A Clinician's BPSD Field Guide 2023

Understanding and helping people experiencing changed behaviours and psychological symptoms associated with dementia

UNSW SYDNEY

CHeBA Healthy Brains Positive Ageing

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Understanding and helping people experiencing changed behaviours and psychological symptoms associated with dementia

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Disclaimer

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

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Contents

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

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Abbreviations used in this Field Guide

Term	Abbreviation	Comments
Alzheimer’s disease	AD	
Activities of Daily Living	ADLs	
Behaviours and psychological symptoms associated with dementia	BPSD	Also known as changed or responsive behaviours
Cholinesterase inhibitors	ChEIs	
Culturally and Linguistically Diverse	CALD	
Dementia Behaviour Management Advisory Service	DBMAS	Dementia Support Australia (DSA)
Dementia with Lewy bodies	DLB	Also known as Lewy body dementia/disease (LBD)
Dementia Outcomes Measurement Suite	DOMS	
Frontotemporal dementia	FTD	
General Practitioner	GP	
International Psychogeriatric Association	IPA	
Mild Cognitive Impairment	MCI	
Parkinson’s disease dementia	PDD	
Pharmaceutical Benefits Scheme	PBS	Australian Government
Residential Aged Care Services	RACS	
Randomised Control Trial	RCT	
Severe Behaviour Response Team	SBRT	Dementia Support Australia (DSA)
Vascular dementia	VaD	

Introduction

Aim

This *Clinician's BPSD Field Guide 2023* was developed by the Centre for Healthy Brain Ageing (CHeBA) at UNSW Sydney to replace and update the document *A Clinician's Field Guide to Good Practice: Managing Behavioural and Psychological Symptoms of Dementia* (2014). The aim of this Field Guide is to provide guidance for clinicians, residential care staff and community care staff supporting people living with dementia, who present with *behaviours and psychological symptoms associated with dementia (BPSD).

A comprehensive evidence and practice-based overview of care principles to support people who present with BPSD is provided in the unabridged version of this document. The empirical evidence supporting the content of the unabridged *Clinician's BPSD Guide 2023* is included as *Appendix 1* to the unabridged *Clinician's BPSD Guide 2023* and is accessible via the CHeBA website.

Terminology

*The term and abbreviation behaviours and psychological symptoms associated with dementia (BPSD) are used respectfully throughout this Field Guide for communication between professionals supporting people with dementia. Terms such as changed behaviours, responsive behaviours, behaviours of concern, neuropsychiatric symptoms (NPS), behavioural and psychological changes in dementia and others are also used to describe BPSD and may be terms preferred by people living with dementia. The term changed behaviours may be more appropriate when clinicians are communicating with a person living with dementia, carers/family and/or community members. For more information on terminology see article published in the International Journal of Geriatric Psychiatry, Language paradigms when behaviour changes with dementia: *#BanBPSD*. For information about consumer preferences on terminology, consult the Dementia Australia *Dementia Language Guidelines*.

The term carers can refer to care staff or family and friends who provide support and care, also known as care partners, informal carers or caregivers. Where necessary, the text differentiates between care partners and formal, paid or professional carers.

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

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

How to use this Field Guide

This *Clinician's Field Guide* has been designed as a set of module summaries to facilitate ease of use and provide BPSD specific information. Each module begins with key messages, to enable quick reference to the most pertinent information of that module. *Module 1: Supporting a person who presents with BPSD* provides a guiding framework for the process of addressing BPSD; outlining the stages of risk assessment, comprehensive assessment and the implementation and evaluation of strategies to address BPSD.

Individual BPSD modules include specific information relevant to the following aspects of the BPSD:

- a description of the changed 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
- evidence and practice-based summaries of intervention strategies including:
    - *Psychosocial and environmental interventions*
    - *Biological and pharmacological interventions*
- conclusions, principles of care and limitations of the evidence presented; where single studies are reported for an intervention, this indicates lack of independent replication which suggests caution should be exercised in accepting the results.

To illustrate the information included in each module, a brief clinical scenario encompassing presentation, assessment and strategies/outcomes is presented. It is anticipated that the evidence summarised in this *Guide*, in combination with clinical expertise may assist in achieving improved outcomes for people with dementia.

The unabridged *Clinician's BPSD Guide 2023* provides details of the intervention studies and the strength of the evidence for the findings reported. Further details are included in *Appendices 2 and 3 to the Clinician's BPSD Guide 2023* via the CHeBA website.

Person-centred care (PCC) principles

In providing assistance, clinicians need to be mindful of the rights of people living with dementia and the obligations of service providers toward people with dementia. People 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 to address dementia-related behaviours and psychological symptoms:

- The rights of people with dementia BPSD are recognised and protected.
- The goal for addressing BPSD is to maximise quality of life and safety within the least restrictive environment for each individual with dementia.
- BPSD are recognised as a form of communication.
- The significant impact of BPSD on the person with dementia, care partners, families, staff who provide care and others around the person is recognised.
- Collaboration with all people affected is the preferred approach to addressing 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. It emphasises the need for health care systems and providers to be aware of, and responsive to, peoples' cultural perspectives and backgrounds. Understanding how these contribute to the interpretation of, and ability to access, appropriate and timely care as well as incorporating these considerations into clinical practice is important in reducing health inequalities. The person's country of origin, family and cultural background, preferred language, education, religion, belief system and socio-political outlook must be acknowledged with an appreciation of how these aspects influence care. Culturally competent clinicians and service providers must understand the difference between culture and language, which do not always go hand-in-hand.

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 and stereotypical assumptions about the person with dementia should not be made on that basis. Each community is unique, as is the connection between community members and the broader community.

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: Clinicians undertaking assessment for addressing BPSD may need to exercise judgement in determining the appropriateness of specific assessment tools. This may include discussion with the person, carers, family and/or service providers regarding the relevance of assessment and assessment tools. Culturally appropriate instruments, where available and appropriate, should be used. See *Module 2* for more information on appropriate assessment tools including the KICA and the RUDAS.

Aboriginal and Torres Strait Islander peoples are made up of many diverse communities and language groups. Variations in cultural norms are relative to multiple factors including community size, 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 addressing BPSD may not be culturally appropriate or relevant for Aboriginal and/or Torres Strait Islander peoples or those from CALD backgrounds. Culturally competent care and clinical practice is vital for comprehensive and appropriate assessment as well as addressing BPSD within these populations.

The unabridged *BPSD Guide* (2023) provides additional information and resources specific to Aboriginal and/or Torres Strait Islander peoples and people from CALD backgrounds which may aid in developing cultural competence.

For further information and support on addressing BPSD see:

A Clinician's BPSD Guide - Apps on Google Play

A Clinician's BPSD Guide on the App Store (apple.com)

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

Module 1: Supporting a person who presents with BPSD

Key Messages

- 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.
- A 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 when addressing dementia-related changed behaviours and psychological symptoms.
- A thorough and detailed assessment of the person presenting with BPSD as well as the interpersonal and physical environment is essential to generate potential strategies and interventions.
- Family members and care staff can be good sources of information on the person with dementia, his or her history, premorbid personality and/or preferences.
- A behaviour support plan, based on analysis of the assessment, should be prepared in partnership with carers to ensure their cooperation and understanding.
- Interventions that are individually tailored to the person living with dementia will likely be most effective in moderating BPSD.
- Follow-up, review and evaluation of the effectiveness of an intervention/strategy after implementation enables interventions to be adjusted as needed.

Module 1: Supporting a person who presents with BPSD

The flow diagram below *(Figure 1.1)* illustrates the process for supporting a person who presents with behaviours and/or psychological symptoms associated with dementia (BPSD). Key considerations in each step are outlined in this module.

Addressing BPSD

Clinicians should seek to understand the context, meaning and perspective of dementia and the changed behaviours or psychological symptoms exhibited for the individual person. It is important to be aware of the different ways dementia and BPSD may be understood when collecting information around the situation. An Aboriginal and/or Torres Strait Island person or those from culturally and linguistically diverse (CALD) backgrounds may have a different understanding and experience of dementia and BPSD.

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.
- *Potential risk* (i.e. no immediate risk). Strategies to prevent future risk should be integrated into the care plan.

When determining the degree of risk consider:

- the nature and severity of the presenting BPSD
- context
- resources available within the care environment

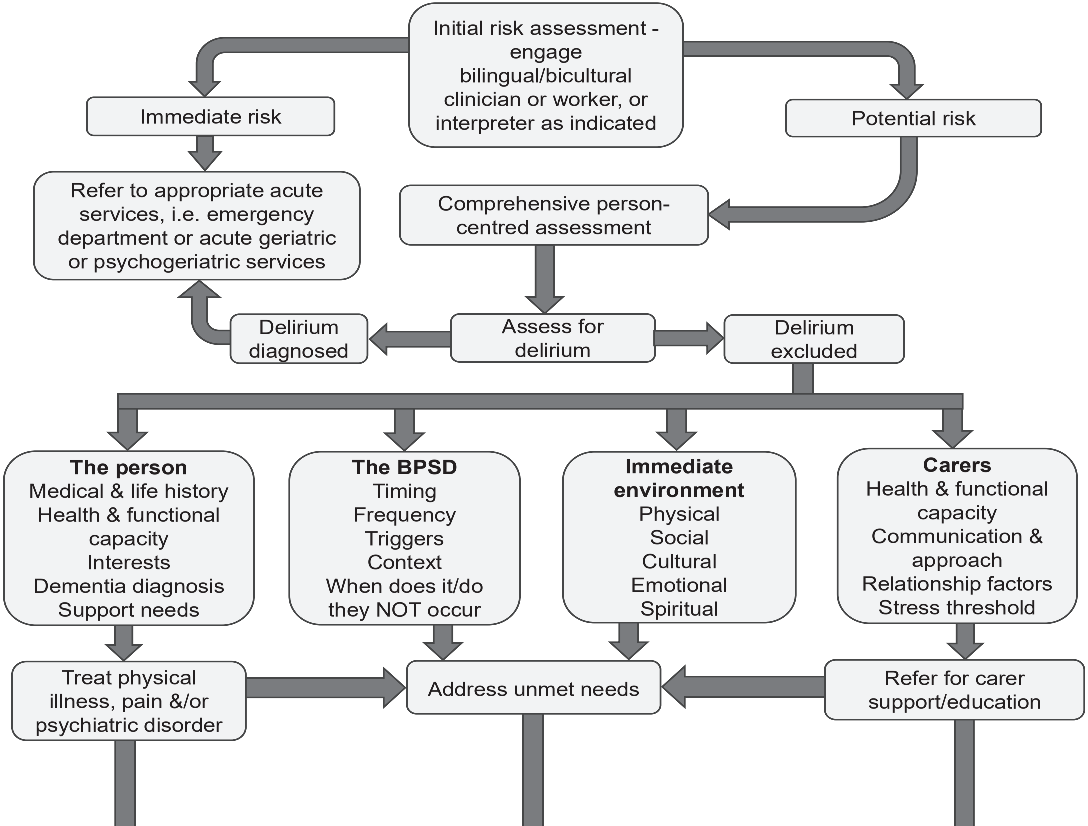
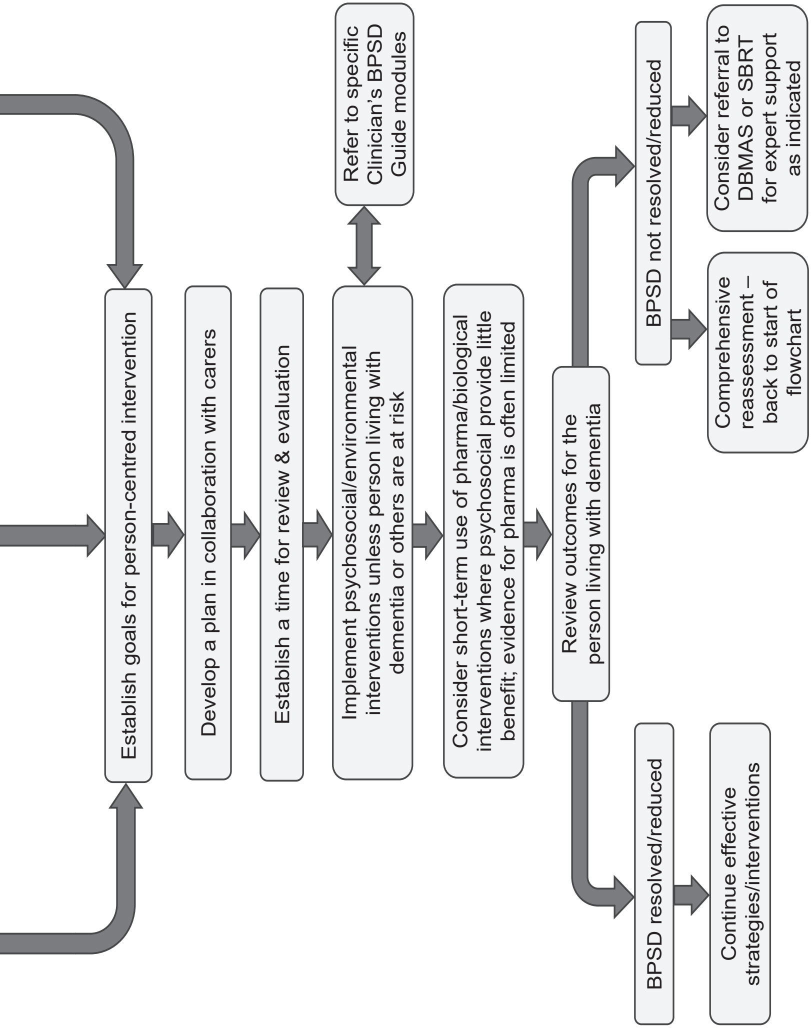


Figure 1.1: Process for addressing changed behaviours and psychological symptoms



Establish goals for person-centred intervention

Develop a plan in collaboration with carers

Establish a time for review & evaluation

Implement psychosocial/environmental interventions unless person living with dementia or others are at risk

Refer to specific Clinician's BPSD Guide modules

Consider short-term use of pharma/biological interventions where psychosocial provide little benefit; evidence for pharma is often limited

Review outcomes for the person living with dementia

BPSD resolved/reduced

Continue effective strategies/interventions

BPSD not resolved/reduced

Comprehensive reassessment – back to start of flowchart

Consider referral to DBMAS or SBRT for expert support as indicated

Potential areas of risk

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 potential risk:

- delirium
- urinary infection
- silent infection
- constipation or urinary retention
- 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-morbidity
- presence of other chronic diseases
- alcohol abuse.

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

- depression and/or anxiety
- suicidal ideation
- psychosis
- psychiatric history
- historical or ongoing trauma
- post traumatic stress disorder (PTSD).

Physical risks

Approach potentially dangerous situations involving physical risk with caution. Avoid escalating the situation and protect all involved.

