# Behaviour Management
## A Guide to Good Practice

*Managing Behavioural and Psychological Symptoms of Dementia*

**DCRC**
Dementia Collaborative
Research Centres

**DBMAS** | dementia behaviour
management advisory service

**Helping Australians with dementia, and their carers**

# Behaviour Management - A Guide to Good Practice

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

**Disclaimer**

This guide was developed by Dementia Collaborative Research Centre (DCRC-ABC) for the purpose of accompanying the Operational Guidelines for the Australian Government funded Dementia Behaviour Management Advisory Service (DBMAS) program. The information contained in this guide was developed to be used as a resource by State and Territory DBMAS service providers. This Guide to Behavioural Management is provided for general information only and does not claim to reflect all considerations. As with all guidelines, recommendations may not be appropriate for use in all circumstances.

The guide incorporates information from the most recent literature and other sources. Every effort has been made to ensure the accuracy and reliability of the information in this guide at the time of publication. Links to Internet Sites and resources are also identified; however these represent only a selection of those available. Links to other Internet Sites that are not under the control of the Dementia Collaborative Research Centre at the University of New South Wales are provided for information purposes only. Care has been taken in providing these links as suitable reference resources. However, due to the changing nature of Internet content, 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 the University of New South Wales.

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# Glossary of Terms

| Term | Abbreviation | Definition/Comments |
|---|---|---|
| Alzheimer's disease | AD | |
| Activities of Daily Living | ADLs | |
| Aboriginal Medical Service | AMS | |
| behavioural and psychological symptoms of dementia | BPSD | Also known as behaviours of concern or challenging behaviours |
| Cornell Scale for Depression in Dementia | CSDD | |
| Culturally and Linguistically Diverse | CALD | |
| Dementia Behaviour Management Advisory Service | DBMAS | |
| Dementia Collaborative Research Centre | DCRC | |
| dementia with Lewy bodies | DLB | Also referred to as Lewy body dementia and Lewy body disease |
| Department of Health and Ageing | DoHA | |
| Dementia Outcomes Measurement Suite | DOMS | Refer to Sansoni, et al. 2007 (1) |
| frontotemporal dementia | FTD | |
| Geriatric Depression Scale | GDS | Refer to Yesavage, et al. 1983 (2). Note: GDS can also refer to the Global Deterioration Scale (3) for rating dementia severity |
| International Psychogeriatric Association | IPA | |
| General Practitioner | GP | |
| Folstein's Mini Mental State Examination | MMSE | Refer to Folstein, et al. 1975 (4) |
| Kimberley Indigenous Cognitive Assessment tool | KICA-Cog | Refer to LoGiudice, et al. 2006 (5) |
| Mild Cognitive Impairment | MCI | |
| Neuropsychiatric Inventory | NPI | Refer to Cummings, et al. 1994 (6) |
| Neuropsychiatric Inventory - Clinician | NPI-C | Refer to de Medeiros, et al. 2010 (7) |
| The National Institute for Clinical Excellence | NICE | |
| Parkinson's disease | PD | |
| Parkinson's disease dementia | PDD | |
| psychogeriatric services | | Also referred to as psychiatry of old age or geriatric psychiatry |
| Residential Aged Care Facility | RACF | |
| Randomised Control Trial | RCT | |
| Rowland Universal Dementia Assessment Scale | RUDAS | Refer to Storey, et al. 2004 (8) |
| Special Care Unit | SCU | |
| vascular dementia | VaD | |

# Introduction

**Aim**

The aim of this document is to provide guidance for DBMAS clinicians in their role of assisting residential aged care facility staff, community care staff and family members caring for persons living with dementia, who present with behavioural and psychological symptoms of dementia (BPSD). A comprehensive evidence and practice-based overview of BPSD management principles is provided with practical strategies and interventions for assisting care staff and family carers to manage behaviours in dementia. The empirical evidence contained in this Guide to Good Practice, in combination with clinical expertise may assist in achieving improved outcomes for those with dementia.

**How to use this guide**

This document has been designed as a set of modules in order to facilitate ease of use and provide behaviour specific information. *Module 1*: DBMAS behaviour management process provides a guiding framework for the process of managing BPSD; outlining the stages of referral, risk assessment, comprehensive assessment and the implementation and evaluation of behavioural management strategies. Each of the following General BPSD and behaviour specific modules begin with a key messages page and a two page summary to enable quick reference to the information in the body of the module.

The main body of each module provides behaviour specific information relevant to the following aspects:
- A description of the behaviour and how it presents in dementia
- Causes
- Differential diagnosis
- Measuring the behaviour
- Prevalence
- Effects on the person with dementia and others living with them or involved in providing care
- Results from the literature search
- Management strategies and the quality of the supporting evidence available for specific interventions for the BPSD
    - *Psychosocial and environmental interventions*
    - *Biological interventions*
- Limitations of the evidence presented
- Conclusions

In order to better guide clinical practice, all intervention studies outlined in the modules have been assessed to determine the strength of the evidence for the findings reported (see *Appendix 7: Methodology* for quality rating criteria). Interventions are classified under *psychosocial and environmental* or *biological* and within these groups, interventions have been further categorised for ease of access (see *Module 2: General BPSD* for definitions of categories). Details of intervention studies and the quality ratings are included in *Appendices 3 and 4*. In order to illustrate the information presented in the specific BPSD modules, each includes an example of a brief clinical scenario encompassing presentation, assessment and strategies/outcomes. All appendices are provided in electronic format.

To access information related to a specific intervention category or a specific study, follow the steps outlined below.

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┌─────────────────────────────────────────────────────────────┐
│ Review key messages and/or summaries to determine which      │
│ behaviour module(s) are relevant                             │
└─────────────────────────────────────────────────────────────┘
                              ↓
┌─────────────────────────────────────────────────────────────┐
│ Within the relevant module(s), refer to the management       │
│ intervention sections (psychosocial/environmental or         │
│ biological) for information on a specific intervention        │
│ and/or study                                                 │
└─────────────────────────────────────────────────────────────┘
              ↓                              ↓
┌─────────────────────────┐    ┌─────────────────────────┐
│ To locate details of a  │    │ To browse an intervention│
│ specific intervention   │    │ category                 │
│ study                   │    │                          │
└─────────────────────────┘    └─────────────────────────┘
              ↓                              │
┌─────────────────────────┐                 │
│ Numbered referencing in │                 │
│ the modules refers to   │                 │
│ combined reference      │                 │
│ list, Appendix 8. Go to │                 │
│ the reference list for  │                 │
│ the first author of a   │                 │
│ specific intervention   │                 │
│ study.                  │                 │
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              ↓                              ↓
┌─────────────────────────────────────────────────────────────┐
│ Refer to relevant intervention table according to the        │
│ intervention type:                                           │
│ Psychosocial and environmental interventions (Appendix 3)    │
│ Biological interventions (Appendix 4)                        │
└─────────────────────────────────────────────────────────────┘
              ↓                              ↓
┌─────────────────────────────────────────────────────────────┐
│ Refer to the appropriate category in the intervention tables │
│ (for example animals in psychosocial/environmental). Studies │
│ are listed in the intervention tables by first author's      │
│ surname.                                                     │
└─────────────────────────────────────────────────────────────┘
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**Terminology**

In this guide, the term BPSD will be used to refer to dementia related behavioural and psychological symptoms, unless otherwise specified. The term *Aboriginal and/or Torres Strait Islander peoples* will be used throughout the document (9, 10) and the abbreviation *CALD* will be used to refer to people from Culturally and Linguistically Diverse backgrounds. Additional considerations relevant to Aboriginal and Torres Strait Islander peoples and those from CALD communities have been included as a series of text boxes. The term carers can refer to family and friends who provide support and care, sometimes known as informal carers, caregivers or professional carers. Where necessary, the text will differentiate between these and formal, paid carers.

**DBMAS operation and practice**

As noted in the DBMAS operational guidelines, the role of DBMAS clinicians requires that they:

> "...provide information and advice on dementia and related behaviour, assessment and diagnosis support, clinical supervision and mentoring of carers and care staff, support with care planning, short term case management, including...guidance related to dementia and other care issues such as environment, safety etc., access to brokerage funds to provide short term interventions and direct services, tailored information and education workshops, liaison and referral to other related

services, and clinical support and advice related to dementia and related behaviours."

Additionally, DBMAS clinicians should seek to *mentor* and *model* as well as be *proactive* and *reactive.* While DBMAS providers do not provide ongoing crisis management, a 24-hour telephone assistance line is available. In providing assistance, DBMAS providers and clinicians need to be mindful of the rights of persons with dementia and the obligations of service providers toward persons with dementia. Persons with dementia must give informed consent for treatments or where this is not possible, proxy consent should be sought.

The following broad principles should apply to all efforts in managing dementia related behaviour:
- The rights of persons with dementia and BPSD are recognised and protected.
- Treatment or management has a goal of maximising quality of life and safety within the least restrictive environment for each individual.
- The behaviour of persons with dementia is recognised as a form of communication.
- The impact of BPSD on the person with dementia, families and staff who provide care is recognised.
- Collaboration with all people affected is the preferred approach to managing BPSD.

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

As a culturally competent clinician and service provider, the difference between culture and language should be understood. The two do not always go hand-in-hand:
- Whilst language is a significant barrier for many people from CALD backgrounds, it is also important to recognise the cultural diversity within English speaking populations. Some of these population groups face cultural barriers, particularly where service providers are unaware of the diversity and do not recognise them as requiring culturally relevant and appropriate services because they are English speaking.
- An awareness of the nuances across and within different groups is also important (11). For example, those with a common language may be from very different cultures which are based on geography and/or religion.

A culturally competent approach requires attention to three important variables (12):
- **Ethnocentrism:** We tend to have a viewpoint based on our own socio-cultural background. As this generally occurs at an unconscious level, it is difficult to distinguish but none-the-less informs how individuals view so-called "normal" or "abnormal" behaviour. This includes all those involved in care, such as clinicians, formal and informal carers and other family members. Clinicians therefore need to develop a conscious awareness of the viewpoint they and others impose. Accommodating the person with dementia's experience and differing viewpoints with regard to symptoms, diagnoses and acceptable treatments can then follow.

- **General understanding of illness within community:** Understanding of illness differs across cultures depending on whether there is an emphasis on individualistic (ego-centric) or collectivistic (socio-centric) focus on health and wellbeing. It is important to recognise the different ways health and wellbeing can be constructed. Core individual differences, such as family dynamics, political views, educational background, religion, socio-economic status and sexuality can inform how health and illness are individually and collectively viewed.
- **The person with dementia and their family's health literacy:** Clinicians should actively strive to improve the health literacy of the person with dementia and their family as this may decrease their fear of illness, assessment and treatment, enabling additional input into their health management. Education about biomedical methods should add to the person with dementia's beliefs, not supersede them. A combination of biomedical and culturally or spiritually relevant medicine may improve the therapeutic relationship and increase compliance with the former.

In addition, 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 it is important to not make stereotypical assumptions about the person with dementia on that basis. Research and literature provide broad knowledge and frameworks for service access issues and the needs of Aboriginal and Torres Strait Islander communities. It is important to understand that each community is unique, as is the connection between community members and the broader community. Clinicians should gain an understanding of and working relationship with local communities, as this may assist in understanding the service access issues, the needs of local communities and the local lores and culture.
- **Communication:** Effective assessment and management of BPSD in persons with dementia from an Aboriginal and/or Torres Strait Islander or CALD background may require additional attention to communication strategies. 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 (see *Module 1* for more information on culturally competent communication).
- **Assessment tools:** It is expected that clinicians undertaking assessment for people living with dementia, use their clinical reasoning skills in making decisions around the appropriateness of specific assessment tools. This will include a discussion with the person, carer and/or family, and may also include a discussion with Aboriginal and Torres Strait service providers and/or clinicians regarding the relevance of all assessments and assessment tools. Culturally appropriate instruments, where available and appropriate, should be used for the assessment of possible cognitive impairment in those from Aboriginal and Torres Strait Islander or CALD backgrounds, where indicated (see *Module 2* for more information on culturally appropriate assessment tools including the KICA and the RUDAS).
- **Raising Awareness:** Providing education and raising awareness around dementia and BPSD is an important aspect of the DBMAS clinician's role. Raising awareness of, not only dementia and BPSD, but also of DBMAS services is particularly pertinent for Aboriginal and Torres Strait Islander communities and those from a CALD background. These population groups often have difficulty accessing services and awareness of the

services available tends to be lower than in the mainstream population. An understanding that dementia and BPSD are not part of normal ageing and that potential management options for BPSD and "culturally safe" assistance may be lacking.

- **Auditing and benchmarking:** Auditing of the organisation's written materials, resources, referral processes, telephone manner, performance appraisals, benchmarking and service provision for cultural competency should identify areas where services are weak in these areas.

*See the following for further information specific to cultural competency in working with Aboriginal and Torres Strait Islander peoples:*

- Aboriginal Health and Medical Research Council of NSW. (2009) (accessed May 2012) Aboriginal practice checklist: A cultural assessment tool for MERIT Teams (13) (accessed May 2012). Source from: http://www.health.nsw.gov.au/pubs/2010/pdf/aboriginal_practice_check.pdf.
- NSW Department of Health (2010). *Aboriginal older peoples' mental health project report* (14).
- Mungabareena Aboriginal Corporation and Women's Health Goulburn North East (2008) *Making two worlds work: Working with Aboriginal people and communities resource kit* (15) (accessed May 2012).
  Source from: http://www.whealth.com.au/mtww/resource_kit.html
- NSW Department of Health (2007). *NSW Aboriginal Mental Health and Well Being Policy 2006-2010* (16) (accessed May 2012). Source from: http://www.health.nsw.gov.au/policies/pd/2007/pdf/PD2007_059.pdf

The Purnell Model of Cultural Competence (11, 17) and accompanying framework provides a tool for use in all health settings to promote culturally competent assessment of cultural perspectives of health and health care. The model outlines the 12 cultural domains and associated concepts that impact on health care provision for people from a CALD background (building on the points outlined above), including, but not limited to heritage, family roles and organisation, nutrition, spirituality and health care practices. Using this model the authors provide an overview of 27 different cultural groups in the United States with a list of comprehensive assessment questions (17). The model can guide clinical practice including assessment from a culturally competent perspective and the development and implementation of individualised, person-centred management interventions.

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

**Additional cultural considerations for service provision to those with dementia in Aboriginal and Torres Strait Islander communities**
Aboriginal and Torres Strait Islander peoples are made up of many diverse communities and language groups within Australia. Variations in cultural norms are relative to multiple factors which include size of the community, geography, climate, urbanisation, language as well as traditional, historical, political and social influences (18). Issues relevant to Aboriginal peoples and Torres Strait Islander peoples are typically considered together although some research has been done around specific geographic regions, Aboriginal cultures and/or Torres Strait Islander cultures.

While Aboriginal and Torres Strait Islander cultures incorporate extensive diversity, for the purposes of this guide, aspects related to Aboriginal and Torres Strait Islander peoples will be considered together. Further investigation is required if these aspects are to be more descriptive and specific even within the context of the variations in cultural norms and multiple factors. These investigations are outside the scope of the development of this guide. While significant heterogeneity presents across Aboriginal and Torres Strait Islander peoples living in urban, regional and remote locations, commonality arises from a shared history of dispossession, disadvantage and poor health outcomes. An understanding of the unique needs of communities at a local level is essential to providing holistic, culturally appropriate services.

An awareness of cultural differences is only the first step toward cultural competency. Aboriginal and/or Torres Strait Islander cultural competency requires an awareness of 'culture' within the context of community/family and the life experiences which guide the additional considerations for working with families living with and/or caring for a person with dementia. DBMAS clinicians' usual manner of assessment may not be culturally appropriate for Aboriginal and/or Torres Strait Islander peoples and cultural competency is essential for the comprehensive and appropriate assessment of BPSD.

### *Perceptions of dementia and health literacy*
There is reportedly no exact translation for the term dementia and considerable variations exist around how the meaning and context of dementia and/or memory loss is defined by different Aboriginal or Torres Strait Islander communities across different parts of Australia (19-21). Terminology and interpretations of dementia can include the perception that the condition occurs as the result of a curse, "payback", "bad spirit", "sick spirit" or natural spiritual ageing. Dementia can also be viewed as a form of punishment because there are no dreaming stories relating to memory loss. Communities living in urban areas tend have a greater awareness of dementia.

Aboriginal and/or Torres Strait Islander persons with dementia may retain long-term autobiographical memories and still be able to maintain their story telling role, although they may have difficulty performing basic ADLs. This can lead to a diagnosis of dementia being questioned by the community. Additionally, Aboriginal and Torres Strait Islander Elders have a duty to pass on their knowledge. Difficulties can arise when symptoms of dementia occur, as their position of respect may mean the community is reluctant to acknowledge problems. In some areas, community services see little dementia because Aboriginal and Torres Strait Islander peoples typically don't present to health services until they are admitted to inpatient facilities during a crisis. Community education, with regard to the long and short term memory issues that impact on functioning in dementia, may be a further aspect of the clinician's role.

### *Developing partnerships with Aboriginal and Torres Strait Islander service providers and communities*
Building positive partnerships with Aboriginal and Torres Strait Islander communities, health workers and service providers is essential for establishing appropriate and sustainable connections (22) which may generate referrals to DBMAS Services. Acknowledging healthcare access issues and inequalities that have been commonplace for Aboriginal and Torres Strait Islander peoples for many years is a necessary step in this process.

> ***Key considerations for developing appropriate partnerships with Aboriginal and Torres Strait Islander service providers*** *(adapted from Taylor and Thompson 2011 (23))*
> - Ensure partnership services are developed in response to the needs expressed by the Aboriginal and Torres Strait Islander communities
> - Honour Aboriginal and Torres Strait Islander ways of building relationships and allowing development of trust over time
> - The commitment of executive with leadership and vision is essential
> - Ensure equal participation in planning and power sharing
> - Ensure the partnership is built on realistic resources to support its ongoing development
> - Ensure local Aboriginal and/or Torres Strait Islander communities are aware of and engaged with the project
> - The process needs the commitment of motivated individuals at all levels
> - If appropriate, give the partnership project a name
> - Use a facilitator to negotiate historical issues and different approaches to health and culture
> - Ensure a commitment to work through sensitive issues with problem solving processes
> - Develop linkage processes, including formal documentation of partnership service structure. Documentation should be prominently displayed and content explained to all stakeholders.
> - Ensure promotional and information materials are culturally appropriate
> - Ensure clarification of roles, including who will take responsibility for troubleshooting
> - Ensure staff have attended and embraced cultural awareness training
> - Be consistent in holding regular, joint meetings; utilise technology where distance or other factors mean face to face meetings are not always possible
> - Use power sharing methods, such as changing chairpersons and location of meetings
> - Set targets; develop reliable data collection for simple monitoring and outcome indicators
> - Ensure Aboriginal and Torres Strait Islander staff have opportunities for professional development
> - Dedicate time for a development period to build mutually respectful relationships
> - Ensure staff have opportunities to interact and build relationships across services
> - Consider staff exchanges with partner organisations to increase awareness and empathy

- Aboriginal and Torres Strait Islander community Elders, health workers and/or service providers can assist the process of developing relationships and trust when DBMAS services are attempting to work in partnership with Aboriginal and Torres Strait Islander communities. A trusted person or service provider is important, and often essential, for overcoming barriers between DBMAS services and local communities.
- Expectations of partnerships need to be defined. Aboriginal and Torres Strait Islander specific services are not able to take on the roles of multiple conventional services. It is important that each service does its job effectively and that they do it in partnership. Services should seek ways to support each other for the betterment of dementia and BPSD management in Aboriginal and Torres Strait Islander communities.
- Improving models of care to ensure culturally appropriate access, assessment, management of BPSD and follow-up is essential to maintaining partnerships (24).
- Service providers' initial contact with an Aboriginal and/or Torres Strait Islander community may be simply a step toward building rapport and trust. Trust is considered very important for coordinating action between agencies (25).
- Trust in the context of developing partnerships emphasises the expectation that:
  - obligations will be fulfilled
  - organisations will behave in a predictable manner and
  - will act fairly when the possibility for opportunism presents (26).

