB are disappointing. The best evidence is for risperidone; however, current guidelines recommend against the use of atypical antipsychotics for in this group.
- Limited evidence for galantamine and donepezil in the management of VDB in AD dementia has been reported.

Presentation

Miss T has been in a RACF for some years. With the progression of dementia, Miss T has become largely unable to communicate verbally but her calling out, for no obvious reason, has steadily increased. When staff members attend to her personal hygiene Miss T frequently screams loudly. Although the changes have occurred gradually, Miss T's chronic VDB now causes significant stress and/or distress to the other residents living in the RACF. In spite of their concern for Miss T, staff members express their frustration and distress, while trying to avoid her room whenever possible. Families of other residents and visitors frequently complain to staff and management that their relative shouldn't have to put up with Miss T's noise. On occasion, neighbours have made angry complaints to police, demanding investigation of possible maltreatment. Miss T's previously attentive sister and nieces now visit infrequently because they are embarrassed by the obvious reactions of others in the RACF.

Assessment

In order to reduce the presenting behaviours, potentially contributing factors must be identified:

- Unreported pain/discomfort/infection
- Medication review: interactions, dosage, adverse effects
- Overstimulation (noise, people, activities)

- Altered routines, new staff, particular staff and/or family members prompting anxiety/distress
- Unfamiliar/altered/deprived physical environment
- Identification of potentially unmet needs
- Reduced threshold for coping with stress

Assessing the situation:

- Encourage Miss T to indicate her needs as far as she is able
- Directly observe what may trigger the behaviour
- Ask staff who know Miss T well if they can assist in identifying her needs or possible reasons for her VDB
- Consult Miss T's life history as well as behaviour and clinical charts for further information with regard to triggers for the VDB
- Assess the immediate environment for possible triggers
- Consult family members to identify potential triggers for VDB that are unknown to staff and not previously documented

Strategies/outcomes

- Miss T has a long-term history of arthritis. Although she has been prescribed prn analgesia, medication charts indicated that Miss T currently receives pain relief irregularly and less frequently than when she was able to request it.
- A pain assessment indicated that Miss T may be experiencing frequent discomfort and/or pain, particularly in relation to personal care activities. Her analgesic medication was reviewed and non-pharmacological pain relief interventions, such as gentle heat, implemented.
- Some staff members had little knowledge of dementia and were unaware that pain can be a trigger for BPSD

- Miss T's shower was rescheduled to occur 30 mins after the morning dose of analgesia was administered.
- Continence aids were reviewed to source products that may reduce Miss T's need for frequent changes but still protect her skin.
- Resident room allocation throughout the RACF was reassessed and Miss T was relocated to a room where her VDB was less disruptive to other residents.
- Behavioural observation charts indicated that Miss T responded positively to gentle touching and stroking. A NH volunteer was trained to provide appropriate touch several times weekly. When Miss T's family were asked, they reported that they had felt anxious about touching Miss T, helpless to help her and distressed when they visited. Family members were trained and encouraged to gently touch or stroke Miss T's hands and arms.
- Willing family members subsequently developed an informal roster around the volunteer's visits to provide Miss T with maximum benefit. They reported that they now felt their visits were purposeful.
- Miss T's favourite music and aromatherapy were also trialled with mixed results.
- Overall, Miss T's VDB was substantially reduced and when she did call out, staff felt better able to provide strategies that may afford her some comfort.

Module 12: Wandering

Key messages

- Wandering can be one of the most challenging and problematic BPSD
- There are many types of wandering which for definitional purposes describes locomotion occurring over time and space
- Wandering behaviours have been classified as classic, moderate and subclinical, largely based on the duration and rate
- Absconding and becoming lost associated with wandering can have severe negative consequences
- By contrast, independent but safe wandering can potentially have positive effects
- The crucial task for the clinician is to understand what is driving the wandering in the individual
- Treating underlying depression or pain, where indicated should be a priority
- Environmental, sensory, exercise, music and touch therapy interventions provide some evidence for psychosocial management
- The use of chemical restraint by medication is not recommended or justified

Wandering

What are wandering behaviours and what do they look like in dementia?

The construct of wandering has been used to capture a range of observable motor behaviours. An operational definition proposes that wandering can manifest in the following patterns:

- Lapping: locomotion which is circular
- Pacing: locomotion back and forth between two points
- Random: locomotion without a direct path and with multiple directional changes
- Direct: locomotion from a point to a destination without diversion

A descriptive typology has also been outlined: increased motor activity, trailing, pottering, aimless walking, inappropriate walking, appropriate but excessive walking, attempts to leave place of residence, being brought back home and night-time walking.

Causes of wandering

Wandering has different meanings and causes for each individual, such as:

- looking for a loved one
- a habitual pattern of activity
- a reaction to medication
- a symptom of depression
- escaping from a perceived threat
- intrinsic to dementia-related brain pathology

- wishing to return to a familiar environment, e.g. home
- a response to pain, infection or bodily discomfort

Differential diagnosis

- Wandering is often subsumed within the syndromes of agitation and restlessness.
- Restlessness and a physical, non-aggressive form of agitation are used interchangeably to refer to wandering.
- Wandering, in the form of restlessness, has been linked to side-effects of psychotropic medications, particularly akathisia with antipsychotics.

Measuring wandering behaviours

- Wandering is differentiated by pattern, severity, rate, duration, peak period of occurrence and frequency.
- The Neuropsychiatric Inventory (NPI), NPI-Clinician (NPI-C) and the Cohen-Mansfield Agitation Inventory (CMAI) include items pertaining to wandering.
- The Revised Algase Wandering Scale for Long Term Care (RAWS-LTC) and the community version (RAWS-CV) are the only assessment tools specifically designed to measure wandering.