Potential physical harm to the person with dementia:

- 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

A high-risk environment includes one of extreme carer stress or the risk of being moved due to BPSD.

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
- changes to physical environment
- leaving the home unsecured
- allowing strangers into the home.

Potential loss of accommodation:

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

Communication

Effective and respectful communication is an essential factor in the assessment with the person with dementia to develop a behaviour support plan to address BPSD. Based on observation and some direct questioning, ensure your communication and interaction style is appropriate to the person's cultural background. This includes the way you approach the person, your tone of voice and whether eye contact is made or not. This is particularly important when aiming to provide culturally competent services to people 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.

Communicating with people from Aboriginal and Torres Strait Islander communities

- 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 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 arise from the many different Aboriginal and Torres Strait Islander languages across Australia and the legacy of historical factors.

Communicating with people from culturally and linguistically diverse backgrounds

- Culturally appropriate assessment requires working with language-concordant and proficient bilingual/bicultural clinicians as a first preference and bilingual/bicultural workers as a second preference.
- 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 issues 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 from a variety of sources to assist in the investigation of the potential underlying factors prompting the BPSD.

A comprehensive assessment should incorporate a person-centred approach. The following may influence the BPSD, as well as the development and implementation of an effective behaviour support plan:

- Characteristics of the **person** with dementia
- Description of the **BPSD**
- Characteristics of the **carers** and the **care relationship**
- The **care environment** including the physical, social and cultural dimensions of the immediate and extended environment, particularly the care setting.

The person living 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.

- *Dementia diagnosis:* If a formal diagnosis has been made this can provide important information on the type of dementia, length of time since diagnosis and/or symptom onset, as well as associated cognitive and functional losses.
- *Aspects of the person's life story:* Collecting a social history and life story can assist in developing a comprehensive picture of the person with dementia. Include details of the person's interests, routines, social networks, social roles, cultural background, spirituality and sexuality as well as special and/or traumatic life events.
- *Physical and mental health:* Co-morbid physical and/or mental health issues, including depression or delirium, may contribute to BPSD (also see *Risk Assessment*). Ensure physical needs of the person have been addressed, including pain or discomfort.

The changed behaviour(s) or psychological symptom(s)
Gathering a detailed description of the BPSD and the context in which it occurs is necessary for assessment and establishing an appropriate behaviour support plan.

- Family carers and/or of aged care staff are often of the most important sources of information.
- Assist the informant to describe the BPSD and the context as accurately as possible. For example, describing a person as agitated does not describe how this is manifested, such as motor restlessness, calling out, picking at clothes, pacing.
- Be aware that perceptions of BPSD may vary with 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 situation.

Assessment of the BPSD requires investigation of the following aspects:

- frequency, duration and intensity
- details/clarification of events which occurred prior to the BPSD (antecedents)
- locations where the BPSD occur
- other people present
- consequences of, and responses to, the BPSD by others
- circumstances that prevail when the BPSD do NOT occur
- extent of discomfort that the BPSD cause the person with dementia
- extent of concern for the person and others in the environment, including the emotional effect on those exposed to the situation

Aboriginal and Torres Strait Islander considerations

The person with dementia and BPSD

Holistic perspective of health

- Aboriginal and Torres Strait Islander communities traditionally view physical and mental health holistically in a way that encompasses social and emotional wellbeing.
- The wellbeing of community members is maintained when the interconnected elements of spiritual, physical, emotional, social and cultural life are balanced.
- Addressing 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 their unique cultural and historical background.
- Be aware of the relevant local history of the place, family and community.
- Consider the person with dementia's cultural losses as well as experiences of historical and ongoing trauma.
- Appreciate the resilience that has developed within families and communities.
- Recognise and acknowledge sources of strength within communities for the person with dementia and their family in understanding and addressing BPSD.

Culturally and linguistically diverse considerations

The person with dementia and BPSD

Holistic perspective of health

- Depending on their cultural and spiritual perspectives, people 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.

Cultural and historical considerations

- Be aware of the potential influence culture and migration experiences can have on the course of dementia and the manifestation of BPSD.
- Gather information about the older person's life history, including their migrant and settlement experiences.
- A lack of knowledge and understanding of these aspects in carers and service providers 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 because of their refugee, refugee-like or a war survivor's history and impact in later life.

The carer and carer relationship

The effect of other people on the person with dementia and the way the changed behaviour and symptoms of the person with dementia affects others will, in turn influence BPSD. Factors relating to care partners, care staff, clinicians and/or family members include their:

- knowledge, skills, experience, understanding and training in dementia
- Aboriginal and/or Torres Strait Islander or CALD background
- knowledge of, and history with, the person with dementia
- general emotional and physical health
- informal and formal supports as well as services received
- attitude and empathy
- communication and approach toward the person with dementia
- stress levels
- other demands on them, and
- 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 *community* is typically not limited to family/blood connections but may include wider kinship.
- The leadership responsibilities of older Aboriginal and Torres Strait Islander people can come with a heavy workload.

Aboriginal and Torres Strait Islander considerations

- Home visits to an Aboriginal or Torres Strait Islander person with dementia may include many family members; the key person(s) to supply information need(s) to be identified.
- 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 people 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 people with dementia, with the entire family sometimes being involved. However, the decision-making role may not necessarily be undertaken by a primary carer.
- An awareness of the multiplicity of carers and decision-makers is important 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 people 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 changed behaviours or psychological symptoms by keeping them involved throughout the process.
- Providing information/education for carers around potential triggers for BPSD may reduce unintentional effects on the person with dementia.

The care environment

The care environment includes the interconnected physical, social and cultural dimensions in which care is provided.

Physical factors

The physical and sensory environment is well documented as a contributing factor in BPSD. It includes a diverse range of elements including noise, access to outdoors, safety, security, glare, lighting, layout, size, furnishings, space for wandering, number of people, traffic through the area and time of day. Observation and discussion with the person's support network will provide opportunities to uncover elements of the physical environment which are disorienting, limiting, unsupportive, confusing, not enabling, over stimulating, under stimulating and/or impacting on the person with dementia in some way.

Social and cultural factors

The social and cultural dimension of the care environment comprises all people who come into contact and interact with the person with dementia as well as the shared values and practices of the group(s) in the person's immediate environment. A lack of culturally competent staff and/or cultural, spiritual and social needs not integrated into care can contribute to BPSD.

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 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 residential aged care services (RACS), have historically been seen as places to die and not places of healing.
- 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 effective 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, admission to an ethno-specific RACS should be sought before accepting a place in a mainstream facility.
- As this is often not possible, mainstream RACS staff must 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 community, hospital 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.
- Identify whether a RACS has bilingual staff and other residents who speak the same language (and dialect) as the person with dementia.
- Be aware of the potential for racism from the person with dementia directed toward workers and vice versa in all 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 help to identify factors which separately or collectively suggest potential causes of the BPSD and provide a basis for a behaviour support plan and possible interventions.

Behaviour support plan

A behaviour support plan, based on analysis of the assessment, should be prepared in partnership with carers to ensure their cooperation and understanding. The aim of a behaviour support plan is to eliminate the inappropriate use of restrictive practices in aged care. It is important for behaviour support plans to include best practice support strategies, be responsive to *individual's* needs, and provide individualised support. Dementia Support Australia (DSA) offers resources and templates to assist in the development of a behaviour support plan. This should consider the following elements:

- a description of the changed behaviour or psychological symptom for which the person needs support
- baseline measurement of BPSD frequency and severity
- any urgent actions implemented after the initial risk assessment
- possible precipitating factors
- details of strategies/interventions previously trialled
- aspects of care, treatment, daily routine, environment and carer relationships relevant to providing support
- resources, steps, strategies and changes necessary to implement the plan
- details of who has provided consent where required
- timetable and milestones for implementation
- tools for monitoring and evaluating the BPSD as well as changes and outcomes of interventions
- date for review

Planning and communicating the intervention

- Involve care staff and family in developing and tailoring 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 with dementia.

Review and evaluation

Schedule follow-ups, reviews and evaluations of the effectiveness of the intervention for the person, staff and/or family. Monitor the situation so interventions can be adjusted as needed.

Part 4A of the Quality of Care Principles 2014 set out the requirements that must be met for the use of restrictive practices in residential aged care settings. These specific requirements do not apply to aged care services delivered in a home or community setting. However, under 15NB(2A)78, a provider of services delivered in home or community settings must meet certain requirements for the use of a restrictive practice. See the Aged Care Quality and Safety Commission website for more information.

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:
    - the person living with dementia
    - the changed behaviour(s) or psychological symptom(s): details, frequency, severity, precursors and sequelae
    - the care partner/care staff
    - the care environment
3. checked for, and addressed, reversible causes of the changed behaviour and/or psychological symptom.

Module 2: General BPSD

Key messages

- Behaviours and psychological symptoms associated with dementia (BPSD) impact significantly on the person living with dementia, and their care network.
- BPSD can manifest as changes to perception, thought content, mood and/or behaviour.
- BPSD occur in all care settings with prevalence rates reportedly ranging between 56% and 90%.
- 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.
- Ethical considerations, in particular the well-being of the individual person, should be a primary consideration.
- Psychosocial, environmental, pharmacological and biological interventions for addressing BPSD are not mutually exclusive.
- Potential side-effects must be carefully weighed against potential benefits to the person when considering pharmacological interventions for addressing BPSD.
- Pain and trauma can affect the presentation of BPSD and must be considered in the approach to treatment.
- Restrictive practices, including chemical restraints, must only be used as a last resort, for as short a time as possible, and after all legislative requirements have been met.
- Monitoring and evaluating the impact of an intervention is an integral part of addressing BPSD.

General BPSD

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

- Behaviours and psychological symptoms associated with dementia (BPSD) are defined as symptoms of disturbed perception, thought content, mood, behaviour frequently occurring in people living with dementia.
- BPSD are also commonly referred to as behaviours of concern, responsive behaviours, challenging behaviours and non-cognitive or neuropsychiatric symptoms of dementia.
- The most common BPSD are included in this *Field Guide:* aggression, agitation, anxiety, apathy, delusions and hallucinations, depression, disinhibition, nocturnal disruption, vocal disruption and wandering.
- BPSD occur at different levels of severity with the stages of disease progression. A wide range of symptoms and severity are encompassed by the term BPSD.

Prevalence of General BPSD

- Reported prevalence rates of changed behaviours and psychological symptoms range between 56% and 90%.
- BPSD occur in community, hospital and RACS however, they tend to occur more frequently in residential care.
- The prevalence of dementia in Aboriginal and Torres Strait Islander people in some areas is reportedly three to five times higher than that of the general population, suggesting the potential for high rates of BPSD.
- The culturally and linguistically diverse (CALD) population is ageing at a greater rate than mainstream communities; their prevalence of dementia is predicted to rise significantly.
- The most frequently occurring BPSD are apathy,

depression and anxiety although individual BPSD fluctuate over time, with many occurring episodically.

Effects of General BPSD

- BPSD impacts significantly on the person living with dementia and their carer(s).
- The quality of life of the person with dementia can change considerably, particularly during relocation to a residential aged care home.
- Pain and other unmet physical and/or psychosocial needs may provoke BPSD.
- BPSD contribute to stress and burn-out of residential care staff, particularly where support from management is lacking.
- The degree of carer burden can impact significantly on their ability to address BPSD.

Differential diagnosis

It is important for clinicians to distinguish between BPSD and delirium for appropriate treatment options to be implemented. Delirium superimposed on dementia is often under- recognised. Delirium can be identified by an abrupt onset of behaviour which is out of character for the person with 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 under-recognised, unrecognised and under-diagnosed pain and the risk increases with dementia severity as the capacity for self-report diminishes.
- Poorly managed 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 the Pain Assessment in Advanced Dementia Scale (PAINAD), Pain Assessment Checklist for seniors with Limited Ability to Communicate (PACSLAC) and the Abbey Pain Scale.

The potential impact of trauma on BPSD

Many people with dementia have experienced trauma, grief and loss in their life. Knowing how trauma affects the person can assist in understanding their needs and the impact on the presentation of BPSD.

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).

Addressing BPSD

- The treatment of BPSD can include psychosocial, environmental, pharmacological and/or biological interventions. These are not mutually exclusive.
- Unless the person with dementia is very distressed or at risk of harm to themselves or others, introduce psychosocial methods first and attend to environmental contributors to the BPSD.
- Individually tailor interventions to the person and monitor symptoms for a suitable period before considering pharmacological therapy, as symptoms may resolve spontaneously or in response to psychosocial interventions.

Adverse effects of psychotropic medications

The use of psychotropic medications, particularly antipsychotics, in dementia has been associated with higher risk of functional and cognitive decline as well as serious adverse effects. Their use should be reserved for severe symptoms that are unresponsive to nonpharmacological strategies. *See Table 2.1* for further information.

Restrictive practices and BPSD

A restrictive practice restricts a person's rights or freedom of movement for the primary purpose of influencing their behaviour. People with dementia are reported as being more likely to be subjected to the inappropriate use of restrictive practices. Serious adverse physical and psychological outcomes have been associated with restrictive practices, including the death of residents in residential aged care homes.

Circumstances may occur where a restrictive practice is considered necessary as a last resort measure to protect the health, safety, and dignity of the person with dementia or others. By implementing strategies to prevent or reduce BPSD, including through comprehensive risk assessment, the inappropriate use of restrictive practices can be minimised.

Limitations

Limitations in the methodology of the studies included in this review inevitably affect the validity of the outcomes reported. Difficulties arise when studies treat BPSD as a homogenous group and individual behaviours are not reported separately. Few studies examine the long-term maintenance of benefits after interventions ceased.

Conclusions/Principles of care

- Thorough assessment of the person (including physical health), the interpersonal and physical environment as well as details of BPSD are essential to uncover the factors that may be contributing to BPSD, and potential interventions.
- The number, quality and complexity of studies investigating interventions to address BPSD, particularly psychosocial and environmental approaches, have increased substantially since 2012.
- Research findings suggest that interventions have a limited effect when applied as a generic treatment for general BPSD, largely attributed to the diverse aetiology and types of BPSD.
- Person- and behaviour-specific interventions that are tailored to individual situations tend to be the most effective and are recommended; an intervention may be effective in one set of circumstances and not in another.
- Potential side-effects and drug interactions need to be carefully weighed against the potential benefits to the individual person with dementia when considering pharmacological interventions for addressing BPSD.