- The demands on Aboriginal and/or Torres Strait Islander specific services can be broad and extensive. Service providers are frequently required to be flexible and deal with practical issues such as transport, accommodation and advocacy for clients in their dealings with other services. Regional services, particularly, tend to have a wider portfolio and are often called upon to provide a greater range of services within the one organisation.
- All services should recognise Aboriginal and Torres Strait Islander health workers as primary contacts for health-related issues (27). Service providers however, should not lose sight of the fact that Aboriginal and Torres Strait Islander health is the responsibility of all services.
- Because health issues are amplified within Aboriginal and/or Torres Strait Islander communities and there are less health workers to deal with the issues overall, the need arises for them to work across many different domains that impact on the multiple aspects of Aboriginal and/or Torres Strait Islander health.
- Challenges can arise when a service provider relies solely on an individual for a connection to Aboriginal and/or Torres Strait Islander communities. Where trust is placed in the person working in the health worker role, rather than in the position within the service, and that staff member leaves, trust must be re-established.
- When developing partnerships or working with local Aboriginal and/or Torres Strait Islander peoples gaining an understanding of the meaning and potential effects of "shame" in relation to BPSD is important and can impact on the outcomes of service provision (14). Within the context of Aboriginal and/or Torres Strait Islander culture, "shame" is reportedly a difficult concept to define, bearing little resemblance to a dictionary definition. It is a set of feelings rather than a single emotion (28).
- Evaluation and indicators of success are not only about numbers of referrals or occasions of service with Aboriginal and Torres Strait Islander peoples (23). Consider:
  - Successful communication with local Aboriginal Medical Services
  - Attendance at local community meetings
  - Take up of Aboriginal and Torres Strait Islander specific brochures
  - Acceptance of offers to provide information sessions at community groups
  - Other subtle signs that partnerships are developing

*Developing partnerships with Aboriginal and Torres Strait Islander communities*
- Clinicians need to be aware of their own existing values, ethics and construct of health (ethnocentrism) to be open to the possibility of developing partnerships with Aboriginal and Torres Strait Islander communities.
- Knowledge of the local community is needed for an understanding of which family groups can be invited concurrently for awareness-raising activities and which should be invited separately. An error in this area may mean considerable ground is lost in developing connections. Generalised, as well as targeted strategies may be necessary.
- Approval to engage with an Aboriginal or Torres Strait Islander community may need to be provided by a person of the same Nation, *Country*, community and/or kinship structure as those the service provider is seeking to access.
- Making connections with a key person in the Aboriginal and/or Torres Strait Islander community requires finding the right pathway which can be different in each instance. Access may be via another service provider which is already visible and accepted as culturally safe.
- The development of all official documents relevant to services for Aboriginal and Torres Strait Islander peoples requires engagement with local communities at every

level of the process. This includes, most importantly, the identification of joint priorities and joint planning in the preliminary stages (see Aboriginal and/or Torres Strait Islander Health Partnership Agreements in each State and Territory).

- Depending on the region, Aboriginal Medical Services (AMS) and/or Land Councils may be relevant to developing effective connections with Aboriginal and/or Torres Strait Islander communities.

- Developing relationships and trust with Aboriginal and Torres Strait Islander communities may take months or years before referrals to DBMAS are forthcoming. Valuable knowledge sharing, in both directions, occurs during the process.

- Clinicians need to recognise this two way process as an opportunity to develop an understanding of the historical traditions and culture which must be respected and acknowledged in culturally appropriate service delivery.

- With successful and respectful encounters, word of mouth may indicate that the health worker and/or service provider is 'culturally safe'. Further contact with the community may follow in time.

*Access to services for Aboriginal and Torres Strait Islander communities*

Many Aboriginal and Torres Strait Islander people do not engage with healthcare providers and the reasons behind this are numerous and varied (29).

- While services are theoretically available to Aboriginal and/or Torres Strait Islander people, access is limited as they are not tailored to their needs.

- For some Aboriginal and Torres Strait Islander people, a lack of confidence in official or Government agencies and/or church organisations continues (22). Arising from the traumatic history and maltreatment around "welfare services" and enforced institutionalisation, service providers may be associated with a history of traumatic experiences with Government agencies (30).

- Presentation to health services may be involuntary and law enforcers and/or police may be feared or resented by Aboriginal and/or Torres Strait Islander people.

- Limited specific services for Aboriginal and/or Torres Strait Islander peoples are available; however these services often lack "expert" practitioners and clinicians. This situation is gradually changing with increasing clinical and medical training opportunities for Aboriginal and Torres Strait Islander peoples.

- Among Aboriginal and Torres Strait Islander communities, older males reportedly tend to resist services to the greatest extent. However, when a male Aboriginal and/or Torres Strait Islander health worker is involved response rates improve.

- Aboriginal and/or Torres Strait Islander people may prefer to access non-Aboriginal or Torres Strait Islander services at times to circumvent the local community becoming aware that assistance is needed and potentially avoid the shame associated with this situation.

- Practical barriers such as a lack of private and/or public transport or significant distances, particularly in regional and remote areas, can preclude access to services.

In addition to building partnerships with Aboriginal and/or Torres Strait Islander service providers and communities, medical and/or clinical interventions are best delivered using a holistic service delivery approach. This may require clinicians learning the meaning, understanding and context of dementia for the person and their carer, family and/or community. Services with appropriate cultural protocols are lacking as are services which provide a good match for referrals for Aboriginal and/or Torres Strait Islander people with dementia.

**Additional cultural considerations for service provision to those with dementia in CALD communities**

When working with CALD communities it is important to recognise the myriad differing understanding 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' approach to assessment and management may not be culturally appropriate or relevant for CALD communities. Therefore, culturally competent care and clinical practice is vital for comprehensive and appropriate assessment and management of BPSD within CALD communities.

*Perceptions of dementia and health literacy*

While awareness of dementia and related terminology has increased across CALD communities over the past 10-20 years, dementia is typically not well understood. Some of the more established CALD communities have greater access to education, more resources in general and a better awareness of dementia although this varies with geographical location. Less established CALD communities tend to have less access to education and services and thus, may have relatively little awareness of dementia.

*Awareness of dementia:*
- For many CALD communities, forgetfulness is seen as a natural part of the aging process, with no connotations relevant to disease. Family members' experience of grandparents and/or elderly relatives when growing up in Australia may be limited or non-existent, dependent on their history and experience of migration. They may therefore have had very limited experience of "normal" forgetfulness in older people and dementia and/or BPSD may not be seen as a medical issue.
- In some languages the words used to describe dementia can be negative and stigmatising. For example, in Cantonese terms "stupid" and "dumb" have been used.
- If a person becomes particularly forgetful, family members may recognise that all is not well, however they may be reluctant to seek help or do not know how to access help.
- Shame and secrecy can be associated with mental health issues and/or dementia in CALD communities. This may be due to fear of how the person with dementia will be perceived by the rest of the community and the potential for isolation and stigma, not just for the effected person, but for the whole family.
- The belief that a diagnosis of dementia and/or BPSD may result in forced removal from their home to a RACF can generate a fear of service providers, possibly exacerbated by past traumatic events.

*Awareness and understanding of BPSD:*
- BPSD associated with dementia can be particularly difficult to comprehend and may pose a major issue for families when trying to explain such behavioural changes to others in their community (31, 32).
- Fluctuating behaviours can mean that conceptualising the link between dementia and BPSD is challenging.
- BPSD can reinforce ideas of a person being possessed. This has subsequent implications for service utilisation as well as the treatment and management of dementia and/or BPSD, such as families not seeking out or consulting a GP.
- BPSD within different cultural contexts may not fit or appear 'normal' in a conventional context. Service providers may not understand the frustrations for some CALD people regarding language, food and/or activities. For example, some CALD groups may not

have traditionally used a fork to eat with or taken a shower or bath. Their response to the situation or resultant distress may be labelled as BPSD.

### Developing partnerships with CALD communities and service providers

Working towards constructive partnerships with CALD communities, health practitioners and organisations is essential for establishing appropriate and sustainable connections which may generate referrals to DBMAS Services.

*Developing partnerships with organisations:*
- Partnerships need to be developed with ethno-specific and CALD-specific organisations and multicultural health workers.
- CALD health workers, religious leaders and/or community elders can provide links to health information and services that are usually difficult to access.
- Expectations of partnerships need to be defined. All those involved should be mutually respectful, with an awareness of the important role played by bilingual/bicultural workers who may not have the equivalent professional qualifications, but bring an important set of skills and knowledge. Partnerships and individual services should seek ways to support each other and promote good BPSD management in CALD communities.
- Clinicians need to be willing and competent when working in partnership with bilingual/bicultural clinicians or workers that can assist with dementia screening, assessment and care in a culturally competent and sensitive manner (33) (see *Module 1* for more information).
- Improving models of care to ensure culturally appropriate access, assessment and management of BPSD as well as follow-up is essential to maintaining partnerships.
- Service providers should be mindful of the fact that CALD health and wellbeing is a responsibility for all services, not only multicultural or ethno-specific services.
- Evaluation and indicators of success are not only about numbers of referrals or occasions of service with CALD communities. Consider:
  - Successful communication with local multicultural and/or ethno-specific services and organisations
  - Attendance at local community meetings
  - Take up of CALD specific brochures and information resources
  - Acceptance of offers to provide information sessions at community groups
  - Other subtle signs that partnerships are developing

*Developing partnerships with CALD communities:*
- As part of culturally competent care for people from CALD backgrounds clinicians should also understand the importance of working with families.
- DBMAS clinicians need to be aware of their own existing values, ethics and construct of health (ethnocentrism) to be open to the possibility of developing partnerships with CALD communities
- There may be a need to talk to the family first about the situation and then the person with dementia while keeping the family informed throughout the process. This may also involve talking to family members overseas and enabling their involvement in the decision making process, particularly when making the decision to transfer the person with dementia to residential care.
- This can prompt a need to explain the Australia health care system and associated processes, which can be very difficult for those unfamiliar with the system.

- Formal carers in RACF and/or community care settings can be from migrant or ethnic backgrounds which are different to that of the person with dementia from the same CALD group. This can have significant implications for cultural sensitivity and safety.
- Developing relationships and trust with CALD communities may take months or years before referrals to DBMAS are forthcoming. Valuable knowledge sharing, in both directions occurs during this process.
- Clinicians need to recognise this two way process as an opportunity to develop an understanding of the traditions and culture of different CALD communities and individuals, which must be respected and acknowledged in culturally appropriate service delivery.

# MODULE 1: DBMAS behaviour management process

The flow diagram (*Figure 1.1*) illustrates the standard process involved in responding to a request for assistance with managing BPSD. This process may involve a telephone and/or in person consultation. The key considerations in each step of the process are outlined in the following sections.

*Figure 1.1 Flow diagram of behaviour management process*
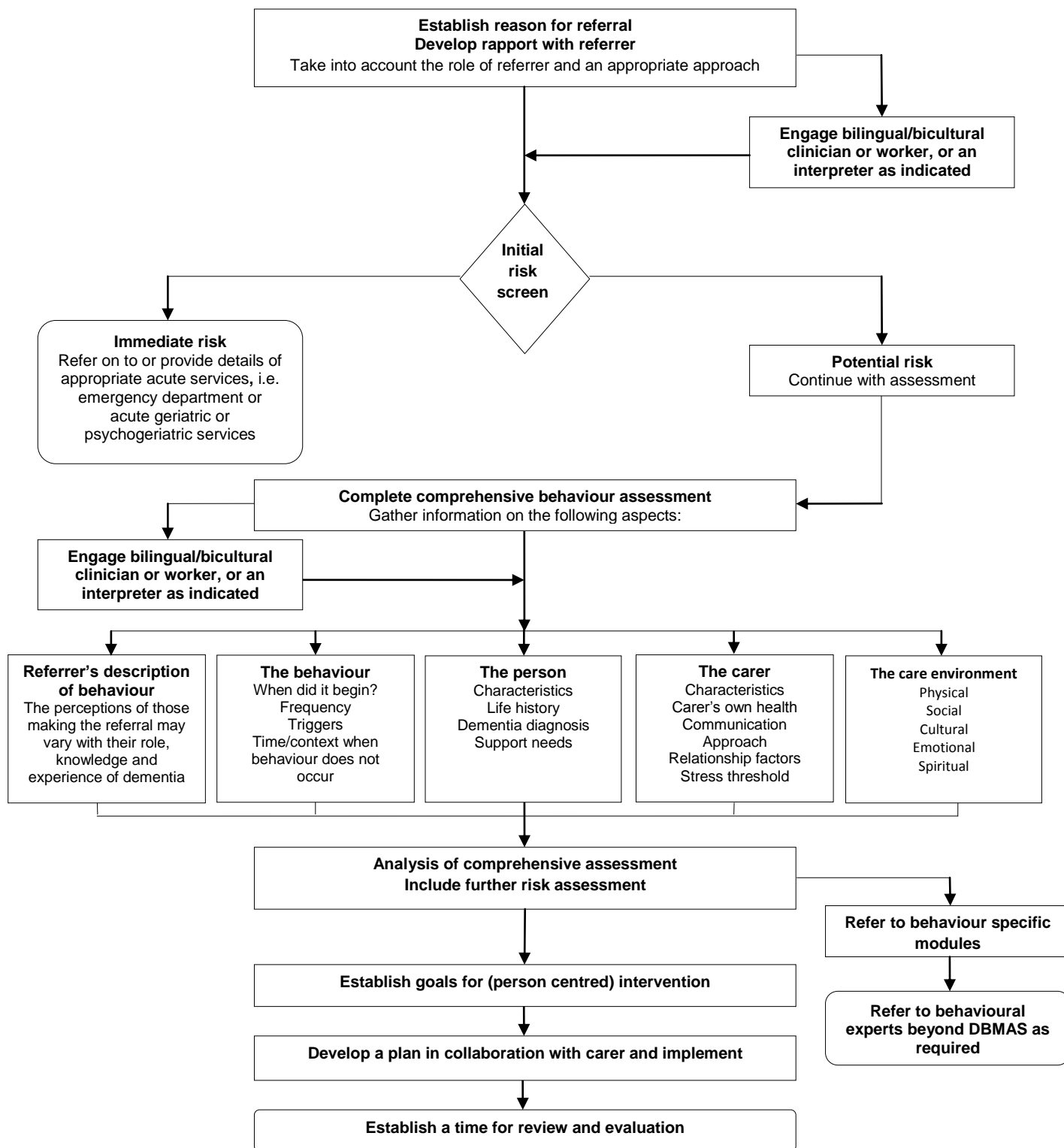
**The referral**

It is important to establish a rapport with the person making the referral from the outset whether this is over the phone or in person. The required approach to the conversation will differ depending on the role of person making the referral, for example whether it is a family carer, or staff from a residential aged care facility (RACF). The level of concern the referrer is conveying about the situation needs to be taken into account. Outlining the assessment and referral process as well as providing assurance, early in the conversation, that action will be taken as soon as possible will enhance the process of describing and investigating the behaviour.

> When receiving referrals, clinicians should seek to understand the context, meaning and perspective of dementia and the behaviours exhibited for the individual. A referral from a person who is from an Aboriginal and/or Torres Strait Islander or CALD background may have a different cultural understanding of dementia and BPSD. It is important to be aware of the different ways dementia and BPSD may be understood when collecting information around the situation (see *Introduction* for further information).
>
> The person making the referral may not be fluent or comfortable speaking in English. If this occurs, an appropriate phone or in-person interpreter may be required to ensure optimal information exchange and understanding (see *Communication section, p. 24* for further information).

**Risk assessment**

The most immediate consideration during an initial consultation is the degree of risk, or the potential harm or danger, inherent in the situation for the person with dementia, family members, care staff and/or members of the public. 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*: There is immediate medical, mental health, physical and/or environmental risk to the person with dementia or other people.
- *Potential risk*: The risk to the person with dementia or others is potential at this time. Strategies to prevent future increased risk should be integrated into the care plan.

When determining the degree of risk the following aspects should be taken into account:
- the nature and severity of the presenting behaviour
- the context of the behaviour
- the resources available within the care environment to manage the situation

*Areas of risk*

When conducting a risk assessment the potential medical, mental health, physical and/or environmental areas of risk should be considered. See *Table 1.1* for possible areas of risk to both the person with dementia and other people.

*Medical and mental health*

Delirium is potentially a significant risk. *Module 2* provides further information on differential diagnosis of delirium and guidelines for the recognition and investigation of delirium as well as additional resources. The person with dementia may be at risk from untreated medical causes of the behaviour or co-morbid mental illness that may progress rapidly without urgent treatment. The most common causes of mental health issues are profound depression or psychosis. If the person with dementia is severely depressed, suicidal or not eating and drinking, urgent referral should be made to a psychogeriatrician or psychiatrist. If the person is psychotic and acting on hallucinations or delusions in a way that may be dangerous, immediate referral to a psychiatric emergency/crisis team or hospital emergency department is indicated.

*Physical*

Some dementia related behaviours, including aggression, wandering and sexual disinibition, can pose a risk of physical harm. Similarly, abuse of a physical, financial, emotional and/or sexual nature is an important consideration for the person with dementia and others around them. Dangerous situations involving physical risk must be approached with caution. If a high physical risk situation arises, advise the referrer to avoid escalating the situation and protect all involved by:

- not arguing or attempting to reason with the person with dementia
- maintaining contact with local assistance via a mobile phone if possible
- if necessary, isolating themselves from the person with dementia and seeking assistance from others nearby and/or contacting local emergency services such as police or ambulance

*Environmental*

High risk to the person with dementia can be associated with an unsafe environment. This can include extreme carer stress or the risk of loss of accommodation, particularly in residential care settings. BPSD can place the person with dementia in imminent danger of being moved from their current accommodation unless an intervention is implemented promptly. Relocation due to behaviour can be an irreversible catastrophic event permanently changing the life of the person with dementia. The *Aged Care Act* [1997] and *Residential Care Manual* [2009] provide legislative guidance on the rights of people living in residential care.