Prevalence of wandering behaviours

Prevalence rates for wandering reportedly range from 12.3% to 63%. The rate and duration of wandering increase as cognition declines but then subsides in late-stage dementia.

Effects of wandering behaviours

- Wandering has been associated with high carer burden and anxiety around the associated risks as well as earlier transfer to RACFs.
- Adverse effects of wandering include falls and subsequent injury and/or fractures, weight loss, resident to resident violence, the use of restraint and social isolation.
- Absconding and becoming lost present safety risks, at times resulting in death.

Technologically mediated devices

- Devices to disguise exits and a range of technological devices, such as Global Positioning System (GPS) tracking, signal transmitting and sensor monitor devices, are available to alert carers when persons with dementia attempt to exit.
- Such devices have been developed for use in the community and RACFs.
- The use of technology should only be implemented after careful consideration of the autonomy of the individual with dementia and the risks involved.

Management interventions

- Understanding the cause of the wandering will enhance the clinician's ability to reduce the behaviour. Although finding the cause is not always possible.
- It is important to identify the significant aspects of the behaviour including the issues for the person with dementia versus those of carers and/or staff.

Psychosocial and environmental interventions

- The majority of studies fell within the environmental interventions category.
- Subjective barriers generally involve visual manipulation of the environment to reduce exiting. Moderate support is provided for the effectiveness of two dimensional grid patterns and the use of mirrors and modest support for camouflage and concealment.
- Aromatherapy and touch therapies such as slow massage provide some evidence for psychosocial management of wandering behaviours.
- Most studies reported positive results or a trend toward reduced wandering. Quality of the evidence varies and reports of sustainability are limited.
- Although results are mixed, the effectiveness of exercise and music studies lends initial support for their use.
- Reduction in wandering has been associated with comfortable, ambient lighting, variations in sound levels, proximity to others, addressing emotional needs and underlying distress as well as positive social interaction. Published research is lacking in these areas.
- Environmental ambience in NHs and assisted-living facilities was a more robust predictor of wandering behaviours than were MMSE scores.

Biological interventions

- One randomised controlled trial provided strong evidence for a reduction in wandering with antipsychotic medication, however expert consensus recommends against their use.

- Pharmacotherapy for underlying depression or pain may be helpful where this results in wandering in the form of motor restlessness.

Conclusions/recommendations

- The use of chemical restraint by medication is not recommended, however treating underlying depression or pain should be considered.
- Wandering is multifaceted and most studies focussing on this behaviour have been descriptive and exploratory in nature because it has been understudied, limiting the development of effective strategies to date.
- Some evidence for psychosocial interventions which are cost effective and simple to implement is outlined. While benefits appear to be immediate, it is not possible to determine whether these are maintained.

Presentation

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 family of five children, they maintained strong community links with Aboriginal friends and family in Mr E's original community. His connection to *Country* has remained very important to him. Family and community members have been supporting Mr E in the family home with the assistance of an Aboriginal-specific community service and this arrangement has been working well until recently. On three 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 his family. When the police approached Mr E he became uncooperative and verbally aggressive. Police ultimately located Mr E's daughter who collected him from the local police station to take him home.

Assessment

In order to reduce the presenting behaviour, potentially contributing factors must be identified:

- Investigate possible pain/discomfort and/or illness/infection/constipation
- Medication review: interactions, dosage, recent changes, adverse effects
- Assess the immediate environment for potential triggers
- Exclude underlying depression
- Lack of stimulation/boredom
- Changes to the physical environment
- Searching for family members or childhood home environment

Assessing the situation

- Encourage Mr E to express his needs and concerns as far as he is able
- Arrange medical and pharmacological review to exclude potentially reversible contributing factors
- Directly observe and document Mr E's behaviour preceding wandering incidents and on the occasions when he made no attempts to leave home
- Consult family members to identify possible strategies that may discourage Mr E's wandering attempts

- Consult Mr E's life history for further information
- Ask community workers who have become familiar with Mr E if they have identified situations which provoke his wandering behaviours

Strategies/outcomes

- When asked, the family reported that Mr E's beloved dog had died in recent months. Because he doesn't remember this, Mr E tends to become distressed when he can't find the dog or when the dog doesn't come when he calls.
- Consultation with family and community workers indicated that Mr E was also more restless after phone contact with his younger brother who still lives in the town near their childhood home.
- Mr E's daughters are apparently feeling the stress of caring for Mr E while meeting the needs of their own families. They report that they are feeling increasingly guilty when leaving their father alone but their own husbands are not happy with one of them sleeping at Mr E's home every night.
- Family and community members are experiencing greater difficulty communicating with Mr E as he increasingly reverts to his traditional language.
- The community workers and family have little understanding of the association between Mr E's dementia and his wandering behaviours. Information was provided to increase their awareness of potential triggers for Mr E's behaviour.
- Mr E's history, as outlined by the family, explained his reaction to contact with the police. With the progression of dementia, traumatic experiences from his past have exacerbated his fear of authority figures.

- Mr E's younger brother travelled to Adelaide to participate in a family/community meeting. The family determined that Mr E may benefit from staying with his brother and wife for a period.
- Mr E responded well to returning to *Country* and the company of some of the older family and community members.
- The additional support from multiple community members meant that Mr E was afforded greater supervision.