Table 2.1 Side effects of antipsychotics/neuroleptics

Drug	Extra-pyramidal effects	Prolactin	Anti-cholinergic effects	Seizure risk	Ortho-stasis	Weight gain	Sedation	Haemato-logical effects	Elevated blood sugar	Elevated cholesterol
Clozapine	0	0	+++	+++	+++	+++	+++	+++	+	+
Risperidone	0/++	0/++	+	+	++	+	+	0	0	0
Olanzapine	0/+	0	++	+	++	++	++	0	+	+
Quetiapine	0/+	0	+	+	+	+	++	0	+	+
Ziprasidone	0/+	0/+	+	+	+	?	+	0	+	+
Aripiprazole	0/+	0	+	+	+	+	+	0	+	+
Amisulpride	0/+	0	+	0	+	+	+	0	0	0
Haloperidol	+++	+	0/+	+	+	+	+/++	+	+	0

Pimavanserin and Brexpiprazole are omitted from this table. Pimavanserin was voted by FDA committee (17/6/2022) as not demonstrating "substantial evidence for the effectiveness … for the treatment of hallucinations and delusions associated with Alzheimer's disease". Pimavanserin can cause prolongation of QT interval which can be associated with cardiac arrhythmias and, as with other antipsychotics, it carries a black box warning of increased risk of death (Schneider 2022; https://doi.org/10.1176/appi.ajp.20220519). Brexpiprazole carried similar warnings about increased risk of death (FDA Briefing Document, NDA 205422/S-009, 14th April 2023)

Key

0	no effect
+	present
++	present and major side effect
+++	present and very important side effect

Module 3: Aggression

Key messages

- Aggression in dementia is characterised by physically and/or verbally threatening behaviours directed at people, objects or self.
- Aggression can arise from underlying depression, psychotic symptoms and/or unmet needs such as pain and constipation.
- The prevalence of verbal and/or physical aggression reportedly ranges from 20% to 30% in those with dementia living in the community and from 6% to 95% in residential care.
- Harm to the person with dementia or others and the inappropriate use of restrictive practices can be serious consequences of aggression.
- The crucial task for the clinician is to attempt to understand what is underlying the aggression for the individual with dementia and to address the cause.
- Individualised psychosocial interventions are recommended as the first line approach although the scientific evidence is limited.
- Intervention trials which report combined agitation-aggression outcomes limit the generalisability of findings for aggression alone.
- Pain management should be considered as there is some support for the benefit of analgesic medication.
- Expert consensus guidelines recommend short term use of atypical antipsychotics for physical aggression where necessary for safety.

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 may be a form of communication and/or a manifestation of unmet needs such as poorly managed pain, constipation, illness, infection and loneliness.
- Underlying depression, psychotic symptoms and/or environmental stressors can also give rise to aggression in people living with dementia.
- People with lived experience of dementia have said that aggression may stem from confusion, frustration, insecurity, self-loathing and/or fear.

Differential diagnosis

Aggression can present independently or with agitation. It is also strongly associated with depression and psychosis. Aggression should be differentiated from delirium.

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

The prevalence of aggression reportedly ranges from 20% to 30% of people with dementia living in the community and from 6% to 95% of those living in residential aged care homes. The frequency of aggression tends to increase as dementia progresses and functioning declines, until the later stages when it typically declines. Prevalence also varies with dementia types.

Effects of aggression

Aggression is associated with considerable carer burden and stress, reduced quality of life and earlier admission to residential aged care. Although not common, harm to the person with dementia or others can be a serious consequence, as can the inappropriate use of restrictive practices.

Addressing aggression

- The crucial task for the clinician is to attempt to understand what is the underlying reason for, or communication behind, the aggression.
- Episodes of aggression may be associated with underlying physical symptoms, pain, discomfort, medication effects or specific environmental stimuli.
- Interventions targeting the cause will likely assist in avoiding or reducing aggression.

- 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

- Psychosocial and environmental intervention studies were primarily conducted in residential settings.
- Limited evidence of a decrease in number of episodes of physical aggression was demonstrated for environmental modifications.
- No benefit was found for humour therapy, aromatherapy or care-staff education.
- Individualised, person-centred care based on psychosocial interventions are recommended as a first line approach unless urgent action is required for safety.
- The lack of scientific evidence for psychosocial interventions should not prevent clinicians considering non-drug interventions on an individual basis.

Biological and pharmacological interventions

- Although the adverse effects of pharmacological interventions raise concerns, particularly 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, expert consensus guidelines recommend short-term use of atypical antipsychotics although evidence to support their use is limited. Risperidone is the only antipsychotic approved by the Australian Government Pharmaceutical Benefits Scheme (PBS) for this use.
- Some evidence of effect in reducing aggression was reported for analgesic medications and dextromethorphan-quinidine.

- No benefit was found for cholinesterase inhibitors (ChEIs) or antidepressants.

Limitations

Limited intervention studies were reported for aggression although aggression is often not the primary outcome of the studies. Some intervention trials report combined agitation/aggression outcomes only, which limits the generalisability of findings. Few studies examined the long-term sustainability of benefits after interventions ceased.

Conclusions/Principles of care

- Aggression can have serious consequences for the person living with dementia and others around them.
- The anxiety and fear generated in others by the unpredictability of aggression tends to isolate the person with dementia.
- Individualised psychosocial interventions are recommended as the first line intervention, although the evidence is limited.
- Effective pain management should always be considered.
- Where necessary for safety, expert consensus guidelines recommend the short-term use of atypical antipsychotics for aggression, that is not due to underlying anxiety or depression.

Bob‘s story

Presentation

Bob is a 78 year-old man who has lived in residential care for 6 months. He was widowed some years ago but he has a caring family who visit regularly. Prior to moving into the aged care home Bob lived alone. He frequently expresses his frustration at sharing ‘his home’ with so many other people. At times he has become verbally aggressive with staff and other residents. Some staff are aware of Bob's frustrations and the early indicators of his distress. These staff members are usually able to diffuse these situations before they escalate.

A resident who has recently been admitted to the aged care home is often very talkative. On one occasion when this resident was talking continuously, Bob slapped his hand over their mouth and said, "Would you just shut up?". In response the resident hit out at Bob who then grabbed them by the shirt and pushed them into the closest chair. At this point the other resident was yelling and others nearby were visibly distressed. Bob stormed off, cursing loudly.

Assessment

To reduce the escalating aggression that is placing Bob and others at risk, potentially contributing factors must be identified:

- overstimulation (noise, people, activities)
- reduced threshold for coping with stress due to dementia
- pain/discomfort/illness/infection/constipation
- medication review: interactions, dosage, recently prescribed, adverse effects
- lack of attention to Bob's nonverbal communication
- others expecting too much of him and Bob trying to overextend his capabilities
- altered routines, introduction of new staff, particular staff and/or family members

- unfamiliar/altered/deprived physical environment
- exclude underlying depressive and psychotic symptoms

Assessing the situation:

- Encourage Bob to express his needs as far as he is able.
- Directly observe what may specifically trigger the aggression.
- Ask staff who know Bob quite well if they can assist in identifying his needs or reasons for his aggression.
- Consult Bob'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 potential triggers.
- Consult close family members to identify possible triggers for the aggression which may be unknown to staff or not previously documented.
- Is pharmacological intervention indicated and/or appropriate for treatment of the aggression?

Strategies/outcomes

- Bob's frustration appears to be related to his inability to express his discomfort, around overstimulating aspects of his environment, in an appropriate manner. This is likely contributing to the aggressive outbursts. Investigate if Bob has some favourite, soothing music which helps him to relax before his discomfort escalates.

- Some staff members reported that Bob can become anxious and more confused when there is a lot of activity happening around him and staff are busy.
- Staff identified that Bob has become increasingly socially isolated since his admission to residential care yet he was previously outgoing and enjoyed the company of friends. He is further isolated because other residents and some staff are fearful of his outbursts.
- Inservice training sessions with role plays were held to refresh staff knowledge of risk assessment and de-escalation techniques.
- Several team meetings were arranged to include all relevant staff members and raise awareness of Bob's subtle, nonverbal signs which may indicate escalating anxiety and/or frustration. This enabled staff to recognise the signs more consistently and more effectively deescalate situations before Bob became aggressive.
- Consultation with family members identified activities that Bob previously found relaxing and pleasant such as gardening and playing cards. Family also provided some of his favourite music.
- Bob's visitors were encouraged to sit with him in quiet spaces or outdoors.

- A trial of small group activities conducted away from the main living area of the aged care home was somewhat effective.
- Seating arrangements in the dining room were changed so Bob was able to eat his meals with less talkative residents.
- Bob was assisted to participate in gardening in the aged care home raised garden bed and while he was physically limited in what he could do, he apparently enjoyed being around the garden.
- Bob’s aggression was not eliminated, however follow up assessment indicated that instances were markedly reduced and staff members were better able to address episodes when they occurred.

Module 4: Agitation

Key messages

- Agitation in dementia presents as emotional distress with observable, non-specific, restless behaviours that are excessive, inappropriate and repetitive.
- Agitation occurs as a product of the interaction between the *individual* person and environmental factors.
- Symptoms of agitation can overlap with aggression and delirium which can lead to misdiagnosis.
- Agitation is one of the most common BPSD, with prevalence rates ranging from 30%-80% according to care setting and 22%-50% according to dementia type.
- Agitation is associated with poorer quality of life, an increase in the inappropriate use of restrictive practices and greater burden on carers.
- Individualised psychosocial interventions are recommended as a first-line approach and short-term pharmacological interventions only when necessary.
- Multicomponent interventions provide the best psychosocial evidence.
- Where pharmacological/biological interventions are indicated and other strategies have been unsuccessful, rivastigmine, galantamine or light exposure may warrant a trial, although results were mixed.
- Some evidence is reported for atypical antipsychotics however, these are not recommended due to safety concerns.
- Expert consensus guidelines recommend multidisciplinary, individualised and multifaceted care.

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. It may present as:

- irritability and disruptive vocalisations
- aberrant motor activities such as excessive restlessness and/or pacing
- observed or inferred emotional distress and/or
- excessive negative physical actions directed at objects, self, or others

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

Causes of agitation
Agitation occurs as a product of the interaction between individual and environmental factors:

- cognitive impairment and neurobiological changes intrinsic to dementia such as neurofibrillary tangle burden and neurotransmitter systems
- biological causes extrinsic to dementia including unmet care needs, pain, medical comorbidities and drug effects indicated by evidence of emotional distress
- unmet biopsychosocial needs such as social isolation as well as impairment in interpersonal relationships and daily functioning
- feelings of fatigue, anxiety, frustration and loss of independence not solely due to other comorbidities

Differential diagnosis

Symptoms of agitation in dementia can overlap with aggression. Hyperactive delirium can be misdiagnosed as agitation and both can arise from potentially reversible organic factors. Comprehensive assessment is required to differentiate between these conditions, identify underlying issues and develop appropriate strategies to address agitation.

Measuring agitation

Current guidelines recommend the use of the Cohen-Mansfield Agitation Inventory (CMAI), the Pittsburgh Agitation Scale (PAS) as well as the Agitation/Aggression and Aberrant Motor Behaviour subscales of the Neuropsychiatric Inventory (NPI) and the Agitation subscale of the NPI-Clinician (NPI-C). Other commonly used instruments include the NPI-Questionnaire (NPI-Q), Agitated Behaviour Mapping Instrument (ABMI), the Brief Agitation Rating Scale (BARS) and the Excited Component of the Positive and Negative Syndrome Scale (PANSS-EC).

Prevalence of agitation

- Agitation is one of the most commonly occurring BPSD, with an average prevalence of 30%-80% according to care setting and 22%-50% according to dementia type.
- Highest rates are reported for Alzheimer’s disease (AD) and vascular dementia (VaD).
- Not all instances are clinically significant.
- Prevalence rates vary depending on the different definitions of agitation and the instrument used to measure agitation.
- Increased agitation has been associated with faster rate of cognitive and functional decline and poorer activities of daily living (ADL) functioning.

Effects of agitation

Agitation is associated with poorer health-related quality of life for the person with dementia, an increase in the inappropriate use of restrictive practices, including medications, and premature admission to residential aged care services (RACS). Agitation results in greater burden on care partners and family as well as in-home, community, acute and RACS staff.

Addressing agitation

Potential triggers and/or underlying causes behind the agitation for the individual with dementia should be identified where possible. Where the person with dementia and/or others are not at risk and reversible causes have been eliminated, consider psychosocial and/or environmental interventions as a first option.

Psychosocial and environmental interventions

- 64 studies met our inclusion criteria.
- Psychosocial intervention studies were primarily conducted in residential settings.
- Multicomponent interventions provided the best psychosocial evidence for reducing agitation.
- Education/training interventions incorporated the greatest number of studies and the highest number of strong quality studies however, the majority reported negative outcomes.
- Cognitive rehabilitation/stimulation and reminiscence interventions provided no evidence of benefit.
- Effective interventions should be beneficial to the individual, enjoyable, respectful, culturally appropriate and culturally safe.

Biological and pharmacological interventions

- 20 studies met our inclusion criteria.
- Pharmacological interventions should only be used as a second-line approach in addressing agitation.
- Risk/benefit ratios for the individual person with dementia must be considered.
- Biological and pharmacological intervention studies were conducted in community/outpatient, residential aged

care and inpatient hospital settings.

- The cholinesterase inhibitors (ChEIs) and/or memantine, atypical antipsychotics, tetrahydrocannabinol (THC)/ cannabinoids and brain stimulation categories included four studies each.
- All categories provided some evidence of, at least, limited benefit although adverse effects raise concerns with their use.
- Where pharmacological/biological interventions are indicated and other strategies have been unsuccessful, rivastigmine, galantamine or light exposure may warrant a trial, although results were mixed.
- Although only one trial of analgesic medication was reported and showed benefit, pain management should always be considered.
- Some evidence was demonstrated for atypical antipsychotics however, current guidelines do not recommend their use due to the associated risks.
- The evidence reported for cannabinoids, citalopram and dextromethorphan/quinidine is too limited for recommendations to be made.

Limitations

Many studies have methodological and sampling issues which impact on the outcomes and/or potentially limit the generalisability of results. A definitive diagnosis of agitation in dementia can be difficult due to overlapping symptoms of aggression, sundowning and other BPSD. Limited evidence of sustainability of effects is available as only one study assessed long-term outcomes and five reported short-term outcomes.

Conclusions/Principles of care

Expert consensus guidelines recommend multidisciplinary, individualised and multifaceted care, including individualised psychosocial interventions as a first-line approach when addressing agitation in dementia and short-term pharmacological intervention only when necessary.

Kirra‘s story

Presentation

Kirra is a 70 year-old Aboriginal man from a regional town on the NSW north coast. He is dependent on his daughters for many of his care needs. To provide some respite for his family and hopefully provide him with additional company and quality time, Kirra has recently started attending a day respite service.

He is wary of care staff, particularly those who are from non-Aboriginal or Torres Strait Islander backgrounds. During group activities Kirra often leaves the group and walks around the centre, touching items belonging to other attendees and artwork on the walls. The situation can quickly become risky when Kirra intrudes into the personal space of some of the other attendees and they become angry. Kirra’s reaction is to become increasingly agitated and, at times, verbally aggressive. If anyone approaches Kirra at this point, he can become combative and the situation continues to escalate.