*Table 1.1 Possible areas of risk*

| MEDICAL/MENTAL HEALTH | PHYSICAL | ENVIRONMENTAL |
|---|---|---|
| **Medical issues**<br>• delirium<br>• urinary infection<br>• silent infection<br>• constipation<br>• inability to recognise or report pain and/or other symptoms<br>• reduced appetite, food and/or fluid intake resulting in dehydration, malnourishment and/or electrolyte imbalance<br>• atypical disease presentation, i.e. lack of common features<br>• polypharmacy<br>• medication noncompliance, overdose or toxicity<br>• co-morbidity<br>• presence of other chronic diseases<br>• alcohol abuse<br><br>**Mental health issues/co-morbidity**<br>• depression<br>• suicidal ideation<br>• psychosis<br>• psychiatric history<br>• post traumatic stress disorder (PTSD)<br>• anxiety | **Potential physical harm to the person with dementia**<br>• lack of awareness of exposure to danger<br>• injury as a result of physical aggression directed at others or inanimate objects<br>• wandering from care setting unaccompanied<br>• changes in perception<br>• misinterpretation of environment, including other people<br>• increased risk of falls<br>• extreme carer stress leading to assault<br>• neglect or abuse, i.e. physical, financial, sexual<br>• self-destructive behaviours<br>• impulsive behaviours<br><br>**Potential physical harm to others as a result of the person with dementia's behaviour**<br>• physical aggression<br>• sexual disinhibition<br>• response to delusions or hallucinations<br>• situation exacerbated by alcohol<br>• physical abuse | **Unsafe environment**<br>• safety hazards in care environment<br>• carer's capacity and/or tolerance compromised due to illness or lack of support<br>• avoidable transfer to hospital resulting in increased confusion and/or disorientation<br>• change to physical environment<br>• leaving the home unsecured<br>• allowing strangers into the home<br><br>**Potential loss of accommodation as a result of the person with dementia's behaviour**<br>• transfer from current accommodation<br>• transfer to more restrictive care setting |

**Person-centred approach to dementia care**

Developed by Kitwood and the Bradford Dementia Group (34, 35), the person-centred approach to care provides a holistic framework for understanding the person with dementia as well as the BPSD, rather than focusing solely on the management of BPSD (36). Practices such as physical restraint and neglect of psychological, social and cultural needs can compromise a person's sense of personhood (recognition, respect and trust gained through social interactions and relationships) and also damage their physical wellbeing (37, 38). Furthermore, care that emphasises a biomedical perspective, focused on activities of daily living, can undermine personhood (35), contribute to what Kitwood (37) terms "malignant social psychology", and subsequently lead to emotional stress and increased BSPD (39).

Central to person-centred care in dementia is a focus on supporting relationships and communication (34). Person-centred care (36) encompasses four key elements **VIPS**:
   1. **V**aluing persons with dementia (V)

2. Treating people as **I**ndividuals (I)
3. Looking at the work from the perspective of the **P**erson with dementia (P)
4. A positive **S**ocial environment in which the person with dementia can experience relative wellbeing (S)

The *Person-centred Care Assessment Tool (P-CAT)* is a questionnaire that can be used to assess the extent to which care is person-centred within an RACF (40). By employing a person centred approach to all aspects of dementia care, including the assessment and management of BPSD assessment, a holistic understanding of the person and their life can be incorporated into management strategies that are tailored and therefore appropriate for the individual.

**Communication**

Effective communication is a critical factor in the assessment and management of BPSD. This is particularly important to consider when aiming to provide culturally competent services to persons with dementia and their families from Aboriginal and Torres Strait Islander or CALD backgrounds as language can be a significant barrier when seeking health advice and interacting with services. During a referral or when undertaking an assessment clinicians should ensure they are able to communicate effectively with the person with dementia.

*Culturally competent communication*

General principles for culturally competent communication with persons with dementia include:
- Confirm the persons preferred mode of being addressed (e.g. Mr, Mrs, Aunty, Uncle) and the correct pronunciation of names.
- Based on observation, and some direct questioning, check that 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.
- If providing any written form of communication, ensure that is it is in the person's preferred language and that it is clear and easy to understand. It is also important to be mindful of that fact that some people may be illiterate even in their first spoken language so written resources may be in appropriate for the provision of information.
- Recognise and accommodate the influence of the social and cultural context on communication.

When collecting information regarding dementia and BPSD in Aboriginal and Torres Strait Islander peoples or people from CALD backgrounds, the person with dementia, care staff and/or family members may not be fluent or comfortable speaking in English with clinicians. Enlisting the services of an Aboriginal or Torres Strait Islander Health worker or a bilingual/bicultural clinician or worker is recommended (see below and *Introduction* for more information). Where these options are unavailable, an interpreter may be required to ensure optimal information exchange (24).

> *Communicating with Aboriginal and Torres Strait Islander*
> Culturally appropriate language may vary considerably within and across Aboriginal and Torres Strait Islander communities throughout Australia. Services must be well versed in culturally appropriate English terminology which is acceptable to the communities in their local area (41).

The understanding and use of language can differ considerably during communication with Aboriginal and/or Torres Strait Islander communities in comparison with broader Australian populations. The communication process requires respect, listening, patience, confirmation, clarification and more (42).

In Aboriginal and Torres Strait Islander communities an appropriate spokesperson may be nominated to act as an interpreter and/or support person for the person with dementia. 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 beyond the concept of interpreters as used in a conventional role (see *Care Environment section, p. 44*, for further information). Consent to access a cultural broker must, of course, be obtained from the client, carer and/or key person beforehand.

At times, it is appropriate to consider the separation of "Men's business" and "Women's business". In some communities a female Aboriginal or Torres Strait Islander health worker will not be able to discuss health issues or assist with an assessment of a male client. Likewise, younger clinicians attending BPSD assessment may be hindered by their youth when working with Elders.

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*Communication: CALD considerations for working with bilingual and bicultural clinicians and workers*

Where possible, efforts should be made to work with bilingual/bicultural clinicians (as a first preference) and bilingual/bicultural workers (as a second preference) for ensuring culturally appropriate assessment and management of dementia.

- Bilingual or bicultural clinicians are those registered health professionals who would typically provide assessment of dementia and/or BPSD.
- Bilingual or bicultural workers may be those working with members of the CALD community who may not have formal qualifications but are able to provide information, education, care and/or support to mainstream clinicians. Bilingual workers can act as a communication facilitator, however, in some instance they cannot act as interpreters (due to confidentiality issue etc). In this situation an interpreter may be required.
- 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).
- To be bicultural, the clinician or worker must have a high competence in and/or be from a similar cultural background to the person with dementia so that they are able to facilitate communication and information exchange in a culturally competent manner. This is not restricted to language, as the person with dementia may be proficient in English and come from a different CALD background, thus requiring a cultural broker as opposed to a bilingual clinician/worker.

Pathways to accessing bilingual/bicultural clinicians and workers will vary considerably by State and Territory depending on the support structures in place and networks that have previously been established between and across services. Due to this, it is important for DBMAS clinicians to familiarise themselves with the availability of services and resources for different language and cultural groups in their area and establish connections with appropriate bilingual/bicultural clinicians and workers prior to receiving referrals. Maintaining an up-to-date list of accessible bilingual/bicultural clinicians and workers and bilingual/bicultural resources is useful.

### *Involving an interpreter in assessment*

Clinicians should avoid where possible, relying on family and/or friends to act as interpreters during a specialist assessment (see *p. 29* for exceptions in Aboriginal and Torres Strait Islander communities). A duty of care to the person with dementia requires that the assessment be as objective as possible. However, in doing so family and friends can feel they have a diminished role in the assessment and care planning process. It should be emphasised that family and friends have an important role in other parts of the process, for example interpreting in everyday communication. Ensure that the person with dementia and their significant others are informed, both verbally and in writing in their preferred language, of their right to access an interpreter at no cost to them at any time during the assessment.

Prior to involving an interpreter it is necessary to determine the English language proficiency of the person with dementia. Whilst you should always enquire whether the person with dementia would like an interpreter, it can still be difficult to determine if an interpreter is required. This may be because the older person is not familiar with the role of an interpreter. Alternatively, if their English is limited, or there is a cultural perception that it is better not to cause problems or "be a bother", the person with dementia may agree to all suggestions or requests. They may say "yes" they can speak English without completely understanding what they are agreeing to. It is thus vital to use other ways of determining whether the person with dementia requires an interpreter prior to undertaking a comprehensive assessment:

- Details of language use and fluency may be obtained through the use of short checklists, such as the Marin Short Acculturation Scale (adapted) (43).
- Another helpful way to determine whether someone is fluent in or comfortable speaking English is to ask them to answer three open ended questions that require full sentence answers, rather than merely yes or no.

It may also be necessary to establish the English language proficiency of family carers and/or care staff. Interpreting services may be necessary to ensure comprehension and opportunity for feedback. A sensitive approach is indicated as family members may not require or wish to engage an interpreter, and may find it offensive if asked.

### *Telephone versus in-person interpreters*

As previously noted (see *Referral section, p. 21* for further information), an interpreter may be needed during the initial referral phase if the person making the referral is not confident speaking English. It is *strongly recommended* that wherever possible an in-person interpreter should be present during a clinical assessment. A telephone interpreter service may not be suitable for clinical assessment of a person with dementia for a number of reasons:

- It may be difficult for the person with dementia to grasp the concept of interpreting when they cannot see the interpreter in person.
- Impaired hearing will further limit communication as the interpreter needs to check with the person with dementia that they are hearing all those involved. When the clinician pauses, the interpreter may need to repeatedly reassure the person with dementia that the clinician is still present but silent.
- If dementia severity is such that the client is dysphasic, accurate interpreting over the telephone may be impossible. When the client's speech is confused and/or disjointed, simultaneous interpreting is required which is not practical or appropriate over the telephone in this situation.

- During a telephone assessment, it is not possible to recognise non-verbal cues which aid assessment of BPSD or to assess the comfort of the person with dementia when using an interpreter.

In a situation where it is not practical to conduct the comprehensive assessment in person, possibly due to remoteness, lack of transport or inability to travel, an assessment via telephone or video conference may be the only viable alternative. Clinicians should aim to avoid using fillers such as "Uhmss" or producing distracting sounds by shuffling papers, scraping chairs and/or not switching other telephones to silent mode.

***Key considerations when working with interpreters and persons with dementia:***
*The interpreter*: it is important to assess the appropriateness of the interpreter for the assessment of the person with dementia and BPSD.
- Check the preferred language/dialect and gender with the person with dementia.
- Interpreters may be fluent in the person's language but be from an incompatible cultural or ethnic group.
- Sometimes confidentiality is an issue especially in small communities. Be sensitive to the situation and the needs of the different individuals involved in the assessment process.
- Availability of interpreters varies with geographical locations and degree of remoteness. Booking well in advance for major medical appointments may help to overcome this.

*Briefing the interpreter:* Clinicians need to brief the interpreter on the purpose of the consultation prior to the assessment (44).
- Discuss strategies including length of speaking segments, turn taking, dealing with interruptions and the inability of the interpreter to simultaneously interpret as this may confuse the person with dementia.
- Interpreters need to be aware that they should not use cultural cues or prompts in cognitive assessments.
- If undertaking a cognitive assessment, brief the interpreter on the importance of gathering objective information and advise them not to use their usual cultural cues.

*Seating arrangements:* For easy communication between all parties, seating should be arranged in a triangle allowing a free line of vision for all. A triangular seating formation is ideal as it provides for an equal distance between all those involved in the consultation. This also provides visual access for the interpreter to pick up on all linguistic/verbal and paralinguistic/non-verbal features of the person with dementia's speech, which might otherwise be missed if the interpreter is seated to the side.

Where this is not possible due to a confined space or in the event of potential safety concerns around an unpredictable client with BPSD, seat the interpreter to the side of the person with dementia or slightly behind. If the interpreter finds that this seating arrangement is impeding effective communication, they should raise their concerns immediately to allow a further attempt at rearranging the seating.

*Medical terminology:* Translation can be difficult, especially when working with interpreters who do not have experience within the health system. Mental health terminology can be complex and different contexts, history and meanings exist within cultural groups which can

impact on the translation process. Where possible, interpreters should be accredited in mental health terminology.

*Allow adequate time:* Be aware that a thorough assessment involving an interpreter may need approximately double the time of an assessment for a person who is fluent in English. Be cognisant of the potential for fatigue in the person with dementia and the interpreter during the assessment and take breaks when appropriate.

*For ease of interpretation, use short, easily comprehensible sentences:* If it appears that the clinician has not been understood, questions or statements should be rephrased. Avoid over use of jargon or technical terms. Those present should not raise their voice in an effort to enhance understanding as this may be offensive. Provide concise information, speak clearly but not overly slowly and repeat where required.

*Avoid interruptions* where possible as they can be very challenging for the interpreter and distressing for the person with dementia. Clinicians need to be patient during periods of interpretation and refrain from cutting in wherever possible.

*Verbal and non-verbal cues:* As there are no language cues for the clinician, it is useful to take account of the non-verbal cues to gauge if the client is comfortable. Be alert to non-verbal signals such as facial expressions and body language. Verbal cues such as volume, pitch and tone of voice, which differ from one language to another, can be difficult to read accurately. If unsure, ask interpreter about language and cultural idioms as well as non-verbal cultural cues.

*Cultural sensitivities and nuances:* When using a third party such as an interpreter it is important to ensure that cultural factors and sensitivities are sought and clarified early in the assessment process and respected as the assessment progresses.

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**Interpreters: Aboriginal and Torres Strait Islander considerations**

It is important that clinicians ask appropriate questions to determine whether the person with dementia requires an interpreter. The family/spokesperson may indicate that an interpreter is not required although the person with dementia may benefit from having one present (45). While the use of interpreters, in the conventional sense, for assessment is recommended, practical limitations exist.

- Many different Aboriginal and Torres Strait Islander languages exist and there is no generic language used across Australia (46, 47). In some communities Aboriginal and Torres Strait language(s) may be the main language spoken at home (48).
- Past government resettlement programs can mean that numerous different language groups occupy one geographical region.
- Some traditional languages are lost and specific interpreters may be unavailable. In some northern areas of Australia, a Kriol interpreter may provide an alternative.

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**Interpreters: CALD considerations**

In some cases there is a need for the clinician to be sensitive to the interpreter's country of birth e.g., a Serbian interpreter may be able to interpret in Croatian but their speech will have a different accent. Their name may also indicate their nationality this may lead to trauma or distress in the Croatian client.

> Confidentiality issues can arise in CALD communities, particularly within more recent migrant groups, which tend to be smaller. The person with dementia, interpreter and/or family may be known to each other. In this situation, a telephone interpreter who is external to the person's community, possibly from interstate may be preferred.
>
> It may be appropriate in some instances to seek guidance from relevant ethnic community groups on these issues and to identify suitable interpreters or cultural links.

**Comprehensive Assessment**

Comprehensive assessment requires the gathering of information to assist in the description and investigation of the behaviour. Collecting information from a variety of sources will assist in developing a picture of the person with dementia and the associated behaviour. *Appendix 1* provides suggested questions to facilitate behavioural assessment. Questions to ask care staff and/or family members and extensions to the questions are included as prompts for DBMAS clinicians.

The comprehensive assessment should incorporate a ***person centred approach***. The following aspects may influence the behaviour as well as the development and implementation of an effective management plan:

- A description of the **behaviour**.
- The characteristics of the **person** with dementia. Information regarding their personal history, including migration, language, cultural background, type of dementia, medical co-morbidities and current medication regime.
- The characteristics of the **carer and the care relationship**. Knowledge of dementia amongst care staff and families, degree of experience, their attitudes to caring for those with dementia and the ability to apply their knowledge will vary and may contribute significantly to the behaviour. Staff's abilities, orientation, educational preparation, cultural competency, behaviours towards the person and their family, and dementia care practices
- The **care environment**. This includes the physical, social and cultural dimensions of the person's immediate and extended environment. Care home orientation, systems, policies, workforce skills, leadership and physical care environment.

### *Description of the behaviour*

Gathering a detailed description of the behaviour and the context in which it occurs is necessary for assessing the situation and establishing an appropriate behavioural management plan.

As family carers and staff of aged care facilities are in frequent contact with the person living with dementia they are one of the most important sources of information. When obtaining a description of the behaviour from the carer(s) it is important to be aware that their perception of BPSD may vary with their knowledge and experience of dementia. For example, family carers and staff of RACFs sometimes find it difficult to understand that dementia interferes with the person's ability to control their behaviour. This misunderstanding can result in the perception that the behaviour is deliberate, directed at them personally or otherwise intentionally provocative. In contrast to this, referrals may come from carers who have trialled potentially effective interventions and may be seeking either validation of their approach or a collaborative conversation to explore further options.

It can be useful to ask the referrer to explain why they think the person with dementia is behaving in this manner and to outline strategies they have previously tried in their attempts to address or resolve the situation. This can help to clarify the referrer's perception of the behaviour. This can also assist the carer or RACF staff member to describe the behaviour more accurately and the context in which it occurs. Clinicians may need to provide explanations for general terms such as aggression or agitation as understandings of these BPSD can vary. It is helpful if the description of the behaviour is concrete and specific. For example, rather than stating that the person is aggressive, it could be more useful to describe specific actions, such as the person "swears at other residents" or "hits care staff".

### *The behaviour*
Assessment of the behaviour will investigate the following factors:
- frequency, duration and intensity of the behaviour
- clarification of events which lead to the behaviour occurring (antecedents)
- locations where the behaviour occurs
- people who are involved with the person with dementia when the behaviour occurs
- consequences of, and responses to, the behaviour by other people
- circumstances that prevail when the behaviour is not occurring
- extent of discomfort that the behaviour causes the person with dementia
- extent of concern for the person with dementia and others in the environment, including the emotional effect on those exposed

The greatest challenge for the clinician frequently occurs with determining what is driving the behaviour for the individual with dementia. The underlying causes may be complex, deep-rooted, silent and/or fluctuating. Sound clinical wisdom and practice will largely guide experienced clinicians, however where additional resources are required the following modules cover a breadth of published literature to supplement the clinician's expertise.

It is useful to collect information about the behaviour in a format designed to identify people, places and times of day associated with the behaviour. This encourages a more transparent description of antecedents and consequences of the behaviour as well as helping to establish a clearer impression of the situation and reveal recurring themes. *Table 1.2* provides a list of some of the factors and cultural considerations, including those relevant to Aboriginal and Torres Strait Islander peoples and people from CALD backgrounds, which contribute to BPSD and should be taken into account during the assessment.

Throughout the process of assessment it is useful to consider a range of sources for expanding the information. This may be undertaken by DBMAS clinicians or by carers or RACF staff on their behalf. Some sources of information include:
- **Behaviour charting** is a useful tool to confirm the information from the initial referral. Charting behaviour over several days will provide accurate, objective information and a baseline measure of the behaviour. Three days is typically suggested for most BPSD however, two sessions of 24 hours each with a break in between is recommended for wandering behaviours.
- **Medication review** by an appropriate clinician is essential in most situations. This also needs to include non-traditional medicine.
- Discussion with **care staff and family carers** (if indicated and available) to expand on their perception of the behaviour and its impact; and clarify the capabilities of the

person with dementia. Be aware of different cultural understandings and perceptions of dementia and BPSD and how this will affect the description of the situation.

- **Appraisal of multiple sources of information** including progress notes in RACFs, community services such as Meals on Wheels, neighbours, local retail outlet staff and/or friends.
- Introduction of **multi-disciplinary professionals** (if available) to undertake specific assessments, e.g. neuropsychology, physiotherapy, speech pathology where indicated.
- Discussion with the **general practitioner**.