Kirra’s daughters report that he is increasingly reverting to his Indigenous language which limits Kirra’s communication with some of his family and the day centre staff. His increasing frustration with being unable to communicate with staff and other centre attendees also prompts agitation. At times he has become agitated to the point where he attempted to leave the day respite centre, increasing the risk to his safety.

Assessment

To reduce the presenting agitation that may be placing Kirra and others at risk, potentially contributing factors must be identified:

- chronic or acute pain/discomfort/illness/infection
- medication interactions, dosage, adverse effects, recently prescribed
- exclude underlying depressive and psychotic symptoms
- overstimulation (noise, people, activities)
- lack of attention to culturally-relevant needs and historical trauma
- others expecting too much of him and Kirra trying to overextend his capabilities
- altered routines, new staff, particular staff or family
- unfamiliar/altered/deprived physical environment
- stopping Kirra from what he is doing or wanting to do
- reduced threshold for coping with stress

Assessing the situation:

- Encourage Kirra to express his needs as far he is able.
- Directly observe what may trigger the agitation.
- Ask staff who have got to know Kirra if they can assist in identifying unmet needs, or possible reasons for his agitation.

- Consult Kirra's life history as well as behaviour charts for further information with regard to triggers for his agitation.
- Assess the immediate environment for possible triggers.
- Consult close family members to identify possible triggers for the agitation that may be unknown to day centre staff and not previously documented.
- Are pharmacological interventions indicated and/or appropriate for addressing the agitation?

Strategies/outcomes

- Any one of Kirra's 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.
- When family provided relevant details of Kirra'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 Kirra, for part of the day, to assist in his adjustment to the unfamiliar environment.
- Visual resources and pictorial language aids were developed and/or sourced with the

assistance of community members familiar with Kirra's language. Attempts to locate a language-appropriate interpreter were unsuccessful.

- An older Aboriginal man who is a nearby neighbour to the respite centre was originally from the same Country as Kirra and he had some knowledge of his language. He was willing to assist with communication when he was available and regularly spend some time yarning with Kirra.
- Some staff members at the respite centre had little knowledge of dementia, BPSD and/or trauma-informed care. They became fearful of Kirra, unsure when he may become agitated.
- Education was provided to improve the care and support of clients with dementia as well as increase staff members' confidence to effectively fulfil their role.
- The respite centre was located on different Country to Kirra's own, causing him distress when he forgot that he would be returning home later in the day. With a better understanding of dementia, staff at the centre were able to more effectively provide Kirra with regular reassurance.
- Limited experience and knowledge of dementia and BPSD within Kirra's extended family and community was increasing his daughters' stress and isolation. Local Aboriginal services visited the community to raise awareness of dementia and provide

culturally-appropriate education and information on BPSD.

- Family assisted the respite centre staff to plan appropriate activities, relevant to Kirra's interests and background. Kirra had previously been a keen painter and he responded positively to staff providing large sheets of paper and safe art materials for new paintings.
- Kirra's daughter brought one of her father's earlier artworks to hang in the day centre. These strategies provided staff with opportunities to interact positively and meaningfully with Kirra as well as praise his work.
- The frequency and severity of Kirra's agitated episodes reduced. Staff and family agreed that he was largely enjoying his time at the centre. Kirra's daughters benefitted from the regular respite and were relieved that he was now willing to attend without resistance. Staff reported improved confidence in their capacity to de-escalate Kirra's agitation when they observed the early signs of his distress.

Module 5: Anxiety

Key messages

- Anxiety in dementia presents with thoughts of worry, emotions such as fearfulness, physical sensations associated with autonomic hyperactivity and behaviours such as avoidance and restlessness.
- Anxiety is one of the most disabling and commonly occurring psychological symptoms associated with dementia.
- Where anxiety is secondary to another psychological disturbance in dementia the primary problem should be treated.
- Music interventions provide the best psychosocial evidence for anxiety in dementia.
- Selected reminiscence-based interventions, multicomponent interventions and sensory interventions were also beneficial.
- A multidisciplinary, individualised and multifaceted approach is recommended.
- Evidence of benefit for pharmacological and biological interventions is lacking.
- Where symptomatic pharmacological agents are prescribed to address anxiety, these should be time limited, closely monitored, reviewed, reduced and/or discontinued when indicated and used with appropriate psychosocial interventions.

Anxiety

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

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 and/or other pain, insomnia and/or palpitations associated with autonomic hyperactivity
- perceived need to seek help, flee, fight, or freeze, and
- manifested actions such as hand wringing, pacing or other repetitive activities

Anxiety can become exacerbated to the point of phobias and panic attacks.

Causes of anxiety

Higher rates of anxiety in those with dementia have been associated with unmet needs, pain, mental health, and social and psychological needs, including lack of company and daytime activities as well as staff competence to provide care. Anxiety can occur in response to the person with dementia's reduced capacity to make sense of and efficiently navigate their environment.

A person with dementia may experience an exaggerated anxiety response around changes to a familiar routine or environment, separation from their primary carer, being rushed, overstimulation and/or fatigue. People with lived experience of dementia have said that anxiety may stem from worry over making errors, failing, forgetting, not recognising people, not following conversations, and not finding a toilet in time.

Differential diagnosis

The 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, agitation, and aggression. The presence of anxiety can be difficult to establish when the person with dementia has difficulty expressing themselves, due to impaired language.

Measuring anxiety

Scales most commonly used to measure anxiety in dementia are the Rating Anxiety in Dementia (RAID) scale, the anxiety subscale of the Neuropsychiatric Inventory (NPI) or the NPI-Clinician (NPI-C), the anxieties and phobias subscale of the Behavioral Pathology in Alzheimer's Disease Scale (BEHAVE-AD), the Hamilton Anxiety Rating Scale (HAM-A) and the Geriatric Anxiety Inventory (GAI).

Prevalence of anxiety

- Anxiety is one of the most commonly occurring psychological symptoms associated with dementia, reported as a symptom in 13% to 67% of people with dementia and as a disorder in 5% to 31%.
- Higher rates of anxiety are associated with greater cognitive impairment in older people living in the community and associated with better cognition in aged care settings.
- The incidence of clinically relevant anxiety is higher in those with Alzheimer's disease (AD) than in those with vascular dementia (VaD) and other dementia types.

Effects of anxiety

- Anxiety is linked to earlier residential care admission, other BPSD, overestimation of dementia severity and impaired functioning as well as poor quality of life.
- Excess anxiety may lead to the person with dementia *shadowing* helpers, seeking reassurance as well as

constantly searching for carers, companionship and/or assistance.

- Anxiety can contribute to a higher carer burden due to increased dependence.

Addressing anxiety

Individual antecedents for anxiety, where identifiable, should be considered before addressing symptoms. Where the antecedents and frustrations for the *individual* person with dementia can be identified, minimised and/or avoided, anxiety may be reduced or prevented. Keeping the environment uncomplicated, maintaining structure and routine, reducing the need to make decisions, avoiding overstimulation, providing opportunities to succeed and reinforcing retained skills may help to support the person to experience fewer and less severe symptoms.

Psychosocial and environmental interventions

- Psychosocial intervention trials were conducted in residential aged care, community and hospital settings.
- Music therapy and reminiscence-based interventions provided the best psychosocial evidence. Interventions included listening/playing music, active music, individual autobiographical sessions and a reminiscence-based personalised computer app.
- Therapeutic recreation and multicomponent interventions provided the best evidence for addressing anxiety in hospital and community settings. These included board games, small group singing, painting and a multicomponent intervention combining socialisation, cognitive stimulation and physical activity.

Biological and pharmacological interventions

- Evidence for pharmacological/biological intervention studies is lacking and no studies met our criteria for inclusion here. Refer to Principles of care for guidance.
- Where symptomatic, pharmacological agents are

prescribed for anxiety, these should be time limited, closely monitored, reviewed, reduced and/or discontinued when indicated and always prescribed in combination with appropriate psychosocial interventions.

Limitations

There is limited sound research to guide clinicians and carers in addressing anxiety in people with dementia. Diagnosis of anxiety in dementia can also be difficult due to underlying symptoms of depression, agitation and/or aggression. Few trials investigated the long-term effects of reported interventions.

Conclusions/Principles of care

- Recognised expert guidelines are limited for addressing anxiety in dementia.
- Music therapy, reminiscence, therapeutic recreation and multicomponent interventions provide the best psychosocial evidence.
- Environmental factors may also have a part.
- Evidence of benefit for pharmacological and biological interventions to address anxiety is lacking.
- A multifaceted, person-centred and trauma-informed approach to addressing anxiety is recommended.

Quang‘s story

Presentation

Quang is 80 years old. He migrated to Australia after the Vietnam war under the Family Reunion Scheme and now lives with three generations of his family. When he moved in with the family 6 months ago, they noticed that Quang had some cognitive difficulties. The longer he stayed with them, the more his daughter became aware of his functional deficits. This ultimately led to the local general practitioner (GP) making a diagnosis of Alzheimer's dementia and starting Quang on a cholinesterase inhibitor (ChEI).

Extended family members live in the same street and visit socially but they do not provide care. Quang does not speak, read or write English. Quang's daughter is his primary carer and over past months she has become increasingly concerned about her father's obvious anxiety. Quang reportedly has strong spiritual beliefs but since he has become restless and disruptive during church services, he no longer attends with the family.

A culturally specific in-home community 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 embarrassed and concerned that others will think their father is "crazy".

Assessment

To reduce Quang's presenting symptoms of anxiety, potentially contributing factors must be identified:

- illness/infection/discomfort/pain
- treat or exclude underlying depression where indicated
- medication review: interactions, dosage, adverse effects, recently prescribed
- lack of attention to culturally-relevant needs
- unfamiliar or altered physical environment

- unrealistic expectations of others causing Quang to try to overextend his capabilities

Assessing the situation

- Encourage Quang to report his concerns as far as he is able.
- Directly observe for any environmental aspects or triggers that may contribute to the symptoms.
- Ask Quang's family to keep a record of times (when? how long?) and events (if any) leading up to episodes of anxiety.
- With the family's consent, communicate with staff from the recently ceased community service as to any incidents that provoked Quang's anxiety.
- Consult Quang's family regarding his life history and for further information around potentially relevant factors such as war experiences or historical trauma.
- Consult close family members to identify possible triggers for the symptoms.
- Is trialling pharmacological interventions indicated and/or appropriate for addressing Quang's anxiety?

Strategies/outcomes

- It is important to establish who is able to provide information on Quang's behalf and who is the main decision maker within the family. Communication should be directed to the main person with the understanding that the family must be 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 being unable to cope with their father's care needs which could result in him being removed from the family home. The family was assured that services are available to support them to continue to care for Quang at home.
- Quang's granddaughter is the only family member who speaks English. Access to an interpreter who speaks the same dialect as Quang and his family was offered, where appropriate.
- Quang'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 Quang.
- Information about dementia and BPSD was provided in Vietnamese. The information in written or electronic 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 with the ChEI as they are unfamiliar with western medical practices. Quang's doctor

was informed that he was no longer taking the prescribed medication.

- The family was provided with additional information in Vietnamese around the purpose and potential benefits of the ChEI. Quang's daughter also discussed possible benefits of traditional Asian medicines with the GP.
- The family was able to suggest activities that could be encouraged, such as those that Quang previously found pleasurable, engaging, comforting and/or related to his spiritual beliefs and his favourite music.
- Quang's family was provided with strategies to avoid triggering his anxiety and to help ease his symptoms during acute periods of escalation.
- When extended family members were made aware of the situation, they were willing to assist. Quang was able to resume attendance for part of the church service with others helping to supervise him.
- The possibility of Quang attending a CALD day respite centre with others from a Vietnamese background was investigated.

Module 6: Apathy

Key messages

- Apathy is one of the most challenging and prevalent psychological symptoms of dementia.
- It is associated with increased disability and carer frustration as well as reduced quality of life.
- Apathy is significantly related to reduced independence in activities of daily living (ADL) beyond dementia severity, survival duration after admission to residential aged care services (RACS) and poor rehabilitation outcomes.
- Psychosocial interventions have the potential to reduce apathy.
- Tailored interventions, provided individually or in a group, have the best available evidence for effectiveness in dementia.
- The evidence for the efficacy of pharmacotherapy/ biological interventions for apathy in dementia is limited.
- A single trial of donepezil plus choline alphoscerate (a choline containing phospholipid) and one of donepezil plus memantine showed some benefit for apathy.
- Moderate evidence of efficacy was found for methylphenidate, and limited evidence for repetitive transcranial magnetic stimulation (rTMS).
- Acknowledging individuality, personal history and previous interests may guide strategies for apathy.

Apathy

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

- Apathy can describe lack of interest, behavioural inaction and lack of emotion or affect.
- The apathy spectrum includes reduced initiative, interest, motivation, spontaneity, affection, energy, enthusiasm, emotion and persistence as well as blunted affect.
- Apathy in dementia is frequently accompanied by one or more other neuropsychiatric symptoms.
- Emotional distress is typically absent.
- Symptoms should cause clinically significant functional impairment.

Causes of apathy

Apathy is a major clinical feature of dementia with subcortical and frontal pathology such as behavioural variant frontotemporal dementia (bvFTD), dementia with Lewy bodies (DLB/LBD), Huntington's disease (HD) and vascular dementia (VaD). Apathy in Alzheimer's disease (AD) is also related to older age and depression. Apathy can occur in some psychiatric disorders and as a side effect of drugs.

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

Differential diagnosis

Apathy in dementia should be differentiated from depression and from medication effects. Symptoms of apathy should not be attributable to psychiatric illnesses, intellectual disability, physical disabilities, motor disabilities, change in level of consciousness or direct physiological effects of a substance.

Measuring apathy

Scales designed to specifically measure apathy include the Apathy Evaluation Scale (AES), the Apathy Inventory (IA/AI) and the Lille Apathy Rating Scale (LARS). The Neuropsychiatric Inventory (NPI) and the Neuropsychiatric Inventory-Clinician (NPI-C) include an apathy subscale.

Prevalence of apathy

- Apathy occurs in up to 89% of people with dementia.
- Prevalence rates are higher in progressive supranuclear palsy, FTD and AD.
- Apathy typically appears early in dementia and increases with dementia severity. It may fluctuate but typically persists.

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 family carers, with relationships and family life often disrupted.
- Families not recognising an apathetic state may become increasingly resentful as they misperceive the person as lazy and unempathetic.
- 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.

Addressing apathy

Acknowledging individuality, personal history and previous interests may guide individual strategies for engaging those with apathy, as well as variations in response. 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

- Individually tailored interventions for apathy in dementia can be beneficial. These include brain-activating rehabilitation, biographically oriented mobilisation, one-to-one activities, reminiscence with videos, and active traditional/nostalgic music sessions.