*Table 1.2 Factors which may contribute to BPSD*

| PERSON WITH DEMENTIA | COMMUNICATION | ACTIVITIES OF DAILY LIVING | THE CARE ENVIRONMENT |
|---|---|---|---|
| **Life history:**<br>• family and friends<br>• pets<br>• significant events<br>• anniversaries<br>• sexuality<br>• migrant or refugee experiences<br>• culturally relevant traditions and events<br>• past traumas:<br>  o war-time experiences<br>  o Stolen Generation<br>  o dislocation from *Country* and culture<br>  o intergenerational trauma<br>  o loss of family member, home or Land/*Country*<br>**Physical/sensory health:**<br>• fever<br>• oral pain<br>• pain may be unrecognised and/or untreated<br>• constipation<br>• urinary tract infection<br>• chest infection<br>• other illness<br>• adverse effects of medication<br>• poor or interrupted sleep<br>• headache<br>• fatigue<br>• impaired vision without compensation<br>• impaired hearing without compensation<br>• irritating itch<br>**Mental health:**<br>• depression<br>• anxiety<br>• post traumatic stress disorder<br>• other mental health issues<br>**Emotional and spiritual health (holistic):**<br>• attachment to Land/*Country*<br>• loss of sprit or searching for spirit<br>• spiritual/religious beliefs, e.g. external wrongdoings, curses, payback as reasons for disease and/or BPSD | • speaking too quickly<br>• being condescending<br>• not making eye contact where appropriate<br>• not using person's name/title<br>• arguing with the person with dementia<br>• correcting mistakes by the person with dementia indicating failure<br>• trying to reason with the person with dementia<br>• language spoken is not preferred language of the person with dementia<br>• not following appropriate cultural protocols for communication<br>• not using the correct form of address and mannerisms<br>• Little/no family involvement in communication<br>• no other speakers of person with dementia's first language<br>  o loneliness<br>  o isolation<br>  o frustration | **Meals:**<br>• table setting too cluttered<br>• more than one course at a time<br>• meal times inflexible<br>• table companions cause irritation/agitation<br>• changes in personnel<br>• oral pain not recognised<br>• person's eating space not defined<br>• insufficient contrast between table cloth and crockery<br>• food not liked or culturally inappropriate<br>**Personal care delivery:**<br>• care plan not maintained<br>• care delivery rushed<br>• lack of gentle approach<br>• too many staff involved<br>• gender roles<br>• resident not involved<br>• bathroom may be uncomfortable, cold, claustrophobic and/or noisy<br>• no choices offered or choices too complex or inappropriate<br>• poor selection of type of personal hygiene, e.g. bed bath may be more appropriate than shower<br>• previous personal hygiene practices may be relative to past environment and resources available<br>• previous dental hygiene practices ignored<br>• over/under expectations of abilities by staff<br>• staff members talking over resident<br>• painful movement of limbs<br>• lack of bilingual or culturally competent staff where required<br>• cultural and spiritual needs not integrated into care | **Indoor environment:**<br>• overwhelming size<br>• no orienting cues<br>• glare from lighting/sun<br>• cluttered environment<br>• contrasting surfaces<br>• noisy environment<br>• too many others or isolated within the group<br>• personal space not personalised<br>• room is difficult to find<br>• culturally or spiritually inappropriate or offensive objects<br>• lack of a space to pray or carry out spiritual/religious activities<br>• lack of privacy<br>**Outdoor environment:**<br>• lack of points of interest or colour<br>• insufficient shade<br>• does not encourage sitting<br>• does not encourage walking<br>• not readily visible from indoors<br>• not readily accessible from indoors<br>• does not encourage engagement<br>• physically unsafe<br>• paths lead to frustrating dead ends<br>• Aboriginal and/or Torres Strait Islander peoples - removal from Land/*Country*<br>• outdoors may have dominated over indoors in previous lifestyle<br>**Stimulation levels:**<br>• lack of structured physical activity<br>• fatigue during the day<br>• boredom/ lack of meaningful activity<br>• overstimulation<br>• under/no stimulation in the environment<br>• lack of company<br>• dislocation from family, community and/or *Country* |

***The person with dementia***

Discovering as much as possible about the person with dementia is vital. Many aspects of the person's health and life experiences may contribute to the behaviour.

*Type of dementia:* Determine if a formal diagnosis has been made and the length of time since diagnosis, as well as associated cognitive and functional losses. Where the prevalence of particular BPSD varies significantly with dementia type, figures are included in the specific behaviour modules following.

*Aspects of the person's life story or personal history:* Collecting a social history and establishing a sense of the life story can assist in developing a comprehensive picture of the person. This may include details about the person's interests, routines, social networks, social roles, cultural background, spirituality, sexuality and special or traumatic events in their lives. Life Story book templates (see *Appendix 2*) or a Talking Photo Album (particularly where English is not the person with dementia's first language) can be used to assist family members and/or care staff to develop a picture of the person with dementia from their early life to the present.

*Physical and mental health:* Aspects of the person with dementia's physical and mental health may contribute to BPSD. Co-morbid mental health issues including depression or delirium should be considered (see *Risk Assessment section, pp. 21-22*, for further information). It is important to check that all the physical needs of the person have been addressed, including pain or discomfort. Acute and/or chronic pain may be present but underreported by the person with dementia (49). Their perception of, and ability to, articulate the presence of pain may be altered by cognitive impairment and/or BPSD. Delirium and/or BPSD can present as markers for the manifestation of pain (50). Access to tools for the verbal and nonverbal assessment of pain may be required to determine the potential contribution to BPSD (see *Module 2* for further information on delirium and pain).

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**Holistic wellbeing: An Aboriginal and/or Torres Strait Islander perspective**

Aboriginal and Torres Strait Islander communities traditionally view health holistically (14). Social and emotional wellbeing is used interchangeably with health within Aboriginal and/or Torres Strait Islander communities (51). The social and emotional wellbeing of community members is maintained when the interconnected elements of spiritual, physical, emotional, social and cultural life are balanced (47, 52). Factors, including ancestry, connection to land, culture, identity physical health and family relationships can affect social and emotional health (14, 53). Management of dementia and BPSD in this group requires an understanding of ill health from a cultural perspective, including approaches to wellness.

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**Holistic perspective of health in CALD communities**

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

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***Additional considerations for dementia and BPSD in Aboriginal and/or Torres Strait Islander communities***

Aboriginal and/or Torres Strait Islander peoples are a diverse group, comprised of many language groups. Whilst, Aboriginal and/or Torres Strait Islander peoples tend to live in urban areas, compared to the non-Aboriginal and/or Torres Strait Islander, the population is widely spread across Australia. As a result, there is a much higher proportion of Aboriginal and/or Torres Strait Islander living in remote areas (54) where access to quality health services is typically limited (24, 55). To understand the multitude of factors that may affect dementia and BPSD within Aboriginal and Torres Strait Islander communities it is important to recognise the unique cultural and historical background of these communities in Australia since pre-contact/prior to colonisation. In the following sections, key historical and cultural experiences of Aboriginal and Torres Strait Islander communities are outlined.

**History of Aboriginal and Torres Strait Islander peoples**

*Pre-contact Aboriginal and Torres Strait Islander communities*

Aboriginal people have lived in Australia for between 5000 and 12000 years (56). During the pre-contact period, there were around 260 different language groups and 500 dialects spoken by Aboriginal peoples. Aboriginal communities lived in communal family groups and were semi-nomadic, hunter-gatherer people (56). Membership of family groups was founded on birthright, shared language and cultural obligations and relationships, with the roles and relationships between different family members predetermined (56). Family groupings were diverse, with their own ancestry, history and culture (56). Common cultural beliefs placed an emphasis on the role of social, spiritual and religious dimensions in shaping day-to-day living and the environment (57, 58).

Torres Strait Islander people are thought to have lived in the Torres Strait for 70,000 years (56). Knowledge about pre-contact Torres Strait people is mostly derived from late 18th century European sailors' oral histories and journals (56). Torres Strait Islander peoples are a diverse population, reflecting differing conditions across the islands as well as interactions between populations in Papua New Guinea and around the Cape York Peninsula (56). The main languages spoken within Torres Strait Islander communities are Kala Lagaw Ya, Meriam Mir and Torres Strait Kriol (59), with Torres Strait English, a regional version of Standard Australian English, spoken in the Torres Strait and on the mainland (60). Similar to pre-contact Aboriginal communities, Torres Strait Islanders peoples tended to live in communal villages, relying on inter-island trade of mainly agriculture and/or fishing (56). Inter-island trading signified a key mechanism for sharing of resources and the development of relationships across the islands (56). The Torres Strait Islander peoples were skilled sailors and navigators (22, 56).

Fundamental to the belief systems of both Aboriginal and Torres Strait Islander peoples is the Land (56). Dreaming creation stories provide the basis for individual and collective spiritual connections to particular *Country* (61). In contrast to European understandings, the land is not owned. Instead, individuals within family groups belong to the land (56). Aboriginal and Torres Strait Islander people maintain a strong symbolic and spiritual experience of, and connection to, the Land with religion "based on a philosophy of oneness with the natural environment" (56).

*The impact of colonisation and oppressive legislation*

European settlers landed on the shores of Botany Bay in 1788, signalling the beginning of colonisation. The impact of colonisation for Aboriginal and/or Torres Strait Islander people was profoundly devastating, marked by death, displacement and disease. Aboriginal and Torres Strait Islander people experienced the dispossession of their Land, the introduction of new diseases, including small pox, measles and influenza, and direct warfare with colonisers, which contributed to the significant loss of life (14, 56). Under federation, States and Territories introduced oppressive and racist policies in order to restrict the rights of Aboriginal and/or Torres Strait Islander people and further alienate them from their culture (56). Whilst such legalisation was abolished in the late 1960s, direct and indirect effects of these policies continue to impact lives of Aboriginal and/or Torres Strait people today (62, 63).

The most notable ongoing effect of colonisation arises from the forced removal of generations of Aboriginal and Torres Strait Islander children from their families, resulting in the Stolen Generations (10, 56, 63). Since colonisation, children were forcibly removed from their families and culture and placed in missions, reserves and other institutions (10, 41, 56, 63). Reports indicate that during the first half of the 20th century, when the practice was formalised by Government policy, between one in seven and one in ten Aboriginal and/or Torres Strait Islander children may have been removed from their families (63). Exact numbers are not known as records were either lost or destroyed (64). Aboriginal and Torres Strait Islander children continue to be removed from their families at higher rate today than those of non-Aboriginal and Torres Strait Islander background. In some communities the effect on families and individuals can be profound and ongoing, contributing to psychological and/or psychiatric symptomatology (30).

Past practices have been officially recognised, documented and acknowledged by Australian Governments (27) and policy changes since the 1960s have targeted increased access to appropriate services for Aboriginal and Torres Strait Islander peoples (14). Although a National Apology has been issued and attempts have been made to address earlier injustices and inequities (30), the legacy prevails through alienation and racism (56). Evidence of the continuing impact of past policies and practice is demonstrated by the significant overrepresentation of Stolen Generation victims in deaths in custody (65). For those Aboriginal and Torres Strait Islander people with dementia, the impact continues to have great significance. The fear of transfer away from their community and/or *Country* to a RACF is one example of the enduring relevance.

**Service access issues for Aboriginal and Torres Strait Islander peoples**
As a result of colonisation, successive oppressive government policies, and the significant loss of land, Aboriginal and Torres Strait Islander people are the most economically disadvantaged population group in Australia (10, 56). Compared to the non-Aboriginal and Torres Strait Islander population, Aboriginal and Torres Strait Islander people experience poorer outcomes across all major determinants of health and wellbeing including housing, education, employment and engagement with the justice system (30, 66).

Trans-generational trauma, refers to the impact of past and current historical and political events on current generations, and is significant issue for Aboriginal and Torres Strait Islander communities (14, 67). Past government policies created dependence which ultimately led to the forced breakdown of vital social structures and values (41, 68). This is apparent in the levels of family violence, substance misuse and family dislocation experienced within the community (14, 68). Previous research has consistently shown that while Aboriginal and

Torres Strait Islander people are less likely to consume alcohol when compared with the non-Aboriginal and Torres Strait Islander population, those that do consume alcohol are more likely to do so at harmful levels (69-71). The excessive consumption of alcohol in Aboriginal and Torres Strait Islander people often relates to transgenerational trauma from colonisation practices, previous oppressive legislation and resultant cultural dislocation (72).

Racism, on the part of individuals and in a broader systemic sense, through institutional and governmental practices, has continued to maintain the legacy of colonisation and impact on current generations of Aboriginal and Torres Strait Islander communities (10, 56). Experiences of racism can negatively impact on individual physical and mental health (73). Older Aboriginal and/or Torres Strait Islander peoples who access services have been found to report negative experiences including stereotyping and racial discrimination and as a result are less likely to access such services (14).

In line with a social determinants perspective of health, *Figure 1.2* provides an overview of the multiple factors that shape chronic health outcomes for Aboriginal and/or Torres Strait Islander people. These include socio-economic factors and a higher incidence of chronic conditions associated with an increased risk of dementia, such as cardiovascular disease and diabetes (74-78). Dementia may occur against a background of dealing with trauma and multiple losses as outlined above. Where the losses are not acknowledged by society (i.e. the society offering services) the disenfranchised grief carries an increased risk of complex grief reactions and potential complications (79, 80) which can impact on BPSD. An older Aboriginal and/or Torres Strait Islander person with dementia may also have "unfinished business" around historical issues such as Native title, self determination, cultural heritage, Indigenous rights and more. The resultant emotions will likely impact on the presentation of dementia and BPSD (81). An understanding of the social determinants of health effecting Aboriginal and Torres Strait Islander peoples is essential to developing effective partnerships and working toward reducing the impact of past practices. Clinicians who are cognisant of the multitude of historical factors impacting on the individual presentation of BPSD in an Aboriginal or Torres Strait Islander person may approach the situation more appropriately (72).

Despite the negative impacts of colonisation and associated practices which remain in their communities, the significant resilience of Aboriginal and Torres Strait Islander peoples must be acknowledged. Strength within communities is evidenced by:
- a strong commitment to family and community
- valuing cultural heritage and spirituality
- continued connection to Land
- traditional knowledge of ancestry, health, wellbeing and *Country*
- traditional methods of storytelling and healing
- traditional lore and ceremony
- traditional roles of Healers, Elders and community carers (52, 82)

Where these aspects provide a source of strength for an Aboriginal and/or Torres Strait Islander person with dementia and their family, it is important to recognise and acknowledge them in the management of BPSD as part of person/family/community-centred care. It is equally important to recognise that historical issues have broken down the resilience of some Aboriginal and/or Torres Strait Islander communities, leading to significant health and socio-economic issues.

*Figure 1.2 Factors contributing to chronic disease in Aboriginal and/or Torres Strait Islander peoples (adapted from NSW Health, 2005)*

**HISTORICAL**
Dispossession
Loss of land
Loss of culture
Forced family separation

**ECONOMIC**
High unemployment rates
Poverty

**PSYCHO-SOCIAL/ CULTURAL**
Physical, emotional abuse
Trans-generational trauma
Racism
Low self esteem
Depression & related disorders
Stress
Educational disadvantage
Disempowerment

**HEALTH CARE SYSTEM ACCESS**
Affordability
Availability
Appropriateness/ responsiveness
Utilisation

**NON-MODIFIABLE RISK BEHAVIOURS**
Age
Gender
Genetics

**RISK BEHAVIOURS**
Physical inactivity
Poor diet and nutrition
Smoking
Excessive alcohol use
Substance abuse

**ENVIRONMENTAL**
Inadequate housing
Unsafe environment
Physical isolation
Lack of transport
Poor food supply
Lack of recreational facilities

**BIOMEDICAL RISK FACTORS**
Body mass
High blood lipids
High blood pressure
Impaired glucose metabolism
Low birth weight

**CHRONIC CONDITIONS**

**Cardiovascular diseases, kidney disease, diabetes, chronic obstructive pulmonary disease, asthma and cancer**

***Additional considerations for dementia and BPSD in CALD communities***

As a large proportion of the Australian population was either born overseas or from a CALD background, an awareness of the influence of culture and migration experiences can have on the course of dementia and BPSD is important. This section includes a brief overview of Australia's migration history followed by an outline of key factors that can trigger BPSD in older migrants and refugees with dementia.

*History of migration and settlement in Australia*

Under Australia's Immigration Restriction Act [1901], more commonly referred to as the White Australia policy, there was an active effort to limit the intake of non-European migrants and promote that of British migrants in an attempt to preserve the White Australian population (83). However, in response to population decline, Australia launched a post World War II immigration program from 1945 to attract displaced European migrants, particularly those from Southern Europe (84). In the 1970s, following the formal abandonment of the White Australia Policy, Australia began to encourage large numbers of migrants from non-European countries, mainly from parts of Asia and the Middle East. *Figure 1.3* (adapted from 85, 86) provides a timeline of migration flows to Australia and associated policy developments since 1945.

Today, migrants can enter Australia through two immigration programs (87):

The **Migration Program** allows those who wish to work in Australia or be reunited with their families to enter the country (83). The family migration stream, which allows for the migration of immediate family of Australian citizens or permanent residents (87), is often used by older migrants as there is no "points test" for applications. Family reunion migrants can also include *refugee-like* people that come to Australia through this migration stream to join existing family living in Australia (see below).

The **Humanitarian Program** supports refugees and others in refugee-like situations to resettle in Australia. A refugee is a person "outside their country of nationality who is unable or unwilling to return because of a well-founded fear of persecution for reasons of race, religion, nationality, political opinion or membership of a particular social group" (88). In addition refugee-like communities are those who have migrated to Australia through migration programs, but have similar experiences to refugees such as coming from areas of war and/or organised violence (85).

*Factors that may trigger or contribute to BPSD*

It is important to gather as much information about the older CALD person's life history, not only their cultural background but also their migrant and settlement experiences as these aspects can impact on BPSD. When carers and service providers have no knowledge or understanding of these experiences, BPSD can be inadvertently exacerbated.

*Migrant settlement experiences*

Many of the older migrants in Australia arrived and settled in the White Australia policy period (between 1945 and the mid-1970s). During this time, migrants were forced to assimilate, often suppressing their own culture and language to adopt "Australian" ways. Consequently, in later life older migrants may have lost those connections with their past.

Many migrants faced racism and discrimination when they arrived and attempted to settle into Australian society. For example on arrival to Australia, many migrants unwillingly had their

names and surnames changed by government authorities to make them more appropriate for Anglo-Saxon society. With the onset of dementia, older migrants may revert to their previous name and not respond to the name that family and friends know them by.

Discrimination at the time of migration and settlement can result in a loss of identity, which may remain unresolved. Older migrants with dementia may relive previous traumatic experiences and memories. Because of the associated shame, pain and/or trauma these stories from early life may have remained untold for many years. The children of those migrants with dementia may thus be unable to report the family history which may be contributing to BPSD. They may feel that they no longer know their parent or they don't understand the situation because the BPSD appears to be out of context.