- Some positive results were reported for music, physical activity, multi-sensory stimulation, reminiscence, cognitive rehabilitation/stimulation, and multicomponent interventions.
- Interventions with higher levels of support and elements of guided reminiscence and social interaction provide the best evidence of efficacy.

Biological and pharmacological interventions

- Cholinesterase inhibitors (ChEIs) have demonstrated small to medium benefits for apathy; specifically, donepezil in combination with either memantine or choline alphoscerate. There is no clear indication that any one ChEI is superior.
- Good evidence indicates that antidepressants do not significantly improve apathy in people with dementia.
- Moderate evidence has demonstrated efficacy for methylphenidate although side effects may be a concern.
- Limited evidence has been demonstrated for repetitive transcranial magnetic stimulation (rTMS).
- No evidence was found for analgesics, traditional medicines or antipsychotics.

Limitations

Few strong quality studies are available for addressing apathy in dementia. Research into the treatment of apathy is, particularly, hampered by the difficulties of recruiting and retaining study numbers to ensure sufficient power. Further, there is little to no evidence of sustainability of effects after interventions cease.

Many studies treat participants as a homogenous group yet, dementia type and severity likely influence the effectiveness of interventions trialled.

Conclusions/Principles of care

- Psychosocial and environmental interventions are warranted in the treatment of apathy, particularly individually tailored activities.
- Of the pharmacological treatments reviewed, donepezil with or without choline alphoscerate or memantine, and methylphenidate demonstrated moderate evidence of maintaining or improving apathy levels.
- Limited evidence has been reported for repetitive transcranial magnetic stimulation (rTMS).
- Antidepressants and antipsychotic medications are not recommended for apathy in dementia.
- A lack of quality research is not necessarily indicative of a lack of efficacy. Stabilisation of apathy, as dementia progresses, may indicate that the intervention is beneficial even without evidence of improvement.

Francis‘ story

Presentation

Francis has always been active and busy. She enjoyed the demands of her extended family and work life. A diagnosis of younger onset dementia six months ago was devastating for Francis and her wife, Anne but they have been doing their best to meet the challenges as they arise. Recently Francis has had to stop work and Anne has reduced her work hours to spend more time at home. Their children are providing additional support when they can.

Although Francis remains physically well, family have noticed that she no longer starts her day with her usual walk. They often find Francis sitting unoccupied, staring into space. Anne is distressed and frustrated when she arrives home from work to find the lunch she prepared for Francis untouched. Small tasks left for Francis have also not been started.

Francis continues to respond positively to family visits and outings, although not with the same level of enthusiasm, and she will join one of them on a walk. She enjoys chatting with friends when they call but Francis is often unable to answer the calls in time, as she misplaces her phone. When this happens Francis doesn't return their calls. Friends are feeling uncomfortable and unsure of how best to respond to Francis' situation. Family members are concerned that Francis appears to 'do nothing' whenever she is home alone.

Assessment

To address Francis' presenting apathy, potentially contributing factors must be identified:

- pain/discomfort/illness/infection
- medication interactions, dosage, adverse effects, recently prescribed
- impaired hearing and/or eyesight
- exclude underlying depression, grief reaction to the diagnosis
- lack of stimulation
- unfamiliar/altered/deprived physical environment
- reduced ability to initiate activities for herself

- activities offered no longer of interest/ unfamiliar/becoming too difficult

Assessing the situation:

- Encourage Francis to express her interests as far as she is able.
- Directly observe and share Francis' response to activities offered so successful events can be repeated.
- Consider Francis' previous interests for further potentially appropriate activities.
- Ask Anne for feedback re Francis' response to activities after the events.
- Reassure Anne that Francis is not distressed about her inactivity and that apathy is not depression.

Strategies/outcomes

- Francis' care partner, family members and friends are distressed as her quality of life appears to be diminishing quickly. They were provided with information about the changed behaviours and psychological symptoms that frequently occur in dementia, including apathy.
- It was explained that Francis' reduced ability to initiate activities for herself and apparent lack of interest is not necessarily an indication that she does not enjoy the activities offered. They were encouraged to focus on supporting Francis in activities that she was previously particularly invested in or

that were very well practised as these were likely to be the most successful.

- The importance of establishing a routine was discussed as Francis is also adjusting to the change from her structured work life. A defined sequence of events reduced the need for Francis to make decisions or question the situation.
- Family members and friends worked with Anne to develop a roster to provide extra support and encouragement around Francis' routine.
- In-home and community aged care services were investigated for an option to accompany Francis during her walks and/or daytime activities, some days. Anne is aware that additional support from services will be needed in the future, and it could be beneficial to all for Francis to become familiar with the care workers during these pleasant and familiar experiences.
- Francis' friends and family have a better understanding of ways to engage with her and assist her to enjoy activities of interest. They now phone again if Francis doesn't answer their call the first time.

Module 7: Delusions and hallucinations

Key messages

- Psychotic symptoms are delusions and hallucinations which are indicative of a disturbance in the perception and/or recognition of objective reality.
- Prevalence rates in dementia range from 9% to 76%.
- Delusions and hallucinations occur in delirium, schizophrenia and other primary psychotic disorders which must be differentiated from psychosis secondary to dementia.
- Delirium and potentially reversible causes must be excluded.
- At times, the presence of delusions and hallucinations can be more distressing for carers than for the person with dementia.
- Although research evidence is lacking, individualised psychosocial interventions are recommended initially unless symptoms are causing significant distress or safety concerns.
- A lack of evidence should not prevent clinicians from considering culturally appropriate psychosocial approaches on an individual basis, where there is potential for benefit.
- Where pharmacological treatment is indicated, due to significant distress or safety concerns, atypical antipsychotics with appropriate psychosocial interventions may be of benefit.
- Some evidence indicates pain management with analgesic medications may reduce delusions.

Delusions and hallucinations

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

Psychotic symptoms are delusions, which are fixed, false unshakable beliefs not shared by others from that person's culture, and hallucinations which are disturbances in the perception and/or recognition of objective reality. People with dementia may develop psychotic symptoms secondary to brain changes or driven by cognitive decline compromising their ability to process reality logically. Prominent agitation or depressive symptoms can occur with delusions and hallucinations. What are sometimes called delusions or hallucinations may result from the person with dementia misconstruing the environment or interactions of others.

Criteria for psychosis of dementia include symptoms severe enough to disrupt the person's functioning and/or others' functioning or pose a threat to the safety of the person and/or others. Symptoms are not better accounted for by the effects of substances, delirium, another medical condition, primary psychotic disorder or mood disorder and are not considered culturally appropriate.

Causes of delusions and hallucinations

- Interaction of potentially reversible causes include sensory deprivation/impairment, inappropriate sensory stimulation, depression, psychological distress, and iatrogenic causes.
- Delusions and hallucinations can also arise from delirium, substance use and other medical conditions such as infection and/or metabolic, blood, and endocrine disturbance.
- Individual characteristics including age, gender, type of dementia, psychiatric history, age at dementia onset and

illness duration, family history of dementia/psychiatric illness, and genetic mutations can influence the risk of experiencing psychotic symptoms.

Differential diagnosis

Delusions and hallucinations in dementia should be differentiated from schizophrenia or other primary psychotic disorders based on past history of psychosis, content of delusion or hallucination, presence of misidentification phenomena, active suicidal ideation, family history and the dosage and duration of antipsychotic treatment. It is also important to rule out delirium.

Measuring delusions and hallucinations

Psychotic symptoms can be assessed using the delusions and hallucinations subscales of the Neuropsychiatric Inventory (NPI), 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). The clinician-rated Dementia-related Psychosis 3 (DRP3™) brief screening tool may be useful in busy clinical settings.

Prevalence of delusions and hallucinations

Psychotic symptoms occur in 9.2% to 76% of people with Alzheimer's disease (AD). Delusions are the most frequently reported psychotic symptom, followed by hallucinations. Hallucinations are more prevalent in dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD) and are rarely reported in frontotemporal dementia (FTD) or vascular dementia (VaD).

Effects of delusions and hallucinations

Delusions and hallucinations have been associated with more rapid cognitive decline, impaired real-world functioning, lower quality of life, higher risk of comorbid BPSD, earlier admission to residential care, higher healthcare costs and increased carer burden.

Addressing delusions and hallucinations

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. The presence of delusions and hallucinations may be more distressing for carers than for the person with dementia. Those who experience more distressing symptoms, particularly in DLB or PDD, may require more active treatment.

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

Psychosocial and environmental interventions

- Evidence for psychosocial/environmental approaches to addressing delusions and hallucinations is lacking.
- One study of multidisciplinary care in a specialised hospital ward with homelike features, which met our quality criteria, reported a negative outcome.

Biological and pharmacological interventions

- Where psychotic symptoms are a significant concern or safety risk, pharmacological intervention may be indicated as a first-line treatment in combination with psychosocial approaches.
- Intervention studies included atypical antipsychotics, analgesic medications and brain stimulation therapy.
- Findings for atypical antipsychotics were mixed.
- Some evidence was reported for a stepwise pain management protocol in people with dementia, agitation and delusions.
- Where distress or safety is an issue, risperidone is the only antipsychotic medication that is Pharmaceutical Benefits Scheme (PBS) approved for use in BPSD, where nonpharmacological methods have been unsuccessful, for people with dementia in Australia.

- Clinical guidelines recommend consideration of a cholinesterase inhibitor (ChEI) as an alternative treatment for people living with DLB who cannot tolerate antipsychotic medication.

Limitations

Moderate to high quality studies of interventions addressing delusions and hallucinations in dementia are lacking in the literature. Limited evidence is provided of the sustainability of effects after interventions cease. Further, delusions and hallucinations were typically not the primary outcome in the included studies.

Conclusions/Principles of care

- While delusions and hallucinations can have significant consequences for people with dementia and those providing care, they do not always require intervention.
- Expert consensus guidelines recommend the use of individualised, culturally appropriate psychosocial interventions to address delusions and hallucinations.
- Where distress or safety is an issue, short-term pharmacological treatment with antipsychotics may be indicated as a first line approach in combination with psychosocial interventions.
- No studies published since 2012 provided evidence for the efficacy of psychosocial interventions to reduce psychotic symptoms in dementia.
- Effective pain management, including analgesic medication may help to reduce symptoms.

Maria‘s story

Presentation

Maria is an 85 year-old widow who immigrated from Greece to marry at age 18. She has memories of leaving her family to take the long trip to Australia aboard a converted post-war ‘troop ship’. She slept in triple tiered bunks in the large empty hold converted to the women’s quarters. The plain and inadequate food made her feel homesick. Meeting her intended husband for the first time when she landed in Melbourne, learning English and living in a migrant hostel were major changes for Maria.

Maria’s married life presented many challenges as she supported her husband who was ultimately diagnosed with PTSD. Her two daughters remember their father’s explosive outbursts and the times when Maria took them to a neighbour’s home for protection. When Maria developed dementia, her daughters supported her at home until her admission to residential care became necessary as her dementia progressed.

Maria has become increasingly anxious following the death of a resident who previously shared her room. She described visual hallucinations of the resident in her room and delusions of staff attempting to cause her injury. Maria is eating poorly and losing weight due to suspicions that her food is poisoned. Staff members report that she can be uncooperative and resistant, particularly during medication administration and personal care. Maria is becoming increasingly isolated as other residents are frightened by her response to her symptoms and they avoid her. At times she has tried to run away from the facility, which places her in considerable danger.

Assessment

Potentially contributing factors to delusions and hallucinations should be identified. Exclude potentially reversible causes:

- misinterpretation of reality and/or others' intentions
- sensory deprivation/impairment or inappropriate sensory stimulation
- illness/infection/delirium/depression
- pain/discomfort not well managed
- medication review: interactions, dosage, recently prescribed, adverse effects, compliance
- lack of attention to culturally relevant needs
- altered routine, unfamiliar people, reduced time spent with family
- unfamiliar/altered physical environment
- reduced threshold for coping with stress

Assessing the situation:

- Consult family members to identify possible reversible causes for delusions and hallucinations and/or underlying reasons for Maria's distress.
- Has a recent medical review been conducted?
- Encourage Maria to express her concerns as far as she is able.
- Directly observe what may specifically trigger the symptoms.
- Assess the immediate environment for possible triggers.

- Consider Maria's life history and previous experiences of trauma for further information with regard to triggers for the symptoms.
- Are the delusions and/or hallucinations troublesome to Maria? If not, do they need treatment?
- If so, is pharmacological intervention indicated? Is it possible and/or practical?
- What are her family's wishes?

Strategies/outcomes

- Medical review was arranged, including bloods and urine. An interpreter was engaged to assist with a psychogeriatric consult. Underlying depression was excluded.
- Maria suffers from visual impairment due to bilateral cataracts which could potentially contribute to her misinterpretation of items in the environment. The feasibility of cataract surgery was raised with her doctor.
- Family reported distressing situations that Maria experienced in communal living when migrating to Australia by ship and living in a migrant hostel. Maria's initial move to residential care and any subsequent changes to her environment provoke anxiety around her fear of communal living.
- A small night light was provided by the family to assist Maria's orientation if she wakes during the night.
- Some staff members had little knowledge of dementia and they became fearful of Maria

when she tried to describe her symptoms. Staff training sessions in dementia, BPSD and trauma-informed care were provided.

- As Maria is reverting to her first language and her opportunities for formal education as a child were minimal, her ability to communicate her concerns and care needs to staff are increasingly limited. Visual resources and pictorial language aids were developed with the assistance of family.
- A language-appropriate telephone interpreter service was trialled but attempts were largely unsuccessful.
- Maria’s new roommate is a friendly and sociable lady who is settling in well. Maria has responded positively to her company, despite communication limitations.
- Maria’s family continue to visit frequently but they feel she lacks companionship between their visits. A referral was made to Greek-specific services including a request for a Greek-speaking visitor to spend time with Maria each week.
- The frequency of Maria’s delusions and hallucinations decreased over time. With reduced isolation and increased support Maria is less distressed by the symptoms when they do occur. Staff indicate that they feel more skilled in dealing with these situations as they arise. A follow-up psychogeriatric review is scheduled in 2 months.

Module 8: Depression

Key messages

- Symptoms of depression in dementia include unhappiness, irritability, social withdrawal, inactivity, fatigue, tearfulness and loss of interest.
- Depression may be a presenting feature of dementia and it is one of the most challenging psychological symptoms to diagnose and treat.
- Cultural differences and experiences of trauma may influence symptom presentation and manifestation.
- Depression in dementia should be differentiated from apathy, anhedonia, sleep disturbance, quiet delirium and the underlying dementia.
- The prevalence of depressive symptoms in dementia ranges from 10% to 78% and reportedly clusters around 39%.
- Expert consensus and guidelines recommend individualised psychosocial interventions as a first-line approach.
- Music and reminiscence approaches provide the best psychosocial evidence.
- Few studies indicate effective pharmacological treatment and strong evidence demonstrated limited efficacy for antidepressants.
- Three studies provided moderate quality evidence that light therapy techniques outperformed placebo and usual lighting.
- Psychotic depression and suicidal ideation require urgent psychogeriatric review.