In order to adapt, some migrants learnt English for the workplace, however following retirement they may not have used English regularly for many years. With increasing age and/or dementia, the need to interact within the health system arises but these people may find it difficult to communicate as they have not used English for an extended period of time. As a result older migrants may be labelled as resisting care, uncooperative or exhibiting BPSD, when in fact they may be struggling to communicate.

*Refugee and war-time experiences*
Refugees and refugee-like people often come from situations where they have encountered significant traumatic events such as war, persecution or harassment by government authorities, torture, rape and witnessing loved ones suffer violence as well as the disappearance and death of family and friends, including children (88).
- Past experiences can influence behaviours in dementia such as hoarding food, feeling like they are being watched, hallucinations, misinterpreting people/strangers as threatening and/or re-experiencing the trauma over the loss of a child or family member (85). Service providers may be seen as representatives of government agencies.
- Because of past fears, for many refugee and refugee-like persons, it can be difficult to trust people who work for government authorities and at times even their own family (85).
- Refugees in residential care may be reminded of previous trauma by uniforms, corridors and queuing as well as shared spaces for sleeping, eating and bathing.
- Common traumatic triggers for Holocaust survivors include showers, hospital identification bands, medical procedures, surgery and medical gowns (89).
- Hospitalisation is often a very traumatic experience for persons with dementia from CALD backgrounds which may worsen BPSD.

It can be challenging for care staff and even family to recognise that a person with dementia is a refugee who requires additional support, particularly when they hide their past. The person with dementia may deny their past experiences because of fear of being stereotyped as poor, uneducated or viewed as a victim (85). It is important for clinicians to explore why the person may be acting this way and how it may be culturally relevant. Clinicians may also need to work with RACF staff to develop an understanding of the reasons and triggers for the BPSD.

*Post traumatic stress disorder (PTSD)*
PTSD can occur as a result of a refugee, refugee-like or war survivors' past and impact on changing behaviours in later life. While many older refugees adapt well to new circumstances,

cognitive changes with normal ageing or dementia can undermine this ability to adapt (85). This can mean that ageing and/or dementia may be an additional risk factor for those who have experienced trauma in the past and this can trigger a change in behaviour. With cognitive decline, PTSD severity in Holocaust survivors may worsen as repressed memories come to the fore (89). Persons with dementia have a diminished capacity to hold back traumatic memories, which can result in a re-emergence of PTSD symptoms, including feelings of anxiety and depression (90). It is important to distinguish between PTSD and BPSD as they may occur independently or in combination.

Figure 1.3 Timeline of migrant and refugee settlement in Australia 1945 – 2010.

**MIGRATION HISTORY**

| 1945 - 1950 | 1950 - 1960 | 1960 - 1970 | 1970 - 1980 | 1980 - 1990 | 1990 - 2010 |
|---|---|---|---|---|---|
| (1947) First post-WW2 European refugees arrive, mainly Estonians, Latvians and Lithuanians. Later arrivals from Poland, Ukraine, and Germany and from the Balkan states (mainly Croatia). Some Indian and Sri Lankan migrants | Yugoslavia, Poland, Hungary, USSR, Romania Czechoslovakia and Bulgaria. Some Assyrian arrivals (Christian minority from what is now Iraq, southern Turkey, Iran and Syria) | Soviet-bloc countries such as Hungary, Latvia, the USSR, Ukraine and the then Czechoslovakia | Germany, Poland, Vietnam, South America (Guatemala, El Salvador, Nicaragua), Afghanistan, Cambodia, Iraq, Lebanon, Sri Lanka | Balkan states (Bosnia, Serbia, Croatia, Kosovo), China, Iraq, Afghanistan, Somalia, Ethiopia | Refugees from Sudan, Iraq (Mandean community), Afghanistan, Burma (Myanmar), Iran, Democratic Republic of Congo, Liberia, Sierra Leone, Burundi, Ethiopia and Sri Lanka |

→ White Australia Policy [1901] →  |  1973 White Australia Policy abolished

| ASSIMILATION POLICY | INTERGRATION POLICY | | MULTICULTURAL POLICY | |

**POLITICAL CONTEXT IN AUSTRALIA**

| 1945 - 1950 | 1950 - 1960 | 1960 - 1970 | 1970 - 1980 | 1980 - 1990 | 1990 - 2010 |
|---|---|---|---|---|---|
| (1945) First Department of Immigration established  (1947) Post WW2 Migration Program launched. Displaced Persons' Scheme - Australia to settle 12, 000 displaced persons per year with provision to increase this number | (1952) The Displaced Persons' Scheme ended  (1956) Operation Reunion introduced. Scheme negotiated with USSR and other East European countries to reunite relatives in Australia  (1957) Non-Europeans with 15 years' residence in Australia allowed to become Australian citizens  (1959) Australian citizens can sponsor non-European spouses and unmarried minor children | Introduction of Special Passage Assistance Program  (1960's) Immigration agreements signed with Middle East and Turkey  (1967) Australia becomes a signatory to the Refugee Protocol (rights of refugees to protection from persecution) | (1972) Immigration policy altered to allow entry to people not on the basis of race but on Australia's needs and humanitarian reasons, priority given to family reunion  (1975) *Federal Racial Discrimination Act* passed. Unlawful to discriminate on basis of race, colour, descent, or nation/ethnic origin | Mainstreaming becomes government policy. Immigration policy focused on increased intake of skilled migrants  (1981) Humanitarian Program launched  (1983) Migration Amendment Act – end to favoured treatment of British migrants | (Early 1990s) The onset of recession and a reduction in migration targets  National Integrated Settlement Strategy introduced |

### *The carer and carer relationship*

The effect of other people on the person with dementia and the way the behaviour of the person with dementia affects others will, in turn influence behaviour. Factors relating to the carer's ability to interact with the person with dementia include the carer's:

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

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**Family and community structures in Aboriginal and Torres Strait Islander communities**

Family and community structures, as well as social connectedness, are often extremely strong within Aboriginal and Torres Strait Islander communities (22).

- In some regions different Aboriginal and Torres Strait Islander Nations are considered separate communities, hence an Aboriginal or Torres Strait Islander person may be part of one community or many different communities. Understand the person's connection to their community and Land is important. A service catchment area may include many different communities who are traditionally from that area or not.
- Knowledge of the local situation will assist services to appreciate the differences and/or tensions between the families/communities/groups in a geographic area and how this impacts on service provision (91).
- The concept of family is not restricted to westernised bloodlines and the *community* is typically not limited to family/blood connections but may include wider kinship.
- Families tend to be large. Home visits to an Aboriginal or Torres Strait Islander person with dementia may include many family members but the key person or persons to supply information need to be identified.
- The "decision-maker" for the person with dementia may not be a blood relative or geographically close. Access and contact may be limited as a consequence but their role must be respected, nonetheless.
- It is important for clinicians to be aware of the status of an older Aboriginal or Torres Strait Islander person within their community and any potential implications dementia and the need for care may have on their status (91).
- The leadership responsibilities of older Aboriginal and Torres Strait Islander people can come with a heavy workload. The demands of their position may be incongruent with their health status.
- Because services may be dealing with the entire family or kinship, there are often multiple carers involved and some will typically be young.
- 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.
- Aboriginal and Torres Strait Islander older people are often carers for the extended family and hence, greater flexibility in approaches to care is required.
- 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. Usual

> - service guidelines on communicating with relevant others may require clinicians to maintain contact with other services out of area.
> - Awareness of the local history of the place, family and communities is important in an understanding of the cultural losses experienced by the local Aboriginal and Torres Strait Islander people. This is relevant to an appreciation of the subsequent strengths and resilience that has developed within families and communities.

> **Additional considerations for CALD carers and families**
> The care of persons with dementia varies across CALD communities and families, in terms of the roles of different family members and the importance placed on the care of the elderly.
> - There can often be multiple carers for CALD persons with dementia, with the entire family sometimes being involved (31, 32). However, the decision-making role may not necessarily be undertaken by a primary carer. For example, a husband, who previously made all the decisions, may now be the person with dementia. The wife will continue her role as carer, in relation to his physical needs, but the son or another male member of the family may assume the decision-making position. This can include family members living overseas.
> - It is important to understand the 'multiplicity' of carers and decision-makers when dealing with a CALD person with dementia as this will influence the information gathered and the care relationship.
> - As in all communities, denial can occur within the family around the symptoms of dementia. The propensity for this is increased when family members are living overseas. It is thus important to work with CALD families when undertaking assessment of behaviour by keeping them involved throughout the process.
> - At times carers may unintentionally trigger behaviours, unaware of the effect on the person with dementia. For instance, carers may attempt to reason with the person with dementia without understanding their confusion, which may further frustrate the person and trigger behaviours. In this situation it is important to educate carers around behavioural triggers.
> - When making home visits, depending on the family, there may include many family members present. The key person or persons to supply information need to be identified.

### *The care environment*

The care environment includes the physical, social and cultural dimensions of the environment in which care is provided. All these factors are interconnected and can impact on BPSD so it is important to obtain a holistic understanding of the care environment.

### *Physical factors*

The physical and sensory environment is well documented as a contributing factor in BPSD (92, 93). It includes a diverse range of elements including noise, access to outdoors, safety, security, glare, physical layout, size, furnishings, space for wandering, number of people, traffic through the area and time of day. Observation and discussion with carers provide opportunities to uncover elements of the physical environment which are disorienting, limiting, confusing, not enabling, over stimulating and/or understimulating.

### *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 and the shared values and practices of the group(s) in the person's immediate environment.

- The quantity and type of activity provided to the person with dementia and the level of meaningful social interaction they receive can contribute to behaviour. Likewise, the manner in which care is provided, including the flexibility of the routine and the way families or care staff interact with the person with dementia also has an impact.
- The degree of support provided to carers in such settings can affect the time and resources they have to provide care. DBMAS clinicians may need to assess these aspects of the care environment through discussions with different levels of staff, family members and management.
- The overall cultural appropriateness of the environment whether this is a community or RACF setting can contribute to BPSD.

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***Additional considerations related to the care environment for Aboriginal and/or Torres Strait Islander Peoples***

Specific services for Aboriginal and Torres Strait Islander peoples are limited, emphasising the need for all service providers to ensure care is delivered in a culturally competent manner.

- In acknowledging the holistic view of health, care services for an Aboriginal or Torres Strait Islander person with dementia must be linked to services for other family and community members of all ages who are also affected by the dementia and BPSD.
- Person-centred care for those with dementia in Aboriginal & Torres Strait Islander communities needs to be "family-centred" and "community-centred".
- 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 appropriate care.
- Hospitals and RACFs are typically not set up to accommodate large extended family groups visiting. Where possible, a room with alternate access will minimise disruption to other residents. Likewise an additional telephone line will allow increased contact with kinship and community.
- Separation from *Country*, family and community can precipitate BPSD. Many Aboriginal and Torres Strait Islander peoples don't live on their Land.
- Enabling physical and/or visual access to the outdoors can be important for an Aboriginal and/or Torres Strait Islander person.
- Separate "men's business" and "women's business" may impact on staff rostering (91).
- Hospitals, and by association RACFs, have historically been seen as places to die.
- Emotional and spiritual aspects of the care environment warrant careful consideration.

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***Additional considerations related to the care environment for CALD people***

Where residential care is indicated for a CALD person with dementia, clinicians should attempt to arrange admission to an ethno-specific RACF before accepting a place in a mainstream facility. As this is often not possible, mainstream RACF staff members need to have a basic awareness of the potential antecedents that could make the CALD person with dementia uncomfortable and/or possibly trigger BPSD.

Culturally competent workers:
- Bilingual and/or bicultural clinicians or workers should be engaged in the provision of care in community and residential care settings wherever possible (see *Communication section, p. 27*, for further information).
- This can assist with building trust, promoting self-care for carers and recognising the significance of culture in the care of the person with dementia (33, 47).
- It can be useful to identify whether a RACF has bilingual staff who speak the same

language (and dialect) as the person with dementia and how much contact they have with the resident. Consideration should be given to scheduling rostered hours to maximise coverage of those who speak the client's language throughout any 24 hour period.

- Building this link may assist with providing successful interventions. Whilst the involvement of a bilingual and/or bicultural worker can make a service more acceptable to the older CALD client, this is not always the case, particularly in the case of a RACF (33).

It is important to be aware of the potential for racism from the person with dementia directed toward workers and vice versa in RACFs and community care settings. The possible implications of this for care and for BPSD are significant. For example, racism can be an issue which precipitates BPSD in war veterans when care is provided by staff of "Asian" appearance or those with an apparent German accent.

**Analysis of the comprehensive assessment**

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

*Frameworks for analysis*

A framework or structure to assist analysis of the assessment information can be useful. Examples of such models follow.

The **Progressively Lowered Stress Threshold (PLST)** model is based on the proposal that the person with dementia is increasingly less able to manage stress as dementia progresses. This approach focuses on supporting those with dementia by facilitating the use of retained skills and abilities while reducing the environmental triggers for BPSD (94-96). This is a useful model for analysing assessment information against stressors such as:

- Fatigue
- Change of routine, environment or carer
- Internal or external demands that may exceed functional capacity
- Misleading stimuli or inappropriate stimulus levels
- Affective response to perceptions of loss, including anger or depression
- Physical stressors, such as acute illness, adverse reactions to medication, infection, pain or discomfort.

The **Need-Driven Behavioural (NDB)** model (97, 98) is suitable for use independently or in combination with PLST. The Need-Driven Behaviour model proposes that BPSD is an indication of unmet needs, as the person with dementia becomes progressively less able to meet their own needs The model takes into account the influence of *background factors* including neurological, cognitive, health and psychosocial aspects as well as *proximal factors* such as aspects of the person with dementia and the impact of environmental factors on the behaviour.

A **Concept Mapping** approach incorporates the use of visual representations of the structure and relationship between linked ideas or knowledge (99, 100). This model aims to improve understanding of the complex, interacting factors contributing to BPSD and hence, facilitate development of an effective behaviour management plan (101, 102).

The **A_B_C** model utilises behavioural observation and analysis to develop strategies for modifying BPSD (103). "**A**" refers to the antecedent or triggering event that precedes the problematic behaviour, "**B**" is the behaviour and "**C**" is the consequence of that behaviour. The importance of observing and recording BPSD is emphasised. The goal of the **A_B_C** approach is to reinforce appropriate behaviours while discouraging those that are dysfunctional.

**Management Plan**

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

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

**Planning and communicating the intervention**

Interventions that are individually tailored to the person living with dementia will likely be most effective in moderating BPSD. An intervention which is soothing and calming to one person with dementia may be perceived as an invasion of personal space by another (104). The strengths and limitations of the specific care environment are equally important. Interventions may involve psychosocial, environmental and/or biological methods or all three with the balance dependent on the results of the assessment. The intervention tables (see *Appendices 3 and 4*) provide additional detail on specific psychosocial, environmental and biological interventions.

When planning and communicating the intervention it is important to involve care staff and family in the development of specific responses and determination of clear goals/outcomes for each aspect of the intervention. In particular, consider the following aspects when implementing the intervention:

- ability of staff or family carers to implement the changed approach based on their current skills and resources
- the education and additional support required to assist application of new knowledge and strategies
- expectation of the time for changes to impact on the behaviour
- where indicated, the estimated time needed for a pharmacological agent to provide therapeutic benefits.

**Review and evaluation**

It is important to follow-up, review and evaluate the effectiveness of an intervention or strategy after it has been implemented. Maintaining contact with the RACF or family to monitor the situation enables interventions to be adjusted as needed. The time frame for introducing an intervention or strategy and evaluation of the effectiveness will depend on the individual

circumstances. When implementing the management plan discuss an appropriate date for review and evaluation with staff and/or family.

The measure of effectiveness to be applied will need to be determined based on the BPSD and the individual situation. Appropriate measures may assess reductions in the frequency, intensity and/or the impact of the behaviour on the person and/or the carers.

# MODULE 2: General BPSD

**Key messages**

- Behavioural and psychological symptoms of dementia (BPSD) impact on the person with dementia, carers, family, care staff and other residents.
- The manifestations of BPSD are influenced by a wide range of factors.
- A person centred approach that reflects this diverse range of causative factors is likely to be the most effective way of managing BPSD.
- Interventions which focus on addressing the underlying contributing factors rather than the behaviour itself are likely to be more effective.
- A thorough and detailed assessment of the person with dementia and the behaviour in combination with the interpersonal and physical environment is essential to generate potential strategies and interventions.
- Family members and care staff are good sources of information on the person with dementia, his or her history, personality and preferences.
- The skills and knowledge of a variety of professional disciplines may be beneficial in producing a positive outcome.
- Effective strategies may target carer and/or staff approaches, communication, burden or knowledge in relation to BPSD.
- The perception of disturbed behaviour as being a problem is also influenced by a wide range of case-specific factors.
- Psychosocial, environmental and biological interventions are not mutually exclusive.
- 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, should be a primary consideration in the implementation of interventions.
- Monitoring and evaluating the impact of an intervention is an integral part of the process.

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**Before you move on, have the following been done?**

1. A *risk assessment* to identity any immediate risks to the person with dementia or others within the care environment

2. A *comprehensive assessment* that is person centred and considers the following key aspects:
   - Referrer's description of behaviour
   - The behaviour
   - The person
   - The carer
   - The care environment

3. Any reversible causes of the behaviour(s) excluded and/or treated

(See *Module 1* for further details)

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**What are general BPSD and what do they look like in dementia?**
- Behavioural and psychological symptoms of dementia (BPSD) are defined as "symptoms of disturbed perception, thought content, mood, behaviour frequently occurring in patients with dementia".
- They are also commonly referred to as behaviours of concern, challenging behaviours and non-cognitive or neuropsychiatric symptoms of dementia.
- BPSD include aggression, apathy, anxiety, agitation, psychotic symptoms, depression, disinhibited behaviours, wandering, nocturnal disruption and vocally disruptive behaviours.
- BPSD occur at different levels of severity with the stages of disease progression. The seven tiered model of BPSD by Brodaty and colleagues demonstrates the wide range of symptoms and severity encompassed by the term BPSD.

**Prevalence**
- BPSD can occur in both community and residential aged care facilities (RACFs) however they tend to occur more frequently in RACFs.
- Increased BPSD in RACFs have been associated with more residents per room, reduced resident functionality, lower staff to resident ratios, inadequate training, fewer activities to engage residents and management less geared toward managing behaviours.
- Reported prevalence rates of BPSD in dementia range between 56% and 90%.
- The most frequently occurring BPSD are apathy, depression and anxiety, which occur at different stages of disease progression. Individual BPSD have been found to fluctuate over time, with many behaviours occurring episodically.

**Effects of BPSD**
- BPSD impacts on both the person with dementia and their carer(s).
- The quality of life of the person with dementia can change considerably, particularly during relocation to a RACF.
- 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 manage BPSD.

**Differential diagnosis**
Delirium can be identified by an abrupt onset of behaviour out of character for the person with dementia. It is important for clinicians to distinguish between delirium and BPSD in order for appropriate treatment options to be implemented.

**Diagnosing dementia**
- Recommended cognitive assessment tools can be located via the Dementia Outcomes Management Suite (DOMS).
- Aboriginal and Torres Strait Islander or CALD populations require the use of assessment tools specifically developed for these populations, wherever possible.

**Measuring BPSD**

Tools for measuring BPSD globally include the Neuropsychiatric Inventory (**NPI**) and the Behavioural Pathology in Alzheimer's Disease (**BEHAVE-AD**).

**Management of BPSD**

The management of BPSD can include psychosocial, environmental and/or biological interventions. It is important to note that they are not mutually exclusive. Below is a summary of management guidelines for general BPSD.

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*Summary of management guidelines for general BPSD*

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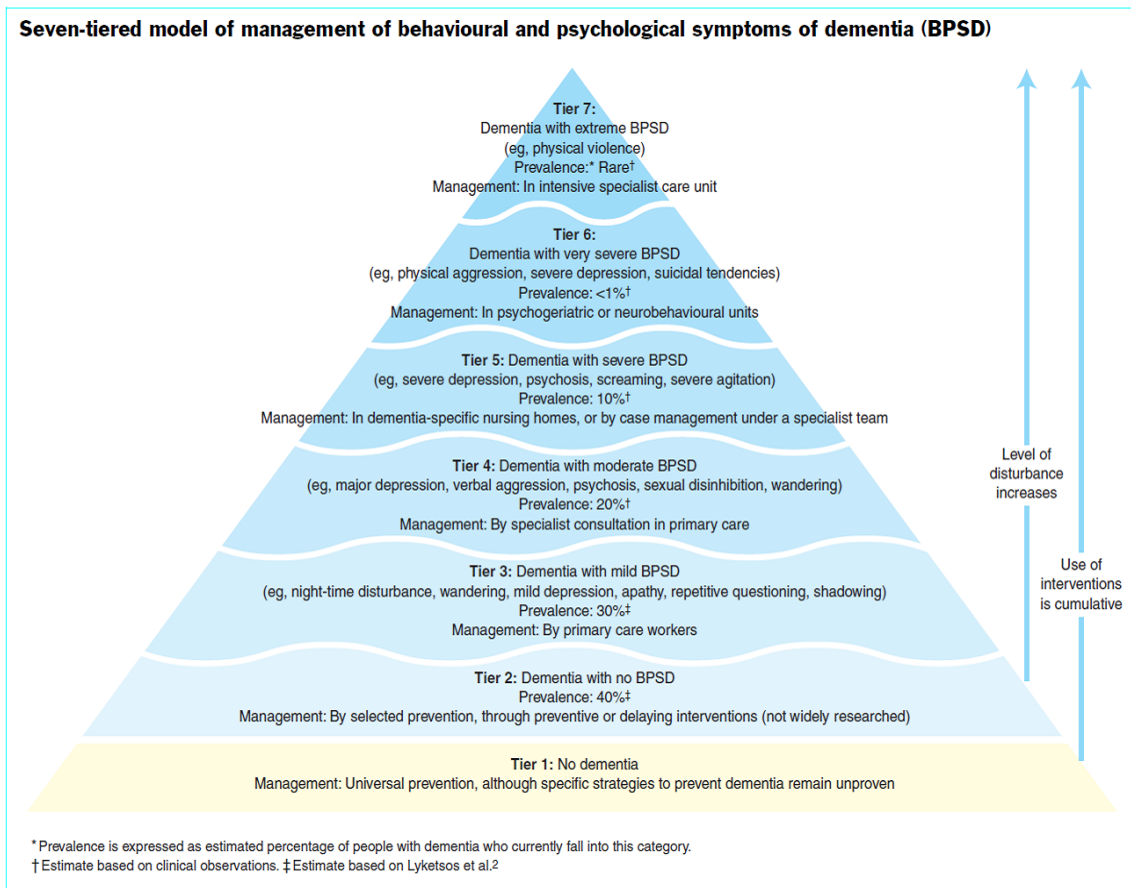
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**Conclusions**

- Research findings suggest that pharmacological and psychosocial interventions have a modest effect when applied as a generic treatment for BPSD.
- This can largely be attributed to the diverse aetiology of BPSD which means that a therapy or intervention may be effective in one set of circumstances and not in another.
- Person- and behaviour-specific interventions that are tailored to individual situations tend to be the most effective and are recommended.
- Potential side-effects and drug interactions need to be carefully weighed against benefits for the individual person with dementia when considering pharmacological interventions for the management of BPSD.

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

Behavioural and psychological symptoms of dementia (BPSD) are defined by the International Psychogeriatric Association (IPA) Taskforce on BPSD (105) as "symptoms of disturbed perception, thought content, mood, behaviour frequently occurring in patients with dementia" (106). Psychological symptoms of dementia relate to anxiety, depression and psychosis whereas behavioural symptoms include aggression, apathy, agitation, disinhibited behaviours, wandering, nocturnal disruption and vocally disruptive behaviours. While some of the features of BPSD such as depression, hallucinations, delusion are defined in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) and the World Health Organisation International Classification of Diseases, Tenth Revision (ICD-10), neither provides clear definitions for BPSD (1, p. 56). Such behaviours are typically identified by observation of the person with dementia and only considered challenging when they impact on other people or cause harm to the person with dementia. BPSD are also known as behaviours of concern, challenging behaviours and non-cognitive or neuropsychiatric symptoms of dementia.

Brodaty and colleagues (107) propose a seven tier model (*Figure 2.1*) for describing BPSD severity and strategies appropriate at each level. The seven tiers reflect an ascending order of symptom severity and descending order of prevalence indicating that the term BPSD covers a wide range of symptoms and severity. The tiers include the community generally from tier one, "no dementia," through to "dementia with moderate BPSD" in tier four and "dementia with extreme BPSD" at tier seven.

*Figure 2.1 reproduced with permission from Brodaty et al. (107)*



Seven-tiered model of management of behavioural and psychological symptoms of dementia (BPSD)

**Tier 7:**
Dementia with extreme BPSD
(eg, physical violence)
Prevalence:* Rare†
Management: In intensive specialist care unit

**Tier 6:**
Dementia with very severe BPSD
(eg, physical aggression, severe depression, suicidal tendencies)
Prevalence: <1%†
Management: In psychogeriatric or neurobehavioural units

**Tier 5:** Dementia with severe BPSD
(eg, severe depression, psychosis, screaming, severe agitation)
Prevalence: 10%†
Management: In dementia-specific nursing homes, or by case management under a specialist team

**Tier 4:** Dementia with moderate BPSD
(eg, major depression, verbal aggression, psychosis, sexual disinhibition, wandering)
Prevalence: 20%†
Management: By specialist consultation in primary care

**Tier 3:** Dementia with mild BPSD
(eg, night-time disturbance, wandering, mild depression, apathy, repetitive questioning, shadowing)
Prevalence: 30%‡
Management: By primary care workers

**Tier 2:** Dementia with no BPSD
Prevalence: 40%‡
Management: By selected prevention, through preventive or delaying interventions (not widely researched)

**Tier 1:** No dementia
Management: Universal prevention, although specific strategies to prevent dementia remain unproven

Level of disturbance increases

Use of interventions is cumulative

* Prevalence is expressed as estimated percentage of people with dementia who currently fall into this category.
† Estimate based on clinical observations. ‡ Estimate based on Lyketsos et al.[2]

**Prevalence of BPSD**

Although there are individual differences, BPSD will occur at some point in up to 90% of persons with dementia, during the course of the condition (108). BPSD are common amongst both community and residential care dwelling persons with dementia (109) with higher rates occurring in RACF settings. A study of residents in Sydney RACFs found that over 90% of residents exhibited at least one behavioural disturbance (110) and of those living in the community, one third are reported to have clinically significant BPSD (111). Reported prevalence rates of BPSD in dementia range between 56 % and 90% (112-116).

Rates should be treated with caution as figures can vary according to different settings, how symptoms are perceived, tolerated and measured as well as severity thresholds (107). Increased BPSD in residential facilities has been associated with environmental factors such as more residents per room, lower resident functioning, lower staff levels and training, fewer activities for residents and management less geared towards managing behaviours (117). Apathy is one of the most commonly occurring BPSD (118, 119), however it does not tend to be well reported and/or viewed as a behaviour requiring referral to DBMAS.

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*Prevalence of dementia in Aboriginal and Torres Strait Islander communities*
While the prevalence of dementia in Aboriginal and Torres Strait Islander people throughout Australia is unclear, evidence suggests that in some areas dementia rates are five times that of the general population (21, 120). In a study undertaken in North Queensland, dementia was identified in approximately 20% of the participants in the community over the age of 65 years compared to 5% in the non-Aboriginal and Torres Strait Islander population  (121). Smith and colleagues (122) , using the *Kimberley Indigenous Cognitive Assessment (KICA-Cog)* to assess prevalence of dementia in the Aboriginal and Torres Strait living in the Kimberley region,  found  that the prevalence of dementia in those over 45 years was 12.4%, significantly higher than the non-Aboriginal and Torres Strait Islander population. Dementia was also found to be more frequent in men than women (17% versus 9%) (122). The prevalence of different types of dementia may vary between regional, remote and urban areas.

Data collection is inadequate and unreliable due in part to poor identification of Aboriginality and the number of Aboriginal and Torres Strait Islander people in remote locations (76). Information on the prevalence of BPSD in Aboriginal or Torres Strait Islander communities is even more limited than information on prevalence of dementia.

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*Prevalence of dementia in CALD communities*
The CALD population is ageing at a much greater rate than mainstream communities and the prevalence of dementia is predicted to rise significantly amongst older people from CALD background communities by 2050 (123).  It is estimated that approximately one in eight people with dementia in Australia (12.4%) do not speak English at home. Of these, approximately 0.1% are Aboriginal and/or Torres Strait Islander peoples (123). According to Access Economics 2005 data, there will be a significant increase, over the next four decades, in the number of people with dementia in Australia whose language spoken at home is either an Asian or Middle Eastern language (123). There is limited information of the prevalence of dementia in specific CALD communities across Australia. Furthermore, there are limited studies that examine rates of BPSD within and across CALD groups in Australia.

In terms of CALD rates of utilisation of RACFs, in 2008-09 approximately 30% of RACF residents with a diagnosis of dementia were born overseas. The most represented overseas region of birth

was UK/Ireland (11%) followed by Southern/Eastern Europe (10%), including Italy, Poland and Germany (124). These figures suggest that there is an under utilisation of RACFs by CALD communities compared to the Australian born population.

**BPSD Prognosis**

The most frequently occurring BPSD, apathy, depression and anxiety (108), tend to increase in severity with disease progression, however they can present at any stage of dementia. Overall rates of BPSD reportedly present in a curvilinear relationship with increasing incidence until the latter stages of the disease when prevalence declines (125). By contrast, the incidence of apathy/indifference tends to continue to increase with dementia severity (125). Limited studies examining the development and persistence of individual BPSD over time (126) indicate that incidence tends to fluctuate over the disease course (127-132). Mood disturbances, agitation and psychosis have been found to occur episodically with limited worsening over time (133) whereas others report that wandering and agitation tend to persist (126).

Given their heterogeneous nature, it has been suggested that clusters of BPSD symptoms provide a framework for assessment and management (108, 118, 134-138). As yet, no consensus beyond the IPA guidelines has been reached in this regard (1).

**Effects of BPSD**

*Impact on the person with dementia*
- BPSD has a considerable effect on the quality of life of the person with dementia in both community and residential settings. Relocation to residential aged care frequently triggers behavioural changes in persons with dementia.
- The behaviour may be a manifestation of adverse effects of medication or unmet physical, medical and/or psychosocial needs (139, 140).
- Symptoms of BPSD may interfere with the identification of underlying potentially treatable conditions such as depression, pain, infection or constipation which can mimic or contribute to the behaviours.

*Impact on Carers*
- The presence of BPSD can lead to exclusion from much needed support services or RACFs.
- The management of BPSD can present a significant challenge to family carers, community care workers and residential care staff alike, resulting in considerable stress and/or distress.
- Factors affecting the family member's ability to respond to behaviours are universally and collectively referred to as carer burden (141, 142). This burden is often willingly accepted due to the relationship between the carer and the care recipient, but this does not negate the difficulty of managing BPSD.
- BPSD is associated with increased burden of care and carer depression (143-145).
- Carers' social and psychological resources, as well as their perception of the behaviours, have been identified as predictors of institutionalisation (141).
- Some of the most stressful BPSD for carers and the most common reasons for institutionalisation include screaming, physical aggression, wandering, depression, and

insomnia at night (143). However, less frequent and severe BPSD, such as agitation and irritability, have also been shown to cause significant stress to carers (146).

- An awareness of the relationships in the home, the knowledge and experience of the family carers and resources available is essential when developing a management plan.
- BPSD contribute to high stress levels and burn-out in RACF staff (117) however, support from management and the potential to relate to residents as individuals predict staff members perception of the behaviours (142).

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**Impact on Aboriginal and Torres Strait Islander family and carers**
Because BPSD are typically managed and/or cared for longer within Aboriginal and Torres Strait Islander families and communities, the situation can be closer to crisis point at the time of referral. Kinship obligations may contribute to the management and tolerance of BPSD and the ongoing sense of duty to provide care, even when community members are close to crisis point. Aboriginal and Torres Strait Islander peoples, reportedly do not access services at a rate which is consistent with the levels of distress in the communities (27).

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**Impact on CALD carers**
CALD carers usually focus on how to keep the person with dementia safe and happy (31, 32). This could involve keeping the person occupied and praying for them. Carers may be more concerned with the person with dementia's physical needs e.g., assistance with lifting, pay little attention to self-care and their own emotional wellbeing, so assisting carers with this aspect is also important.

Carer's migration visas are increasingly becoming a strategy to avoid transfer to RACF in migrant communities. Migrant families who cannot care for their elderly family members with dementia may be able to obtain a carer's visa for a relative to come to Australia and provide the necessary care at home. Currently very little support is available for migrants on a carer's visa. They may have limited English, limited caring skills and tend to become socially isolated because they are caring in the home for long periods of time.

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*Carer strategies*
Carer education and/or support which advances knowledge and ability to cope with BPSD may reduce carer burden and potentially delay RACF admission (96, 145, 147, 148). A review of literature relevant to this area is beyond the scope of this guide. For further information see (149). The International Psychogeriatric Association (150) suggests that interventions that target carers of those with BPSD incorporating the following aspects are the most successful:

- ensuring a focus on the person with dementia as well as the carer
- focusing on training and skill building in addition to education and support
- involving strategies that are multidimensional, flexible, and tailored to the needs of the carer and the person with dementia
- combining pharmacotherapy where indicated
- providing information to carers and family member that includes techniques for dealing with specific BPSD, actions for ensuring the safety and wellbeing of the person with dementia, methods for dealing with difficulties of activities of daily living (ADLs), and avenues for securing personal assistance, physical aid, financial entitlements and respite services
- collaborative care with a professional (such as a nurse working with the carer)

- focusing on the medium to long-term
- including follow-up assessments

**Differential diagnosis**

Serious risk of harm to the person with dementia can arise from underlying, untreated physical or medical precipitants of BPSD. This most commonly manifests as delirium superimposed on the dementia. Delirium can be identified by an abrupt onset of behaviour, out of character for the person, which develops over hours to days. Aggression, restlessness hallucinations, clouding of consciousness, misinterpretation of events, disorganised thinking and sleep disturbance may be evident. Delirium subtypes include hyperactive, hypoactive (quiet) and mixed (151). Evidence indicates that attempting to control the behaviours with medication can delay diagnosis and lead to poorer outcomes for the person with dementia (152). It is in the best interests of all concerned for potential causes of the delirium to be identified and treated as quickly as possible. Basic guidelines for the recognition and investigation of delirium follow (see *Figure 2.1*).

***The Confusion Assessment Method (CAM)***

The Confusion Assessment Method (CAM) is a scale that enables clinicians to detect delirium with or without dementia using "yes/no" answers. It is most suitable for use in acute and RACF settings and can be used with older people who are at risk of developing delirium. For more information and to access the CAM please refer to: www.dementia-assessment.com.au

For further information and comprehensive guidelines on managing delirium please refer to the following documents:

- *Delirium Care Pathway* report (110) (accessed May 2012). Source from:
  http://docs.health.vic.gov.au/docs/doc/Delirium-Care-Pathways-2010
- *Delirium: diagnosis, prevention and management*, Clinical Guideline 103 (153) (accessed May 2012). Source from:
  http://www.nice.org.uk/nicemedia/live/13060/49909/49909.pdf

*Figure 2.1 Clinical features of delirium*

**CLINICAL FEATURES OF DELIRIUM: (See diagnostic criteria: DSM-IV)\***

- Acute onset,
- Disorganised thinking,
- Fluctuation which is erratic, and with occasional lucid intervals
- Hallucinations
- Altered level of consciousness,
- Inattention
- Disrupted sleep-wake cycle
- Delusions (paranoid)

***Symptoms and signs of underlying conditions:***

- Often difficult to assess in an elderly person because common features such as pain and fever may be absent. For example a myocardial infarct can occur without chest pain, with abrupt behavioural change the only indication.
- The acute onset of incontinence or retention of urine may indicate a urinary tract infection and fever, cough and breathlessness could indicate a chest infection.
- Syncopal episodes may indicate cardiovascular (e.g. hypotension, arrhythmia or infarct) or cerebrovascular causes. Speech disturbance and paralysis may indicate a stroke or TIA, but again confusion may be the only obvious sign to observers.
- Careful physical examination, as one would carry out for any acutely ill patient, is essential.

***Routine Examination and Testing:***

- History of onset and course of behavioural change
- Accurate medical history essential
- Symptoms suggestive of underlying cause, e.g. infection
- Previous level of function and cognitive status
- History of pain (acute or chronic)
- Sensory impairments, e.g. visual loss or sensory impairment
- Complete physical examination including temperature, pulse and blood pressure measurement and looking for evidence of infection, pain (such as undiagnosed fracture), dehydration and hypoperfusion states, e.g. blood loss and hypoxia and bladder or bowel obstruction.
- Cognitive assessment e.g. Abbreviated Mental Test Score (AMTS) or Mini Mental State Exam (MMSE)
- Urinalysis: looking for nitrites which could indicate a urinary tract infection and ketones if diabetic.

- Previous psychiatric history (if any)
- Past medical history including recent illnesses, anaesthetics, etc
- Prior history of any drug reaction
- Current medication (including any recent changes in drug or dose
- Changes in patterns of urination or defaecation
- Previous alcohol consumption
- Neurological examination including assessment of speech
- Assessment of attention, e.g. Serial 7s
- Medication review essential, especially looking at most recent changes

***Pathology Testing: Basic screening tests required***

- Full Blood Count
- Urea, electrolytes and creatinine
- Blood sugar
- ECG
- Chest X-ray
- Abdominal X-ray if faecal impaction suspected
- Folate
- Midstream urine
- Blood cultures
- Liver function tests
- B12 TSH
- Calcium, magnesium, phosphate levels

***Other tests sometimes needed***

- Cerebral CT scan: if focal neurological signs, recent fall or head injury
- Lumbar puncture: if meningism, headaches and fever
- EEG: excluding seizures, e.g. temporal lobe epilepsy

***Common difficulties in diagnosis:***

- The unreliability of symptoms and signs in the elderly
- The disease burden of the elderly:
- A patient with dementia and behavioural change may have multiple and chronic diseases.
- The presence of nitrites in urine should not preclude further investigation as it does not necessarily indicate a urinary tract infection as many frail elderly have asymptomatic bacteriuria. There is a risk of other causes being overlooked.