Depression

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

- unhappiness
- inactivity
- tearfulness
- loss of interest
- low self-esteem
- hopelessness
- irritability
- social withdrawal
- fatigue
- negativity
- suicidal ideation
- sleep disturbance
- appetite disturbance

Cultural differences as well as past and ongoing experiences of trauma may influence the presentation and manifestation symptoms.

Causes of depression

Degenerative changes in the brain associated with dementia can lead to depression. Previous history or family history of depression as well as personal history of trauma, abuse or adversity may be contributing factors. Depression in the early stages of dementia may be related to awareness of the prognosis associated with diagnosis.

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

Differential diagnosis

It is essential to differentiate depression in dementia from anhedonia, sleep disturbance, impaired concentration and apathy, bearing in mind that apathy can be a symptom of depression. Apathy can also occur independently and be mistaken for depression. Quiet delirium should also be excluded.

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).

When administered by trained and culturally competent clinicians, the adapted nine-item Patient Health Questionnaire (aPHQ-9) may be an appropriate screening tool for depressive symptoms in Indigenous Australians.

Prevalence of depression

- Depression is one of the most commonly occurring psychological symptoms in dementia.
- Prevalence rates cluster around 39% with a range of 10% to 78%.
- People with vascular dementia (VaD) and Parkinson's disease dementia (PDD) have higher rates of comorbid depression compared to other dementia subtypes.
- People with a past history of depression are more vulnerable to developing depression during their dementia.

Effects of depression

Depression in dementia is frequently underdiagnosed and undertreated, impacting on quality of life. Apart from the distress to the person affected, depression is associated with increased carer burden, earlier admission to residential aged care, increased mortality, medical comorbidity, social withdrawal and reduced quality of life.

Addressing depression

It is important 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 pain may be exacerbating the low mood. Expert consensus guidelines recommend psychosocial interventions as a first-line approach for non-psychotic depression in dementia.

Psychosocial and environmental interventions

- Psychosocial/environmental intervention studies for depression in dementia have increased in number, quality and complexity over the past decade.
- Music and reminiscence approaches, both individual and group, provided the best psychosocial evidence.
- The cognitive rehabilitation/stimulation and multicomponent categories comprised the majority of studies and provided evidence of benefit.
- Multicomponent interventions provided the strongest evidence with the highest number of strong quality studies.
- Therapeutic recreation approaches also provided evidence of efficacy.

Biological and pharmacological interventions

- Pharmacological and biological intervention studies were primarily conducted in the community.
- The evidence for the efficacy of antidepressants is limited and expert guidelines note that these are primarily ineffective for depression in dementia.
- If indicated, there is some evidence that escitalopram or sertraline may provide short-term benefit.
- Findings reported are based on comparisons of group data of antidepressants versus placebo and it is possible that individual patients may respond.

- Light exposure therapy outperformed usual or placebo lighting, although the degree of benefit may be dependent on climate and the person’s usual exposure to sunlight.
- Very limited evidence for cholinesterase inhibitors (ChEIs) and memantine is presented.
- Single studies indicated limited benefit for other pharmacological and biological treatments such as brain stimulation therapies, methylphenidate, traditional medicines and citicoline, a cholinergic supplement; findings from single studies cannot be considered robust and replication is required before recommendations can be made.
- A past history of depression responding to an antidepressant medication may indicate a higher likelihood of response to that treatment.

Limitations

Many intervention studies have limitations around methodology and sampling which impact on outcomes and/or the generalisability of results. Few studies conducted long-term follow-ups to determine sustainability of effects.

Conclusions/Principles of care

- In line with expert consensus recommendations, an increasing number of psychosocial interventions were reported as effective in addressing depression.
- Music and reminiscence approaches provide the most promising evidence.
- Few studies indicate effective pharmacological treatment and the evidence for antidepressants is limited, although individual responses can vary.
- If pharmacological/biological interventions are indicated, these should be provided in combination with psychosocial and/or environmental approaches.

Cathy‘s story

Presentation

Cathy is a transgender woman. She had wanted to affirm her gender for many years but Cathy waited until her children were adults before she transitioned. Cathy was diagnosed with dementia 5 years ago and moved into residential care 3 months ago. Staff report that they are having increasing difficulty encouraging Cathy to attend activities that she previously enjoyed. They often have difficulty getting her up in the mornings with Cathy complaining that she is too tired to come to breakfast. Her family are concerned that Cathy doesn’t appear pleased to see them or enjoy their visits, even when they bring her adored grandchildren. Cathy is sad and tearful much of the time. Her lack of appetite has led to recent weight loss. Cathy’s notes confirm that she has lost 4kg since admission.

Since her admission Cathy has found most of the care staff to be supportive in helping with her grooming. They know that like many of the other ladies, Cathy feels better about herself when her hair is done nicely, and she is wearing some make up. A few staff members have made a special effort to lift Cathy’s mood recently with additional attention to her grooming. Some of the other residents have commented negatively on staff assisting Cathy in this way and expressed their transphobia in front of her. On occasions like this Cathy has been heard to say that she would be “better off not living”. Cathy is further distressed when she is aware that some staff members are not comfortable with providing her care.

Assessment

To reduce Cathy's presenting symptoms, potentially contributing factors must be identified:

- chronic or acute pain/discomfort/illness/infection
- medication review: interactions, dosage, adverse effects, recently prescribed
- past psychiatric history and family history
- overstimulation (noise, people, activities) or impoverished environment/boredom
- lack of attention to Cathy's specific needs and historical trauma
- others expecting too much of her and Cathy trying to overextend her capabilities
- altered routines, new care staff, particular staff, other residents and/or family members
- unfamiliar/altered/threatening physical environment
- reduced threshold for coping with stress

Assessing the situation:

- Encourage Cathy to express her needs as far as she is able.
- Directly observe any situations that appear to exacerbate her depressive symptoms.
- Consult close family members to identify potentially contributing factors.
- Consult Cathy's life history for further information with regard to her symptoms.
- Ask staff who know Cathy quite well if they can assist in identifying any unmet needs

or possible reasons for her increasingly low mood.

- Assess the immediate environment for possible factors contributing to Cathy’s symptoms.
- Is a trial of pharmacological interventions indicated and/or appropriate for treatment of Cathy’s depression?

Strategies/outcomes

- Cathy’s medical history indicates that she has previously been diagnosed with depression in her 20s. Her family reports that, in general, she has been happier and more emotionally stable since she transitioned.
- With the progression of dementia, Cathy has become more inclined to focus on unpleasant memories and express her distress around previous traumatic and discriminatory experiences.
- Staff report a recent incident with a female resident which was particularly distressing for Cathy when she used the communal female toilet near the dining room at lunchtime. The other resident loudly expressed her displeasure at sharing the female toilets with Cathy, complaining to others nearby. One resident responded with “People like that shouldn’t be allowed to live here”. Cathy didn’t return to her table to finish her lunch but headed back to her room in tears.

- Cathy’s GP undertook a medical assessment and medication review. A trial of antidepressant medication was considered. At a family conference, it was explained that a trial of psychosocial interventions are recommended initially. Family members were also made aware that it may be some weeks before the potential benefits of an antidepressant are evident and Cathy may experience side effects but hopefully, these will resolve.
- Some care staff have little knowledge of depression that can occur with dementia, trauma-informed care or the special needs of transgender people. Training was provided to enable staff to develop strategies that may assist in providing respectful care and support to Cathy and other residents as needed. It was highlighted that reminiscence activities may not be appropriate for people with trauma in their past.
- During the training sessions it became evident that some staff felt that caring for Cathy conflicted with their cultural and/or religious beliefs. One staff member was distressed by pressure from her family to avoid Cathy. Additional individual sessions were arranged to consider appropriate strategies and support for staff.
- The recreational officer arranged for Cathy to have additional individual time in a quiet area for activities she previously enjoyed such as listening to music, nail care, hand massage or spending time with the facility’s cat. Some

of Cathy's favourite meals were incorporated into her diet to encourage her appetite.

- Staff were alerted by the family that LGBTIQA+ Pride month was approaching and that this was a special time for Cathy. Her family planned outings to enable Cathy to be part of some of the Pride events and the facility arranged some inclusive activities relevant to Pride month. Many of the other residents responded positively and Cathy enjoyed the additional, culturally relevant attention.
- Cathy's family and care staff indicated that her mood was lifting somewhat and her appetite had improved, particularly when family members brought Cathy some favourite treats. Cathy's depressive symptoms will continue to be monitored with a view to reassessing her potential need for medication.

Module 9: Disinhibition

Key messages

- Disinhibition in dementia presents as behaviours associated with a reduced capacity to edit immediate impulsive responses.
- Disinhibition of a sexual nature is particularly challenging.
- Causes of disinhibition include frontal lobe pathology, substance use or other medical/psychiatric conditions e.g. delirium, mania, cerebral event etc.
- In the case of sexual disinhibition, differential diagnosis requires establishing whether the manifested behaviours are ‘normal’ sexual behaviour for that person or inappropriate behaviours due to impairments in impulse control and moral judgement.
- Disinhibition is common in people with dementia, but rates vary widely, and sexual disinhibition is reportedly less common.
- Addressing disinhibition requires the identification of potentially modifiable factors on an individual basis.
- Strategies to discourage inappropriate behaviours associated with disinhibition and psychoeducation/psychotherapy to support family carers and aged care staff may be helpful.
- Expert clinical guidelines indicate that atypical antipsychotics provide no benefit for disinhibition.
- Sound evidence for pharmacological interventions is lacking.

Disinhibition

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

- Disinhibition in dementia typically occurs with reduced capacity to edit immediate impulsive responses.
- Behaviours include those associated with impaired judgement and reduced awareness of the environment, impaired ability to process emotions and to understand and respond to the thoughts and feelings of others as well as reduced awareness of the impact on others.
- People with lived experience of dementia have said that disinhibition may reflect feeling impulsive, irritated, intolerant and/or trying to maintain control.
- As sexual disinhibition in dementia is particularly problematic, the literature tends to focus on this area.
- Attempts to classify sexually inappropriate behaviours typically differentiate between those that are misplaced in social context and those that would be considered inappropriate in most contexts.

Causes of disinhibition

- frontal lobe pathology
- drugs, alcohol
- social factors and environmental stressors
- secondary to delirium
- secondary to a cerebral event
- secondary to psychiatric syndromes such as mania or psychosis

Differential diagnosis

Consultation with the person with dementia, their family, particularly partners/spouses and formal carers is essential when determining if the presenting disinhibition is indicative of a change, an exacerbation of their pre-morbid behaviour or normal for the person. Where disinhibition presents as a sudden change in the person living with dementia, comorbid psychosis, delirium and/or a cerebral event should be excluded.

Measuring disinhibition

Standardised measures of disinhibition in dementia include the Disinhibition Scale and Middelheim Frontality Score (MFS). The disinhibition subscale of the Neuropsychiatric Inventory (NPI), 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) also include relevant items.

Prevalence of disinhibition

- Symptoms reportedly occur in 1% to 61% of people with dementia.
- Rates of sexually disinhibited behaviour are lower; these behaviours may be underreported.
- The prevalence of disinhibition tends to rise as dementia increases in severity until very late dementia.
- Reports indicate a higher prevalence in males but these reports are inconsistent.

Effects of disinhibition

Disinhibition in dementia can be associated with negative symptoms, hallucinations or delusions, frustration and subsequent agitation and/or aggression. Disinhibition may also provoke an aggressive response from others. Urinary tract infections, physical trauma and/or sexually transmitted infections are potential consequences of sexual disinhibition. Disinhibition can be stigmatising, is one of the most difficult BPSD for carers, leads to earlier admission to residential aged care, and in more extreme cases anti-social/criminal behaviour (for example, causing injury, sex offending) and/or legal action.

Addressing disinhibition

Developing a behaviour support plan for disinhibition begins with a thorough assessment. It is important to determine which of the underlying, *individual* factors driving the disinhibition are potentially modifiable. Consider possible precipitating factors including medications, comorbid physical conditions, stroke, seizure disorder, comorbid psychiatric condition and environmental triggers.

Psychosocial and environmental interventions

Suggested strategies are provided in the following areas:

- supportive psychotherapy or education of family carers and/or aged care staff
- increased, positive contact with family and pets
- identifying potential triggers, social cues and early indicators
- modifying environmental aspects, clothing and aged care staff roles
- providing distraction, redirection and modified learning techniques
- activities to occupy the person's hands
- avoiding overreaction or knee-jerk responses that induce shame or humiliation

Biological and pharmacological interventions

- No randomised controlled trials (RCTs) are currently available.
- Many case studies describe a trial-and-error approach including details of previous unsuccessful attempts.
- Hormonal therapy is controversial as it can be viewed as feminisation or chemical castration of males.
- Expert consensus guidelines note no benefit for antipsychotic medication and recommend against their long-term use.

- Paroxetine (a selective serotonin reuptake inhibitor) has a known side effect of reducing libido and sexual function.
- The potential benefits to the person with dementia and the safety of others must be weighed against the potential side effects of pharmacological treatments.
- Informed consent from the person or their proxy and in some cases, official bodies such as the Guardianship Tribunal is crucial for the use of hormonal agents.

Limitations

Despite the significant challenges inherent in addressing disinhibition in dementia, sound research is lacking. Evidence based on case studies, subscale scores only or clustered BPSD domains which include disinhibition cannot be considered robust.

General principles and considerations to assist in the assessment of a person with dementia's competency to participate in a sexual relationship include:

- Embed the assessment in an interdisciplinary team process.
- Conduct a clinical interview where possible, including behavioural observation, medical/psychological/social history and relationship history.
- Gather information from multiple perspectives.
- Conduct a medical records review for relevant information e.g. conditions affecting sexual functioning, medications that affect cognition and physical safety, pertinent elements of functional status.
- Try to establish knowledge/understanding, reasoning/capacity and voluntariness/choice as well as sexual wishes or values. Consider:

- Is the person with dementia aware 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 delusional belief?
- Is he/she aware of the other person's intent?
- Can he/she state what level of sexual intimacy they would be comfortable with?
- Does the person with dementia have the ability to avoid exploitation?
- Is the behaviour consistent with formerly held beliefs and values?

Conclusions/Principles of care

The limited evidence available suggests that disinhibition must be addressed on an individual basis. Where sexual disinhibition occurs, a dilemma arises in attempts to allow the person with dementia's sexual expression while protecting the safety, rights and dignity of all. The need for a multidisciplinary, individualised and multifaceted approach is stressed.