**Delay in initiating diagnosis** increases morbidity and mortality, particularly if it is compounded by inappropriate psychotropic medication with inevitable side-effects

**Importance of medication review**: Medications are the most common reversible cause of delirium. The risk of delirium increases with the number of medications.

\*No symptom is pathognomonic and some of these symptoms can occur in dementia without delirium. Also acute onset may not be as evident and the picture may be less florid in the elderly.

**The potential impact of pain on BPSD**

Pain frequently occurs with comorbid conditions in the older person with dementia. Research indicates that up to 83% of residents in RACFs experience pain on a regular basis (50, 154-157). Those with dementia are at risk of unrecognised and undiagnosed pain (49, 142, 158, 159) and the risk increases with dementia severity (160) as the capacity for self-report diminishes (161). A lack of appropriate assessment and/or adequate pain management is the likely consequence (162). Poorly controlled pain can impact on many aspects of the person with dementia's quality of life (49) and can contribute to BPSD. Pain can also be misdiagnosed and mistreated as BPSD. The presence of pain has been associated with restlessness, agitation, resistance to care, aggression and vocalisation in individuals with dementia as well as the unnecessary prescription of neuroleptic medications (163-169).

Dementia reportedly influences the experience and reporting of pain (49, 170). Frequently the person with dementia is dependent on the carer to recognise their pain and respond appropriately. This may require skilled assessment and interpretation of the signs and symptoms of pain, many of which will be nonverbal. Some behaviours such as grimacing, moaning or rubbing a body part may be more typically considered pain-related however, BPSD may be unrecognised as an indicator of pain (161). Further, because BPSD can occur in response to numerous and varied triggers unrelated to pain, assessment may be compounded by other factors. Strategies to overcome barriers to pain assessment in people with dementia include knowing the person, education and training, and use of adequate tools for pain assessment (171).

An awareness of cultural and language differences may assist in managing pain in those with dementia from Aboriginal and Torres Strait Islander communities or a CALD background. Acceptable ways of expressing pain can vary across cultures and the influence of educational opportunities and socio-economic differences can be significant. The person with dementia may experience considerable anxiety or fear around their pain, particularly where they have little knowledge of available medications (172) (see *Introductory Module* for further information on engaging interpreters).

Treatment for pain can be more effective when the underlying mechanism is targeted. Types of pain can be classified according to the following mechanisms (172):

- **Nociceptive** pain is due to stimulation of pain receptors which may arise from tissue inflammation, mechanical deformation, injury or disease such as osteoarthritis, fractures, musculoskeletal problems, decubitus ulcers and intra-abdominal conditions.
- **Neuropathic** pain is due to damage to the peripheral and/or central nervous system and may be described as burning, itching, tingling, electric or shooting. Examples include diabetic neuropathy, central post-stroke pain, sciatica, phantom limb pain and neuralgia.
- **Psychological or psychiatric factors** can play a major role in the onset, severity and maintenance of pain. Somatic complaints such as pain may be associated with depression. Diagnosis and subsequent treatment of the underlying psychopathology is indicated.
- **Pain related to mixed or unknown mechanisms** such as recurrent headaches or widespread pain can be unpredictable and more difficult to manage. A combination of approaches may be required.

Potential interventions for pain management include pharmacological, physical, psychological, complementary and alternative therapies. Specific instruments are required for the assessment of pain in those with dementia, particularly where the capacity for self-report has been lost (163). Severity ratings will assist in determining the effectiveness of strategies trialled. The following instruments are suggested:

- **The Pain Assessment in Advanced Dementia Scale (PAINAD)** is a clinically relevant tool which is straightforward to use for the assessment of pain in five areas: breathing; negative vocalisation; facial expression; body language and consolability (157, 163, 172, 173).
- **Pain Assessment Checklist for seniors with Limited Ability to Communicate (PACSLAC)** is appropriate for use with a person with severe dementia. A familiar carer records their observations of behaviours associated with pain on four subscales: facial expressions, activity/body movements, social/personality/mood and physiological indicators (174).
- **The Abbey Pain Scale** is based on observation and knowledge of the person with dementia's typical functional abilities as well as their medical history. It was developed for the assessment of pain in those with dementia who are unable to self-report. Six domains are included: vocalisation, facial expressions, change in body language, change in behaviour, physiological change and physical changes (157, 159).

For further information on pain in dementia see: *Caring for people living with dementia who are in pain: a presentation for Residential Aged Care staff by DBMAS* by Sharon Wall.

**Diagnosing Dementia**

Cognitive assessment tools can be located via the Dementia Outcomes Measurement Suite (DOMS) website (accessed May 2012). Source from: http://www.dementia-assessment.com.au/cognitive/index.html

> ***Culturally appropriate dementia assessment tools for Aboriginal and Torres Strait Islander peoples***
> A lack of timely diagnosis of dementia, and consequently BPSD, in Aboriginal and Torres Strait Islander communities impacts on presentation, management and the provision of timely and appropriate support. Issues using assessment tools that have been developed for non-Aboriginal and Torres Strait Islander populations with Aboriginal and Torres Strait Islander peoples include concepts of functioning that are related to career and employment, concepts of independence framed as positive rather than valuing the level of family dependence, and using examples that may have little meaning, especially in a remote context, such as remembering the name of the high school they attended (1). It is important that cultural, emotional and spiritual aspects are accounted for in screening instruments.
>
> The *Kimberley Indigenous Cognitive Assessment (KICA-Cog)* (5) is the only validated dementia assessment tool for older Aboriginal and Torres Strait Islander peoples. The KICA-Cog has 16 questions that test memory, comprehension, language abilities and limited executive functions and thus the KICA-Cog predominantly assesses memory and language skills (5). Whilst the KICA-Cog has been tested with rural and remote Aboriginal and Torres Strait Islander peoples, further assessment needs to be undertaken in urban settings (1). The scale can be accessed from: http://www.dementia-assessment.com.au/cognitive/KICA-Tool.pdf

> ***Culturally appropriate dementia and BPSD assessment tools for CALD groups***
>
> It is important to ensure culturally appropriate assessments are undertaken with people with possible cognitive impairment from CALD backgrounds (44). For older CALD people, particularly those for whom English is not their preferred language, screening tools must be culturally equivalent, not merely translated from one language to another (44) and have  good psychometric properties (175, 176). It is important that clinicians are aware of the limitations of some existing screening and assessment tools for cognitive impairment in their use with patients from non-English speaking and culturally diverse backgrounds (177). The Australian Dementia Outcomes Measurement Suite (DOMS) Project found that the *Rowland Universal Dementia Assessment Scale (RUDAS),* the *Modified Mini Mental Exam (3MS)* and the *General Practitioner Assessment of Cognition (GPCOG)* were suitable and valid tools in most health care settings for people from CALD backgrounds (1).
>
> The *Rowland Universal Dementia Assessment Scale (RUDAS)* (8) is a cognitive screening tool that was designed to reduce the effects of cultural and/or linguistic diversity on the assessment of baseline cognition in people from CALD backgrounds. The 6-item scale was developed and validated in CALD populations and was found not to be affected by gender, years of education or language (8). It can be directly and easily translated into a number of languages without having to change the structure or format of any item (8). The scale can be accessed from: http://www.dementia-assessment.com.au/cognitive/RUDAS_scale.pdf

**Measuring BPSD**

The description of BPSD should include the context in which the behaviour occurs and the frequency, intensity, duration and impact of the behaviour. *Appendix 1* provides suggested questions to facilitate comprehensive behavioural assessment.

### *Instruments for assessing BPSD*
The following high quality tools are recognised as the most current for the assessment of BPSD. Guidelines and scoring information are included to enable the delivery of improved assessment results while remaining easy to use.

### *Neuropsychiatric Inventory (NPI)*
The Neuropsychiatric Inventory is used to assess psychopathology in the person with dementia and helps distinguish between the different causes of dementia. It is based on informant report for the preceding four weeks and is appropriate for patients in acute, community and residential care settings (6). The NPI assesses the severity, frequency and level of carer stress associated with each behaviour via individual subscales. The NPI-Clinician rating scale (NPI-C; 7) has expanded on many of the original items and enables care staff to act as the informant, providing an alternative to obtaining information from an informal carer.

The reliability and validity of the NPI, overall is well established (178) however, individual NPI symptom domains can be more clinically relevant than the total NPI score (179). Interventions may be effective for managing one, or more, neuropsychiatric syndromes. Evaluating the effect of an intervention on individual symptoms or a cluster of symptoms is more likely to give an accurate depiction of its efficacy in treating neuropsychiatric syndromes. Support for the value of single-item analysis has been demonstrated in pharmacological and psychosocial studies (180, 181). Likewise, single NPI item scores of BPSD severity and frequency can demonstrate change in one behavioural domain, reflecting clinical reality (182, 183). For further information and to access the NPI refer to: www.dementia-assessment.com.au

### *Behavioural Pathology in Alzheimer's Disease (BEHAVE-AD)*
The Behavioural Pathology in Alzheimer's Disease scale (184) measures BPSD in persons with Alzheimer's disease (AD) through informant interview, based on the preceding two weeks. It is appropriate for patients in acute, community and residential care settings. The instrument has well established psychometric properties and it is recommended for the measurement of global BPSD in clinical and research settings (1). While the BEHAVE-AD was developed for use in persons with AD; it has been used in vascular dementia, dementia with Lewy bodies and frontotemporal dementia (FTD, 185, 186-188). Caution is necessary when measuring BPSD in FTD as the BEHAVE-AD may not adequately measure symptoms which occur less frequently in AD such as apathy, disinhibition and emotional inappropriateness (1). For further information and to access the BEHAVE-AD refer to: www.dementia-assessment.com.au

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***Translated BPSD instruments***
Many instruments for measuring BPSD have been translated into languages other than English. See *Table 2.1* for a list of some of the available translated BPSD instruments (please note this is not an exhaustive list of tools).

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*Table 2.1 Translated BPSD instruments*

| TOOLS | LANGUAGES |
|---|---|
| Behavioural Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD) | • Chinese (189, 190)<br>• Dutch (185)<br>• French (191)<br>• German (192)<br>• Japanese (193)<br>• Korean (194)<br>• Malayalam (Indian) (195)<br>• Spanish (US Hispanics) (196, 197)<br>• Spanish (198)<br>• Swedish (199) |
| Challenging Behaviour Scale (CBS) | • Chinese (200) |
| Consortium to Establish a Registry for Alzheimer's Disease – Behavioral Rating Scale for Dementia (CERAD-BRSD) | Details for translations can be obtained from:<br>http://cerad.mc.duke.edu/Library/CERAD-BehaviorRatingScaleForDementia-BRSD.pdf |
| Dementia Behaviour Disturbance Scale (DBDS) | • Japanese (201) |
| Neuropsychiatric Inventory (NPI) | • Brazilian Portuguese (202)<br>• Chinese (203, 204)<br>• Dutch (205, 206)<br>• Farsi (207)<br>• Greek (208)<br>• Italian (209)<br>• Japanese (210)<br>• Japanese (NPI-NH) (211)<br>• Korean (212)<br>• Polish (NPI-NH) (213)<br>• Spanish (214)<br>• Yoruba (Nigeria) (215)<br>Details for translations undertaken by the MAPI Institute can be obtained from:<br>http://npitest.net/npi/translations.html |
| Rating Scale for Aggressive Behaviour in the Elderly (RAGE) | • Chinese (216) |
| Cohen-Mansfield Agitation Inventory (CMAI) | • Chinese (217, 218)<br>• Korean (219)<br>• Dutch (220)<br>Details for translations, including Spanish, French, Chinese, German, Greek and Hebrew can be obtained from: http://www.dementia-assessment.com.au/symptoms/CMAI_Manual.pdf |
| Brief Agitation Rating Scale (BARS) | • Norwegian (221) |
| Geriatric Anxiety Inventory (GAI) | Details for translations including French, German, Spanish, Italian, Greek, Portuguese, and Polish, can be obtained from: http://www.gai.net.au/page1.html |
| Apathy Evaluation Scale (AES) | • German (222)<br>• Chinese (Taiwan) (223) |
| Cornell Scale for Depression in dementia (CSDD) | • Brazilian (224)<br>• Korean (225)<br>• Japanese (226) |
| Geriatric Depression Scale (GDS) | • Chinese (227)<br>• Spanish (228)<br>• Turkish (229) |
| Hamilton Depression Rating Scale (HAM-D) | • Chinese (230) |
| Revised-Algase Wandering Scale-Community Version (RAWS-CV) | • Chinese (Taiwan) (231)<br>• Korean (232) |

**Results**

Intervention studies from the literature search were classified as *psychosocial and environmental* or *biological*. See *Appendix 7: Methodology*, for further details on the method employed in conducting the literature search.

***Psychosocial and environmental interventions***

Psychosocial and environmental interventions from the literature search are grouped according to the following categories:

- *Therapeutic recreation* refers to a range of leisure activities that focus on improving daily functioning, independence and well-being. Examples include cooking activities, gardening or social interventions.
- *Behavioural/cognitive-behavioural interventions* are programs based on behavioural theory (i.e. classical and operant conditioning) and/or cognitive theory (i.e. changing dysfunctional thinking) to attempt to reduce BPSD. In the case of those with dementia, such therapies typically involve the active participation of carers.
- *Reminiscence-based interventions* involve using life histories and experiences to improve well-being. These can include interventions such as simulated family presence, through the use of cds or dvds, and life storybooks.
- *Exercise interventions* entail some form of gentle to medium level physical activity such as walking and/or movement which targets balance, mobility, flexibility and/or strength.
- *Music interventions* engage the regular use of sounds, melodies and/or rhythmic movement in an attempt to reduce BPSD in people with dementia (233). These can be provided through live music, singing or listening to cds or dvds.
- *Animal interventions* (or animal-assisted therapies) involve interaction between the person with dementia and a trained animal, such as a dog or cat, in a controlled environment, with the purpose of providing relaxation, or by including animals as part of physical activities such as brushing or stroking an animal (234). Interventions involving plush toys or robotic animals are also included in this category.
- *Sensory interventions* provide persons with dementia with sensory stimulation, e.g. aromatherapy, bright light therapy and multisensory stimulation (such as Snoezelen).
- *Touch therapies* refer to a range of activities including acupressure and massage which aim to reduce BPSD by promoting relaxation in the person with dementia.
- *Models of care* refer to specific care protocols or services that are implemented within RACFs. These can include emotion-oriented interventions or those which address unmet biopsychosocial needs. Respite care interventions and dementia-specific special care units are also included in this category.
- *Education/training* includes psychoeducation programs for persons with dementia and/or their carers and staff training programs which target BPSD.
- *Environmental interventions* include dementia appropriate modifications to physical environments for persons with dementia with the intention of reducing BPSD.
- *Multicomponent interventions* are intervention trials that compare a combination of interventions from the aforementioned categories.

See *Appendix 3 for table of psychosocial and environmental interventions.*

***Biological interventions***

Biological interventions from the literature search include pharmacological treatment, brain stimulation, electroconvulsive therapy and transcranial magnetic stimulation therapies.

See *Appendix 4 for table of biological interventions.*

*Table 2.2 Generic and trade names for medications relevant to this guide*

| Generic name | Trade name(s) |
|---|---|
| **Cholinesterase inhibitors / Memantine** | |
| Donepezil | Aricept, Aridon, Donaccord, Donecor, Donep, Donpesyn, Lizep, Zepen |
| Galantamine | Galantyl, Gamine, Reminyl |
| Memantine | Ebixa, Memantipin, Memanxa, Memesol |
| Rivastigmine | Exelon, Prometax |
| **Typical antipsychotics (neuroleptics)** | |
| Haloperidol | Serenace, Haldol |
| Perphenazine | *(currently unavailable in Australia) |
| **Atypical antipsychotics (neuroleptics)** | |
| Amisulpride | Solian, Sulprix |
| Aripiprazole | Abilify, Abipra, Abyraz |
| Blonanserin | *(currently unavailable in Australia) |
| Clozapine | Clopine, Clozaril |
| Olanzapine | Aprolan, Lanez, Lanzek, Lonza, Olansyn, Olanzatabs, Olanzo, Orlaaz, Ozanex, Ozin, Torrenia, Zylap, Zypine, Zyprexa |
| Perospirone | *(currently unavailable in Australia) |
| Quetiapine | Delucon, Qualez, Quetaccord, Quetacor, Quetapen, Quipine, Sequase, Seronia, Seroquel, Sular, Syquet, Syzopine |
| Risperidone | Ozidal, Redilep, Resdone, Risdone, Rispa, Risperdal, Risperibell, Rispericor, Risperisan, Rixadone |
| Tandospirone | *(currently unavailable in Australia) |
| **Antidepressants** | |
| Citalopram | Abbapram, Celapram, Celica, Ciazil, Cilopam, Cipramil, Ciram, Citadrl, Citalo, Citalobell, Citalotrust, Dralopram, Lopacit, Pramidral, Talam |
| Clomipramine | Anafranil, Placil |
| Fluoxetine | Auscap, Erocap, Erotab, Foxine, Lovan, Prozac, Zactin |
| Milnacipran | Joncia |
| Mirtazapine | Avanza, Axit, Milivin, Mirtazon, Remeron |
| Paroxetine | Aropax, Extine, Loxamine, Paxtine, Paroxo, Roxet |
| Sertraline | Eleva, Ralset, Reditra, Seralin, Sertra, Sertrabell, Sertracor, Setrona, Tralen, Xydep, Zoloft |
| Trazodone | Desyrel |
| Venlafaxine | Altven, Efexor, Elaxine, Enlafax, Evelexa, Venla, Venlexor |
| **Psychostimulants** | |
| Methylphenidate | Artige, Attenta, Concerta, Ritalin |
| **Anticonvulsants** | |
| Carbamazepine | Tegretol, Teril |
| Gabapentin | Gabaccord, Gabacor, Gabahexal, Gabaran, Gabatine, Gantin, Neurontin, Nupentin |
| Oxcarbazepine | Trileptal |
| Sodium valproate | Epilim, Valprease, Valpro |

| Generic name | Trade name(s) |
|---|---|
| **Sex hormones** | |
| Cyproterone acetate | Androcur, Cyprocur, Cyprohexal, Cyprone, Cyprostat, Procur |
| Diethylstilbestrol | (no longer manufactured, included in support of the concept only) |
| Leuprorelin acetate | Eligard, Lucrin |
| Medroxyprogesterone acetate | Provera, Ralovera, Sayana |
| Conjugated oestrogens | Premarin, Premia, Provette |
| **Sympatholytics** | |
| Prazosin | Minipress, Miniprosin, Pratsiol |
| Propranolol | Deralin, Inderal, Pronol |
| **Anxiolytics** | |
| Oxazepam | Alepam, Murelax, Serepax |
| **Others** | |
| Cimetidine | Magicul, Tagamet |
| Dronabinol | *(currently unavailable in Australia) |
| Melatonin | Circadin |
| Nabilone | *(currently unavailable in Australia) |
| Xanomeline | *(currently unavailable in Australia) |

*Medications currently unavailable in Australia have been included because approval for their use in Australia may be granted prior to a further update of this guide.