Alex's story

Presentation

Alex has a three-year history of vascular dementia. His wife sought residential care placement for Alex when she could no longer cope with his increasing sexual demands, and he accused her of becoming pregnant through an extra-marital affair with one of their neighbours. On admission to residential care Alex presented as generally quite pleasant and friendly. Staff reported some “inappropriate joking” and taking items from other residents as a prank. Staff are aware that these instances could put Alex at risk of harm if other residents react angrily to his intrusions.

Not long after his admission, Alex discovered that a small group of female residents regularly enjoyed watching an evening reality show on television together in a communal sitting area. The show includes near nudity and sexual content. Alex is keen to watch the show with the other residents, but they find his response to the content inappropriate and they feel uncomfortable.

On one occasion Alex approached several female staff members and a female resident in a sexually suggestive manner. Transferring him to another section of the facility was trialled but Alex’s disinhibition soon resumed, escalating 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 the privacy of his room he could become verbally aggressive and threatening.

Assessment

To reduce Alex’s disinhibition that is potentially putting him and others at risk, contributing factors must be identified:

- sexual history and premorbid patterns of sexual interest
- pain/discomfort/illness/infection

- medication reactions, interactions, dosage, recently prescribed, adverse effects
- lack of usual sexual partner/privacy
- altered routines, new staff, particular staff and/or family members
- unfamiliar/altered/deprived physical environment
- psychotic symptoms/misidentification
- loss of premorbid social controls
- misinterpretation of environmental cues
- sensory impairments

Assessing the situation:

- Directly observe for specific triggers for disinhibition.
- Ask staff who have come to know Alex if they can assist in identifying possible triggers that provoke his disinhibition.
- Consult Alex's life history, behaviour support plan and clinical charts for further information on triggers.
- Assess the immediate environment for possible triggers.
- Consult family members to identify additional triggers which may be unknown to staff and not previously documented.
- Is a trial of pharmacological interventions indicated and/or appropriate for treatment of Alex's disinhibition?

Strategies/outcomes

- Direct observation suggested possible triggers for the disinhibition related to the presence of specific female staff members and a very sociable female resident who was seated at Alex's table in the dining room. The female resident was happy to change her seating to join a friend at another table.
- Care staff reported that Alex 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 cover Alex's personal care needs between them, on most occasions.
- A review of Alex's current medication did not suggest any association with his disinhibition.
- When asked, Alex's wife reported that they had been a close couple until recent years. Alex had always been openly affectionate but since his diagnosis he has become increasingly less aware of social boundaries. Information and support were provided to Alex's wife.
- Alex's wife and family members provided additional items of special interest from his home that helped to keep him occupied during periods of reduced environmental stimulation. They also increased their visits and included Alex's beloved dog in their visits to provide Alex with additional positive contact.

- Given the small number of residents involved, the ladies were happy to relocate their television viewing to a rotating roster of their rooms.
- Consultation with staff members indicated that some were shocked and repulsed by Alex's disinhibition. They were unaware that these behaviours can occur during the course of dementia.
- Staff education was arranged with a community Clinical Nurse Specialist around factors contributing to Alex's disinhibition, normal sexual expression in older people with dementia, diminished privacy issues, strategies to avoid provoking and/or address 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 Alex's sexual disinhibition in a safe and enabling environment were provided. While female staff members were encouraged to avoid placing themselves at risk of Alex's sexual advances, it was emphasised that they were in no way responsible for Alex's sexually inappropriate behaviours when these did occur.
- In consultation with Alex's family, strategies to enable him to meet his sexual needs such as additional privacy, magazines, private time with his wife and professional sex therapy were considered.

- Additional behavioural and environmental measures reduced the frequency and intrusiveness of Alex's disinhibition.
- Increased staff awareness of the underlying issues increased their confidence and ability to implement successful strategies for dealing with the disinhibition while allowing Alex to maintain dignity and stay safe.
- Close monitoring of Alex's disinhibition continued with a view to considering a trial of pharmacological interventions if the safety of others was jeopardised.

Module 10: Nocturnal disruption

Key messages

- The presentation of nocturnal disruption varies with dementia subtypes.
- Nocturnal disruption occurs with the degenerative brain changes associated with dementia; multiple physical, medication, environmental and/or social factors can also contribute.
- Differential diagnosis requires eliminating delirium, comorbid medical and/or psychiatric conditions and side effects of some medications e.g. stimulants, prednisone, cholinesterase inhibitors (ChEIs).
- Nocturnal disruption occurs in 20% to 100% of people living with dementia.
- Addressing nocturnal disruption requires identifying potential contributing factors such as pain, hunger, thirst, infection and/or socio-emotional needs.
- Companion robot Parot, acupressure and staff/carer training interventions provide the best psychosocial evidence.
- Light therapy is the only biological therapy recommended by clinical guidelines for irregular sleep-wake rhythm disruption, although the evidence is inconsistent.
- Limited evidence is reported for ChEIs (which paradoxically, may cause insomnia) and analgesic medications.
- Sleep disturbances can occur secondary to depression, anxiety and/or agitation and treating the underlying condition may be helpful.

Nocturnal disruption

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

Nocturnal disruption refers to disturbances of the person with dementia's circadian rhythm and sleep. Symptoms 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

Degenerative changes in people with dementia contribute to nocturnal disruption. Physical factors such as pain, adverse effects of medication, and/or social and environmental factors also play a role. Other BPSD may also become exacerbated at night and disrupt sleep due to reduced environmental cues.

People with lived experience of dementia have said that waking at night in dim light and darkness can be frustrating, scary, confusing, isolating, and lonely.

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.

Measuring nocturnal disruption

Current guidelines recommend the use of actigraphy whenever possible, for at least seven days and keeping a sleep log in the assessment of nocturnal disruption.

Questionnaires such as the Sleep Disorders Inventory (SDI), 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 100% of people with dementia. It can also be inherent to the type of dementia and tends to occur more frequently in dementia with Lewy bodies (DLB), Parkinson’s disease dementia (PDD), Huntington’s disease (HD) and frontotemporal dementia (FTD) than Alzheimer’s Disease (AD) and vascular dementia (VaD).

The occurrence of nocturnal disruption in dementia increases with dementia severity, the presence of APOE ε4 allele, anxiety, depression, loneliness, 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 admission to residential aged care, social disruption, loneliness, poorer cognitive functioning, more rapid cognitive decline, greater functional impairment, poor quality of life and/or wandering in people with dementia as well as higher risk of falls and mortality.

Addressing nocturnal disruption

It is important to determine potentially treatable factors contributing to the nocturnal disruption. Addressing underlying causes may require effective pain management, relieving hunger or thirst, treating infection or adverse drug reactions and/or improving social health. Carer education around sleep hygiene and assessing night-time, environmental disturbance occurring close to the person with dementia may be helpful.

Psychosocial and environmental

- Psychosocial intervention studies were primarily conducted in residential settings.
- Most studies fell under the animal-assisted interventions, touch therapies or education and training categories.
- Interventions using the companion robot Paro, overnight acupressure, and those focused on training for carers and staff in aged care homes provide the best psychosocial evidence for improved sleep-wake parameters.
- Studies of physical activity and models of care interventions found no benefit for nocturnal disruption.
- Although scientific evidence is lacking, traditional sleep hygiene measures may contribute to addressing nocturnal disruption and should not be overlooked.

Biological and pharmacological interventions

- Light therapy interventions provide some evidence and are the only treatment recommended by clinical guidelines, although they are not recommended in combination with melatonin.
- Limited evidence is reported for ChEIs and the short-term benefit for analgesic medications.
- Evidence for melatonin therapies is mixed and current guidelines do not recommend their use in older adults living with dementia.

- Although some evidence of a very small-small effect is reported for suvorexant compared with placebo, review studies indicate equivocal evidence regarding efficacy and risks for people with dementia.
- No evidence of benefit was demonstrated for psychostimulants or antidepressants.
- Sleep disturbance and nightmares are well known potential adverse effects of ChEIs and some antidepressants can worsen rapid-eye-movement (REM) Sleep Behaviour Disorder.

Limitations

There are limited intervention studies in the literature and many studies report no effects or mixed results. Few studies investigated the long-term effects of the interventions, limiting their clinical utility in nocturnal disruption.

Conclusions/Principles of care

- Nocturnal disruption can cause significant distress for people with dementia living at home and their carers.
- Likewise, the challenges for residential care staff and distress for other residents in aged care homes are significant.
- Understanding the potential causes underlying nocturnal disruption will assist e.g., depression, anxiety, agitation and/or pain.
- The potential risk/benefit ratio for the individual with dementia must always be considered before prescribing pharmacological agents for nocturnal disruption.
- A lack of sound evidence should not prevent clinicians from considering person-centred strategies to reduce nocturnal disruption on an individual basis.

Elaine‘s story

Presentation

Elaine is a recent admission to residential aged care from hospital, following a medical crisis. She was diagnosed with Alzheimer’s disease 5 years ago and depression has been excluded during her hospital admission. Elaine previously lived a chaotic lifestyle at home with no routine and presented to hospital as dishevelled and underweight. She reportedly had no regular sleeping pattern at home so was frequently awake at night. Staff reported that her sleep/wake cycle has been irregular since admission to the facility.

When she is often awake late into the night, Elaine wanders into other resident’s rooms while they are sleeping and turns on the lights and/or television. In the mornings, she does not wish to be disturbed by staff and Elaine has become increasingly resistant to their encouragement to eat breakfast or have a shower. She can ill afford to lose weight at this time. Because staff are busy, Elaine frequently falls back to sleep until 11am or later.

Assessment

To reduce Elaine’s nocturnal disruption, potentially contributing factors must be identified:

- chronic or acute pain/discomfort/illness/ infection preventing her from settling at night
- medication interactions, dosage, adverse effects, recently prescribed
- unfamiliar physical environment
- unfamiliar noise/disruption/light from night

staff attending to the needs of other residents nearby
- less flexibility with routine than Elaine previously had at home
- some staff have little awareness that her previous lifestyle factors may be contributing to the nocturnal disruption

Assessing the situation:

- Consult family members to identify possible strategies to assist in addressing Elaine's disrupted sleep patterns.
- Directly observe her pattern across a 24-hour period.
- Monitor Elaine's food and fluid intake.
- With consent, contact the hospital for any additional information available with regard to Elaine's history.
- Is pharmacological intervention indicated and/or appropriate for treatment of the nocturnal disruption?

Strategies/outcomes

- After investigation via the hospital, Elaine's only surviving sibling was contacted. He reported that Elaine used to enjoy her garden and was once very proud of her azalea collection. Elaine would also spend time flicking through newspapers and 'junk mail' brochures.
- Elaine has had two recent relocations which will likely have increased her confusion and

disorientation. Providing familiar items may help her identify her space, making it more comfortable and appealing at night. Although Elaine's brother had not been close to her for some years, he was willing to bring some personal items to the facility. Elaine was pleased to see her brother.

- It became evident that Elaine was further disrupted at night by activity around the nurses' station and staff attending to the high-level needs of the resident in the next room. She was moved to a quieter area.
- The relative inactivity and darkness within the RAC environment at night, provided reduced cues. A small night light in her room assisted with orientation.
- Supporting staff through Elaine's transition to residential care and providing education around the factors contributing to her night-time wandering improved understanding of, and tolerance for, the episodes of nocturnal disruption.
- Keeping Elaine's daily routine as predictable as possible, given her previous lifestyle, provided some structure and ultimately, familiarity.
- Staff members were able to chat to Elaine about her passion for gardening and source local newspapers for her to browse.
- A daily walk to the aged care home letterbox after multiple brochures (recycled by staff) were 'delivered' became a positive activity.

- To further help establish a daily routine, Elaine was encouraged to take a brief nap of 30 minutes and never more than 45 minutes after lunch. Staff monitored how long Elaine napped to ensure she didn't sleep all afternoon.
- Participation in activities relevant to Elaine's history were promoted during the day and if she fell asleep while sitting at the table to eat, care staff assisted her to continue eating.
- Better sleep hygiene minimised opportunities for prolonged sleep during the day. Gradually a somewhat earlier and regular bedtime was established for Elaine.
- While she was still awake later than other residents in the facility, the situation became more manageable and less disruptive to others.

Module 11: Vocal disruption

Key messages

- Differing definitions of vocal disruption yield varying prevalence rates and shape intervention studies.
- Vocal disruption causes significant distress for the person living with dementia and others around them.
- Three key areas can prompt vocal disruption and provide targets for intervention:
  - pain and discomfort (physical and/or psychological and/or social)
  - operant conditioning of vocalisations due to the increased attention they attract
  - reduced-stress thresholds due to cognitive impairment
- The inclusion of disruptive in the definition is based on the perception of others.
- Environmental modifications to support resident orientation provide the best psychosocial evidence.
- Evidence for effective biological/pharmacological interventions overall is lacking.
- Clinical guidelines recommend against the use of atypical antipsychotics for vocal disruption however, short-term use of risperidone may be considered for those with underlying psychotic symptoms.
- Emerging technologies may help to identify pain in people who cannot express themselves verbally.
- As always, a multidisciplinary, individualised and multifaceted approach is recommended.

Vocal disruption

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

- Vocal disruption is also referred to as persistent vocalisation, screaming and verbal agitation.
- Vocal disruption can be described as any vocalisation that causes the person distress and/or causes stress to others.
- Vocalisations include calling-out, screaming, abusive or verbally aggressive comments, perseveration, repetitive questioning, groaning and sighing which can be intermittent or incessant.

Causes of vocal disruption

Causes include pain, physical and/or psychological discomfort including trauma, loneliness and social isolation for example, based on cultural and linguistic diversity. Vocal disruption can also result from reduced stress threshold due to cognitive impairment and operant learning when increased attention is provided when the person is calling out but they are ignored when they are silent. Vocal disruption can also occur in response to visual and/or auditory hallucinations.

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

Differential diagnosis

- Vocal disruption secondary to delirium should be excluded.
- Symptoms of vocal disruption overlap with agitation in dementia.
- Vocalisations can be disruptive whether or not the person with dementia has an awareness of their needs.

- The inclusion of “disruption” in the definition is based on the perception of others.
- The same vocalisation may be disruptive in one context and not in another.

Measuring vocal disruption

- Most scales measuring vocal disruption include it as a subset of global BPSD or agitation.
- The original Neuropsychiatric Inventory (NPI) does not include a subscale relevant to vocal disruption, however the revised NPI-Clinician (NPI-C) includes an additional subscale for measuring aberrant vocalisations.
- The verbal behaviour section of the Disruptive Behaviour Scale (DBS) includes subscales for aggressive and agitated (nonaggressive) vocal behaviours.
- The Cohen-Mansfield Agitation Inventory (CMAI) includes six items relating to vocal disruption.
- The Pittsburgh Agitation Scale (PAS) includes a category which measures aberrant vocalisation.

Prevalence of vocal disruption

Different definitions of vocal disruption yield varying prevalence rates based on how inclusive they are and the setting e.g., residential aged care versus at home. The prevalence of vocal disruption overall is difficult to estimate as reported frequencies often relate to various aspects of vocal disruption. Examples include cursing and/or verbal aggression from 10% to 48%, repetitive sentences/questions from 3% to 31.1% and screaming from 10% to 15%.

Effects of vocal disruption

Vocal disruption causes significant stress and/or distress within residential aged care, hospital and community environments. It has been shown to cause concern, frustration, anxiety, anger as well as complaints from care staff, visitors, other residents and/or neighbours. Vocal disruption can lead to the person with dementia becoming socially isolated and/or the inappropriate use of restrictive practices.

Addressing vocal disruption

The initial step for the clinician in addressing vocal disruption is to attempt to identify and understand the underlying factors provoking the vocalisations for the individual person. Where this is not achievable, the aim of treatment is to minimise distress to the person with dementia and those around them.

Psychosocial and environmental

- Only three psychosocial/environmental intervention studies met our quality criteria for inclusion.
- All trials were conducted in residential care settings.
- Environmental modifications to support resident orientation showed limited evidence of a decrease in the number of episodes of screaming.
- Mixed evidence was found for an educational program Bathing Without a Battle which provided training and support for care staff during personal care activities.
- No benefit was found for psychosocial intervention.
- The potential causes of the vocal disruption may provide clues to appropriate interventions for the individual person.

Biological and pharmacological interventions

- Evidence for biological/pharmacological treatments for vocal disruption overall is lacking and no biological/pharmacological intervention studies met our quality criteria for inclusion.
- Current expert guidelines recommend against the use of atypical antipsychotics due to risk of harms and lack of benefit, unless the vocal disruption is underpinned by psychosis.

- Any potential benefits to the person with dementia must be weighed against the side effects before considering the use of pharmacological treatments.

Limitations

Numerous definitions and aspects of vocal disruption impact on how it is measured and addressed, as well as the evaluation of interventions. There is a lack of good quality evidence available and vocal disruption is frequently not the primary outcome of intervention studies. None of the reported trials investigated the long-term effects of interventions. These factors limit the clinical utility of interventions and the ability to make recommendations.

Conclusions/Principles of care

- Vocal disruption is common in dementia, with significant and distressing consequences.
- Recognised expert guidelines and reports on the outcomes of interventions are limited.
- Environmental modifications and an education program for staff provide the best evidence for psychosocial intervention.
- No good evidence was found for biological or pharmacological interventions.
- Atypical antipsychotics are not recommended due to lack of benefit and risk of harm.
- A lack of sound evidence should not prevent clinicians from considering strategies to reduce vocal disruption on an individual basis.
- A multidisciplinary, individualised and multifaceted approach is required.

Sarah's story

Presentation

Sarah has lived in residential care for two years. During the past year her tendency to repeatedly call out has increased. She constantly calls her daughter's name, at increasing volumes, until she is shouting. Other times she makes grunting noises. Her increasing distress and vocalisations appear to correspond to increasing anxiety, particularly when care staff attend to her personal hygiene needs. Staff and other residents are distressed and exhausted by Sarah's vocalisations. Some of her fellow residents can become very agitated when Sarah's calling out escalates. Families and visitors of other residents have complained to staff and management. Sarah's son and his family are embarrassed and uncomfortable when they visit, reporting to staff that they feel "helpless to ease mum's distress".

Sarah's daughter lives in America. Although she has always phoned her mother frequently and visits each year, Sarah has a history of missing her daughter's company. Staff attempt to assist Sarah to communicate with her daughter during her calls from America, but these currently provide little to no quality contact for either of them.

Assessment

To reduce Sarah's distressing vocalisations, potentially contributing factors must be identified:

- unreported pain/discomfort/infection
- medication review: interactions, dosage, adverse effects, recently prescribed

- overstimulation (noise, people, activities) or understimulation/boredom
- 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 Sarah to indicate her needs as far as she is able.
- Directly observe for specific triggers for the vocalisations.
- Ask staff who know Sarah well if they can assist in identifying potentially unmet needs or possible reasons for her calling out.
- Consult Sarah's life history, behaviour support plan and clinical charts for further information regarding triggers.
- Assess the immediate environment for possibly modifiable triggers.
- Consult family members to identify other potential triggers that are unknown to staff and not previously documented.

Strategies/outcomes

- Sarah has a history of chronic back pain following an accident many years ago.
  She is prescribed analgesia as required. A retrospective review of her medication charts

indicated that Sarah currently receives pain relief irregularly and less frequently than when she was able to request it herself.

- Some staff members had little knowledge of dementia and were unaware that pain can prompt BPSD.
- Pain assessment indicated that Sarah may be experiencing frequent discomfort and/or pain, particularly in relation to personal care activities. Her analgesic medication was reviewed and regular day and night-time doses prescribed. Non-pharmacological pain relief interventions, such as gentle heat, were also implemented.
- Sarah’s care plan was updated to schedule her shower for 30 mins after the morning dose of analgesia was administered.
- An OT assessment was requested to ensure the most appropriate and comfortable shower chair for Sarah’s back pain.
- Resident room allocation throughout the aged care home was reassessed and Sarah was relocated to a quieter room with less stimulation to prompt her calling out, particularly at night.
- A redirection and relaxation program was developed to support Sarah. Gaining Sarah’s attention by taking her hand, using her first name and ensuring eye contact enabled staff to engage her in up to ten slow breaths. This strategy initially stopped Sarah calling out for up to 20 minutes. Staff were trained to ensure consistency across shifts.

- Sarah was positively reinforced by giving her attention when she had not been calling out for a period of time.
- Behavioural observation charts indicated that Sarah responded positively to gentle touching and stroking. A volunteer visitor was trained to provide appropriate touch several times weekly.
- Sarah's favourite music and aromatherapy were also trialled with mixed results.
- Sarah's family members were trained and encouraged to participate in the redirection and relaxation program during their visits.
- Willing family members subsequently developed an informal roster to complement the volunteer's visits. They reported that they felt their contribution was beneficial to Sarah.
- Phone calls from Sarah's daughter were coordinated with times when Sarah was supported by family or a volunteer and hence, more relaxed. Short positive phone contact with her daughter left Sarah quite content.
- With time, the redirection and relaxation program resulted in longer vocalisation-free periods when Sarah was better able to communicate her needs and answer questions.
- Follow-up assessment indicated Sarah's episodes of disruptive vocalisation continued to reduce in frequency, intensity and volume. Her family felt Sarah's anxiety and overall quality of life had improved under the program. When she did call out, staff felt better able to reduce Sarah's distress.

Module 12: Wandering

Key messages

- Wandering in dementia is frequently distressing for a person living with dementia and their carers.
- An operational definition proposes that wandering occurs over time and space and includes four patterns of ambulation: restlessness, agitation, aberrant motor activity, and night-time disturbances.
- Prevalence rates reportedly range from 12% to 63% in the community and 5% to 100% in residential care.
- Wandering that leads to absconding and becoming lost can have severe negative consequences including injury and death.
- By contrast, independent but safe wandering can have positive effects.
- The crucial task for the clinician is to understand what the wandering means for the individual person although this can be difficult to determine.
- Some evidence supports environmental modifications to assist with orientation.
- The inappropriate use of restrictive practices increases the person's risk of harm.
- Treating underlying depression or pain should be considered.
- Sound evidence of the effectiveness of interventions to prevent or reduce wandering is lacking.
- Comprehensive assessment must include aspects of the person with dementia that enable tailored strategies, to support an individual approach.

Wandering

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

The construct of wandering has been used to summarise a range of observable motor behaviours. An operational definition, based on observed patterns of movement in aged care home residents with dementia proposes that wandering can manifest in patterns of lapping, pacing, random or direct locomotion. A descriptive typology of wandering has also been outlined, as opposed to a single definition. People living with dementia have described wandering as "searching" which can occur after distraction or memory lapses interfere with reaching a desired destination.

Causes of wandering

Recognising potential antecedents to wandering can aid in prevention. Wandering can have different meanings and causes for each person with dementia. These may include:

- a response to pain, infection, discomfort or increased confusion
- looking for assistance, a toilet, company or a familiar face/place
- habitual pattern of activity
- medication reaction
- underlying depression, anxiety, delusions or hallucinations
- perceived escape from trauma, threat or an unpleasant situation

Wandering has been associated with greater cognitive and functional impairment, greater gait and balance impairment, conscientiousness, poorer response to stress, younger onset of dementia, and lower level of awareness.

Differential diagnosis

Wandering is often subsumed within the syndromes of agitation, restlessness and night-time disturbances. The term is also used interchangeably with aberrant motor activity. A medication review should be undertaken to exclude adverse effects of psychotropics, hypnotics or stimulants, particularly akathisia with antipsychotics.

Measuring wandering

- Wandering in dementia is differentiated by pattern, severity, rate, duration, peak period of occurrence and frequency.
- 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.
- The Neuropsychiatric Inventory (NPI), the Cohen-Mansfield Agitation Inventory (CMAI), the Consortium to Establish a Registry for Alzheimer’s Disease (CERAD) Behavior Rating Scale for Dementia and the Dementia Behavior Disturbance Scale (DBDS) include items pertaining to wandering.

Prevalence of wandering

Prevalence rates for wandering reportedly range from 12% to 63% in the community and 5% to 100% in care homes. This disparity in prevalence rates can be partly attributed to the imprecise definition of wandering and the variety of measurement tools used in reporting. The rate and duration of wandering tends to increase as cognition declines but then subsides in late-stage dementia.

Effects of wandering

Wandering has been associated with high carer burden and anxiety around the associated risks as well as earlier admission to residential aged care. Adverse effects of wandering include falls and subsequent injury and/or fractures, weight loss, resident to resident violence, the inappropriate use of restrictive practice and social isolation. Absconding and becoming lost present additional safety risks, at times resulting in death. Conversely, providing opportunities for independent but safe walking can potentially be therapeutic and improve wellbeing.

Addressing wandering

The first step is to understand the person and what underpins the wandering for the individual. For example, some people with dementia living in residential care benefit from more room to roam and access to the outdoors. Clearly, addressing the cause of the wandering is crucial, although finding the cause is not always possible. Comprehensive assessment to exclude comorbid illness and pain as well as psychological assessment to identify underlying mood or psychotic symptoms is essential. It is important to identify the significant aspects of the wandering including the issues for the person with dementia versus the issues for carers and/or staff.

Psychosocial and environmental interventions

- Good quality evidence for psychosocial/environmental interventions is lacking and only three studies met our quality criteria for inclusion.
- Some evidence was found for the effectiveness of supportive environmental changes in residential care.
- Negative outcomes were reported for tailored music therapy and interactive robot sessions.

Biological and pharmacological interventions

- Clinical guidelines recommend against the use of benzodiazepines, antihistamines, antidepressants, z-drugs and antipsychotics for wandering as these drugs can worsen confusion and increase the risk of falls.
- No biological/pharmacological intervention studies met our quality criteria for inclusion.

Technologically mediated devices

Technological monitoring devices have been developed in attempts to reduce the risks associated with wandering in the community and RACS. The level of evidence to support the use of such devices is low and further real-world research is required to demonstrate their effectiveness.

Limitations

Wandering is multifaceted and it has been understudied. This has limited the development of effective strategies to date. There is a lack of sound intervention research to guide clinicians and carers in strategies to address wandering. Overlapping of symptoms with other BPSD can mean that a diagnosis of wandering may not be straightforward, and wandering is rarely studied in isolation, further hindering the development of effective strategies.

Conclusions/Principles of care

- Treating underlying pain and depression should be considered.
- The inappropriate use of restrictive practices is not recommended.
- Although the scientific evidence is limited, strategies to reduce wandering should be considered on an individual basis.
- Some evidence for environmental modifications to support visual orientation is reported.

Eddie's story

Presentation

Eddie is a 65 year old Aboriginal man who moved to Katherine from a remote NT community when he was a young man. He lived with his wife until she died recently. While raising their family of five children, they maintained strong connections with friends and family in Eddie's original community.

His connection to Country has remained very important to him.

Family and community members have been supporting Eddie in the family home with the assistance of Aboriginal-specific services. Since their mother's death it has become evident to the family how much she was compensating for Eddie's functional deficits due to his dementia. On three occasions in the past month Eddie 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 Eddie was unable to provide his address or contact details for his family. When police approached Eddie became uncooperative and verbally aggressive. Police ultimately located Eddie's daughter who collected him from the local police station to take him home.

Assessment

To reduce Eddie's wandering which is putting him at risk, 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
- searching for his wife or other family members

- searching for his childhood home environment
- exclude underlying depression, particularly with recent significant loss
- lack of stimulation/boredom
- changes to the physical environment

Assessing the situation

- Encourage Eddie 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 note Eddie's behaviour preceding wandering incidents and also on the occasions when he makes no attempt to leave home.
- Ask community workers who have become familiar with Eddie if they have identified situations which provoke his wandering.
- Consult Eddie's life history for further information.
- Consult family members to identify possible strategies that may discourage Eddie's wandering attempts.

Strategies/outcomes

- In discussions with the family it became evident that Eddie sometimes forgets that his wife has died. When he does not remember this and he cannot find her in their home, Eddie becomes distressed. Family members have put their numbers in Eddie's phone and reminded him to call whenever he needs help, but Eddie is apparently unable to manage this.

- Consultation with family and community workers indicated that Eddie was also more restless after phone contact with his younger brother who still lives in the town near their childhood home.
- Although Eddie's daughters are grieving they are very supportive. They are feeling the stress of caring for their father while meeting the needs of their own families and they are feeling increasingly concerned when leaving him at home alone. They are at a loss as to how to best support their father in his grief when this is complicated by dementia.
- Eddie's multiple comorbid medical conditions are contributing to his mobility and vision limitations, and the family are concerned that he may fall when he wanders from home. Eddie tends to forget to use his walking stick.
- Family and community members are experiencing greater difficulty communicating with Eddie as he increasingly reverts to his traditional language.
- Eddie'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.
- The community workers and family have little understanding of the association between

Eddie's dementia and his wandering. Information was provided to increase their awareness of potential triggers for Eddie's wandering and the impact of historical trauma and discrimination within the context of dementia.

- Eddie's younger brother travelled to Katherine to participate in a family/community meeting. The family determined that Eddie may benefit from staying with his brother and wife.
- Eddie responded well to returning to *Country* and the company of the older family members and community.
- The additional contact with community meant that Eddie was afforded greater supervision, companionship and support for his grief.
- Aboriginal services in Katherine referred Eddie to a service provider in the town where Eddie's brother lives for additional support.