**Adverse effects of antipsychotics/neuroleptics**

Ballard and colleagues (235) assessed differences in neuropsychiatric symptoms between two groups of those with AD who had been previously prescribed neuroleptics for BPSD for at least three months. The treatment group continued medication and the control group commenced placebo. No significant difference between the continued treatment and placebo groups was found in NPI scores at 6 months but at one year there was some evidence to suggest that those with severe neuropsychiatric symptoms at baseline (NPI≥ 15) benefitted from continuing treatment. On the other hand those who continued with neuroleptic treatment had more rapid decline and greater mortality. In most situations neuroleptic medication use should be limited to the short-term treatment (up to 12 weeks) of severe neuropsychiatric symptoms to minimise potentially serious adverse effects (236). See *Table 2.3 Side effects of antipsychotics/neuroleptics* for more information (adapted from 237).

Table 2.3 Side effects of neuroleptics or antipsychotics

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

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

**Alternatives to Restraint**

Restraint involves any aversive practice, device or action that restricts a person's free movement and/or hinders their ability to make decisions. Any form of restraint should only be used as a last resort. Strategies that provide alternatives to the use of restraint should always be considered and implemented first (see *Table 2.4*). Alternatives to restraint can include:

- changes to the care environment (physical, social, cultural and emotional dimensions)
- tailoring nursing care programs, psychosocial therapies and activities to individual needs
- using alternative strategies to bed-rails to promote safety in bed
- using forms of seating and support that do not restrict free movement
- assisting the person with toileting to reduce discomfort and/or risk of falling
- addressing physical triggers of BPSD such as infection, constipation, etc
- using alarm systems and prompt response/action to the person's call bell

After careful consideration of all options and where the use of restraint is deemed to be in the best interest of the person with dementia, safety measures **must** be observed. While the decision to use restraint is made to ensure the safety of the person with dementia, the expected benefits need to be weighed against the potential harm of any form of restraint prior to implementation.

*See the following for further information:*

- Barnes, L. and Price, K. (2004). *Decision-making tool: responding to issues of restraint in Aged Care.* Canberra, ACT: Department of Health and Ageing.
- Joanna Briggs Institute (2002) Physical Restraint Part 2: Minimisation in Acute and Residential Care Facilities. *Best Practice, (6): 4*, Blackwell Publishing Asia, Australia. (accessed May 2012). Source from: www.jbiconnectplus.org/ViewSourceFile.aspx?0=4327

*Table 2.4 Strategies for alternatives to restraint (adapted from Barnes & Price, 2004; 238)*

| | |
|---|---|
| **Physical environmental strategies** | *Personal areas*: <br>• lowered bed height to suit individual needs,  ensure brakes are engaged or remove wheels from beds appropriate mobility aids close at hand <br>• provide familiar objects from the person's home (photos, furniture, etc) <br>• seating to meet the needs of individual residents <br>• appropriate alarm systems to alert staff to situations of risk such as a resident who has wandered into an unsafe area <br>*Indoor areas*: <br>• clutter free and reduced glare corridors within the facility <br>• install non-slip or carpet flooring in frequented areas <br>• appropriate signage and visual reminders to aid orientation <br>• provide safe areas for residents to wander <br>• provide quiet areas and where possible, reduce overstimulation due to environmental noise and bright lighting <br>*Outdoor areas*: <br>• increase ease of access to safe and protected outdoor area |
| **Social and emotional environmental strategies** | • encourage visitors (staggered if indicated) and promote appropriate staff/resident interaction <br>• engage familiar staff <br>• relaxation activities such as therapeutic touch and massage <br>• reality orientation <br>• sensory aids and appropriate stimulation <br>• decreased sensory overload |
| **Psychosocial strategies** | *Develop and implement individualised psychosocial strategies*: <br>• rehabilitation and/or exercise <br>• continence program <br>• physical, occupational and recreational therapies <br>• night-time activities <br>• individual and small group social activities <br>• activities for promoting success through use of overlearned skills (e.g. gardening, folding laundry) <br>• facilitate safe wandering behaviour <br>• offer a change of seating arrangements at regular intervals with their consent, for residents who are not independently mobile <br>• falls prevention program |
| **Care approach** | • increased supervision and observation by all categories of staff <br>• regular evaluation and monitoring of conditions that may alter behaviour <br>• person centred care (i.e. knowing the residents as individuals) <br>• individualised and structured routines e.g. toileting, naps <br>• check 'at risk' residents regularly <br>• improved communication strategies |
| **Physiological strategies** | • comprehensive medical examination <br>• comprehensive medication review <br>• treat infections <br>• pain management <br>• physical alternatives to sedation (warm milk, soothing music, etc) |

**Limitations**

Limitations in the methodology of the included studies inevitably affected the validity of reported outcomes. The best levels of evidence are from randomised, double-blind, placebo controlled studies, but few psychosocial and environmental studies reviewed for this guide met this gold standard. Further, the multiple components of psychosocial and environmental interventions often overlap making it difficult to determine which aspect of the intervention is the active ingredient. Psychosocial and environmental studies conducted within RACFs also face the added complication of potential contamination across groups. It is virtually impossible to introduce an intervention, beyond the normal routine, which does not impact on all those in the immediate vicinity in some way. Visiting researchers (or others gathering observational data) will likely provide a point of interest amongst residents, their families and/or staff. This negates true control conditions for the purposes of comparison with the intervention condition.

Research into management of BPSD tends to be hampered by the difficulties of recruiting and retaining numbers in this group to ensure sufficient power to conduct good quality trials. Ethical issues also arise when recruiting and obtaining consent from participants with dementia. Maintaining compliance with interventions and study design in the "real world" often requires much supervision, support and encouragement on the carers' part. When individual improvements are not evident, carers' motivation and commitment may diminish. Both, formal and informal carers are classically overloaded in their roles thereby increasing the risk of withdrawal from studies. Participant samples often included mixed types of dementia, primary outcome measures used to collect behavioural data were not always validated, follow-up assessment to determine sustainability of effects was rarely conducted and intention-to-treat analyses were frequently not reported. Further, effect sizes could not be calculated because individual BPSD were typically not the primary outcome in the majority of the included studies and standard deviations and/or means were often unavailable.

Where studies report similar interventions, differing care environments and procedures led to difficulty in determining consistency of delivery. Difficulties inevitably occur when studies treat BPSD as a homogenous group and individual behaviours are not reported separately. Consistency in gathering and reporting outcomes would better facilitate useful comparisons between studies and aid in developing effective management strategies. Overall, limited quality research exists for exploring the efficacy of psychosocial and environmental interventions for the management of BPSD and support for the biological management of BPSD is modest.

**Conclusions/recommendations**

Research findings suggest that psychosocial, environmental and biological interventions have a modest effect when applied as a generic treatment for BPSD. Potential adverse effects and drug interactions need to be carefully considered with the use of pharmacological agents. Medications targeting depression or psychotic behaviours tend to have greater efficacy. The limited benefits of generic interventions can largely be attributed to the diverse aetiology of BPSD, implying that a therapy or intervention may be effective in one set of circumstances and not in another. Therefore, case-specific interventions that are tailored to individual situations are recommended. To uncover factors that may be contributing to BPSD a thorough process of information gathering and assessment of the behaviour, the person

with the behaviour and the interpersonal and physical environment is essential. Family members and care staff often hold valuable knowledge and information about the person presenting with the BPSD, his or her history, personality and preferences. This information is important in developing effective intervention strategies. See individual behaviour modules for further information with regard to interventions targeting specific BPSD.

# 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.
- The prevalence of verbal and/or physical aggression reportedly ranges from 20% to 30% of persons with dementia living in the community and from 6% to 95% of those in residential care.
- The crucial task for the clinician is to understand what is underlying the aggression for the individual with dementia, in an attempt to address the cause and reduce this potentially dangerous BPSD.
- Expert consensus guidelines recommend atypical antipsychotics as a first-line approach for physical aggression where necessary for safety.
- Individualised psychosocial interventions are otherwise recommended and support has been demonstrated for light massage, individual behavioural therapy, bright light therapy and *Montessori* activities.
- Where pharmacological management is indicated, some evidence is provided for atypical antipsychotics, ChEIs and memantine.

---

**Before you move on, have the following been done?**

1. A *risk assessment* to identity any immediate risks to the person with dementia or others within the care environment

2. A *comprehensive assessment* that is person centred and considers the following key aspects:
   - Referrer's description of behaviour
   - The behaviour
   - The person
   - The carer
   - The care environment

3. Any reversible causes of the behaviour(s) excluded and/or treated

(See *Module 1* for further details)

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## Aggression Summary

**What is aggression and what does it look like in dementia?**
Aggression in dementia is characterised by physically and/or verbally threatening behaviours directed at people, objects or self. It is often quantified by specific acts which can include:
- verbal insults, shouting, screaming
- obscene language
- hitting, punching, kicking
- pushing, throwing objects
- sexual aggression

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

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

**Measuring aggression**
The following scales are widely used:
- The Rating scale for Aggressive behaviour in the Elderly (**RAGE**)
- The Overt Aggression Scale (**OAS**)
- The physically aggressive subscale of the Cohen-Mansfield Agitation Inventory (**CMAI**)
- The agitation/aggression subscale of the Neuropsychiatric Inventory (**NPI**) and the aggression subscale of the **NPI-Clinician**

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

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

**Management of aggression**
The crucial task for the clinician is to attempt to understand what is underlying the aggressive behaviour for the individual with dementia. Interventions targeting the cause will likely assist in reducing the behaviour.

*Psychosocial and environmental interventions*
- Psychosocial and environmental intervention studies were primarily conducted in residential settings.
- Touch therapies and music interventions incorporated the greatest number of studies. Touch therapies are diverse and include craniosacral still point technique, therapeutic touch, acupressure and tactile massage.
- Support has been demonstrated for light massage, individual behavioural therapy, bright light therapy and *Montessori* activities.
- Individualised, person-centered care based on psychosocial management is recommended.
- The lack of scientific evidence for psychosocial interventions should not prevent clinicians considering these interventions on a case-by-case basis.

*Biological interventions*
- Although the adverse effects of pharmacological interventions raise concerns, particularly with antipsychotics, situations can arise which place the person with dementia and/or others around them at risk, requiring an urgent response.
- Where physical aggression presents a safety risk, expert consensus guidelines recommend short-term use of atypical antipsychotics although evidence to support their use is limited in the recent literature.
- The majority of biological intervention studies focused on examining the efficacy of atypical antipsychotics, ChEIs and memantine.
- No good evidence is available for use of anticonvulsants. Other medications that are used but with very limited evidence are the antiandrogen cyproterone, the alpha-blocker prazosin, and the traditional Asian herbal formulation Yokukansan (Yi-Gan San).

**Limitations**
- There are limited psychosocial intervention studies in the literature, and many reported no effects or conflicting results.
- Psychosocial intervention studies tended to employ small sample sizes or report on clusters of symptoms including aggression. This limits the generalisability of findings.
- Few studies examined the long-term maintenance of benefits after interventions ceased.

**Conclusions**
- Expert consensus guidelines recommend the short term use of atypical antipsychotics as a first-line approach where necessary for safety.
- Individualised psychosocial interventions are otherwise recommended and sensory interventions provide the best evidence for these.
- Where pharmacological management is indicated, some evidence is provided for atypical antipsychotics, ChEIs and memantine.

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

Aggression can be one of the most challenging and disruptive behaviours in dementia. The presentation of aggression in dementia is not always consistent but it is characterised by physically and/or verbally threatening behaviours directed at people, objects or self. Aggressive behaviours are generally perceived as a threat to the safety of those with dementia and the care environment, which includes family carers and/or care staff and other residents (239-241). According to Voyer and colleagues (242), aggression is often quantified by specific acts and includes:

- verbal insults
- shouting, screaming
- obscene language
- hitting, punching, kicking
- pushing, throwing objects
- sexual aggression (see *Module 11*)

**Causes of aggression**

Aggression can be a purposive and overt response to a violation of personal space or a perceived threat (243). Not unexpectedly, it often occurs during personal care tasks involving close carer-/staff-resident contact (242, 244, 245). The neurobiological underpinnings of aggression in dementia are not well understood, but reduced serotonergic activity (240, 243), reduced cholinergic transmission (246) as well as frontal lobe/executive dysfunction (247) have been implicated. Aggression can also occur as a consequence of underlying depression or psychotic symptoms.

Aggressive behaviour may be a manifestation of unmet physiological and/or psychological needs. Within the Need Driven Behaviour (NDB) model, aggression can be seen as a form of communication as the person with dementia is less able to effectively articulate their needs (248). Aggression can also indicate a delirium (248). While there is no single cause (249), common precipitants of aggression in dementia include (250):

- pain or discomfort
- constipation
- hunger and/or thirst
- medical illness including infection
- environmental stressors including staff and/or carer communication
- boredom
- loneliness
- dehydration
- depression

**Differential diagnosis**

The term aggression is often used interchangeably with agitation yet aggression can present independently or as a consequence of agitation (236, 241, 251). Aggressive behaviours are strongly associated with depression (247, 252-254) and psychosis (252, 253, 255).

**Measuring aggression**

Global scales which include items to measure aggression, as well as scales specifically developed for assessing aggressive behaviours, are available for clinical purposes:

- The Rating scale for Aggressive behaviour in the Elderly (**RAGE**) is a 21-item scale completed by carers or RACF staff to quantify the type, frequency and pattern of

three factors (physical aggression, verbal aggression and antisocial behaviour) over the preceding three to five days (256). The reliability and validity of the RAGE is well established (1).

- The Overt Aggression Scale (**OAS**) is completed by staff according to the severity and duration of four factors: verbal aggression, physical aggression against objects, physical aggression against self and physical aggression against others (257).
- The physically aggressive subscale of the **CMAI** incorporates physically and verbally aggressive behaviours. This carer-rated questionnaire assesses the frequency of given behaviours during the preceding fortnight (258).
- The Agitation/Aggression subscale of the **NPI** is completed during an interview with the carer, in which the carer rates the frequency and severity of the person with dementia's aggressive behaviours as well as his or her own subsequent distress (6). The reliability and validity of the NPI overall is well established (178).
- The NPI-Clinician (**NPI-C**) version has since revised the original subscale, allocating aggression a discrete subscale with an expanded list of 14 items (7). The additional items gather information around spitting, pushing, scratching, passive aggression, intrusive behaviours, destroying property, conflict with others, sexual aggression, dangerous activities and throwing food.

## Prevalence of aggression

Aggression has been reported in approximately 20% to 30% of persons with dementia living in the community (111, 259). Prevalence is typically higher in RACFs (259) with 6% to 95% of persons with dementia exhibiting aggressive behaviours (92, 110, 249). Rates of physically aggressive behaviours are comparable to those of a verbal nature (92) however, not all episodes of aggression are clinically significant (243). Aggression in dementia is more common amongst men (260) and has been linked to a premorbid personality trait of low agreeableness (261).

The frequency and intensity of aggressive behaviours tend to increase as dementia progresses and as cognition, activities of daily living (ADL) functioning and language abilities deteriorate (134, 240, 244), until the severe stages when they tend to decline. Aggression is reportedly equal in prevalence in those with Alzheimer's disease (AD) and vascular dementia (VaD) (240, 254), while those with frontotemporal dementia (FTD) present with a higher incidence of more intense physical aggression than those with AD (262).

## Effects of aggression

Aggression, particularly physical aggression, significantly affects those with dementia and others within the care environment (241, 263) with symptoms being very difficult for family carers and RACF staff to manage (241, 264). Aggressive behaviours are associated with considerable carer burden and stress, reduced quality of life and earlier admission to RACFs (239). Although not common, one of the worst consequences of aggression is harm to others in the care environment (243). Approximately 90% of all incidents of assault against RACF staff are reportedly caused by residents with AD (249). Personal hygiene activities, particularly bathing, can provoke anxiety or fear in the person with dementia and hence tend to be the most frequent circumstances around which aggressive behaviours occur (245). Confined spaces and hard surfaces in the bathroom may exacerbate the risks for all involved. When they are anxious around provoking aggressive behaviours, carers may

attempt to complete the task in the shortest possible time which can further inflame the situation (243).

Aggressive behaviours can be very distressing and may directly influence social functioning due to a loss of opportunities for positive interaction with others (246, 262). The person with dementia will likely forget the episode long before others. Aggression is most commonly directed at primary carers (245). This tends to affect the quality of the relationship between the carer and the person with dementia and increases carer stress which, in turn, may exacerbate BPSD (247).

Additionally, aggressive behaviours can lead to the use of physical and/or chemical restraint in an attempt to reduce the impact of the behaviour (249). The use of restraints can negatively influence the quality of life and health of the person with dementia, cause distress for the person and family members as well as exacerbate the behaviours (241, 251) For further information and alternatives to restraint see *Module 2*.

### Results

A systematic literature review to set criteria (see *Appendix 7*) yielded 13 psychosocial and environmental and 26 biological intervention studies with outcomes relevant to aggression in dementia.

> **PRESENTATION**
>
> *Mr B, an 89 year old widowed gentleman who migrated from Italy 60 years ago, had served in the Italian army for 5 years and become widowed 28 years ago. He has a large extended family including two daughters who were his primary carers for the three years prior to his admission to a RACF and continue to visit frequently. Mr B is unable to read or write English and he is increasingly reverting to his first language of Italian. There are no other Italian speaking residents or staff in the facility. His increasing frustration with being unable to communicate with staff and other residents has resulted in physical aggression and verbal abuse.*
>
> *Mr B resists care and direction from staff. He uses his walking stick as a machine gun, attempting to "shoot" staff and residents. He is verbally abusive in Italian; staff and other residents are frightened that Mr B will hit them. Strategies used by care staff have been unsuccessful and reactive to his behaviour e.g., attempting to reason (loudly) with him in English. If Mr B's aggressive behaviour cannot be managed, he is at risk of losing his current accommodation.*
>
> *Adapted from the DBMAS Best Practice Guidelines for People with Dementia from a Culturally and Linguistically Diverse (CALD) Background who have Changing Behaviours (2007).*

Psychosocial interventions were grouped into four broad categories: therapeutic activities, music, multi-sensory and miscellaneous. Biological interventions were grouped into four categories: cholinesterase inhibitors (ChEIs)/memantine, atypical antipsychotics, other pharmacological treatments and brain stimulation therapies.

### Management of aggression

The crucial task for the clinician is to attempt to understand what the aggressive behaviour means for the individual with dementia. Interventions targeting the cause will likely assist in reducing the behaviour. Where underlying depression or psychotic symptoms are prompting aggressive behaviour, treatment of these BPSD may reduce the aggressive behaviours. *Appendix 1* provides suggested questions to facilitate comprehensive behavioural assessment.

### Psychosocial and environmental interventions

Psychosocial and environmental intervention trials were primarily conducted in residential settings with the greatest number falling under the classification of touch therapies or music. Interventions in the touch therapies category are diverse and include therapeutic touch, tactile massage and craniosacral still point technique. A multicomponent study compared acupressure, *Montessori* activities and the presence of a companion.

Moderate support is reported for a reduction in aggressive behaviours with acupressure and a *Montessori*-based activity program (265) which comprised music, sensory stimulation, procedural movements and discussion when compared to the presence of a companion which entailed engaging in conversation and attempting to maintain the person with dementia's attention. A moderate quality study of light tactile massage provided in a quiet space showed a significant reduction in aggression when compared to regular activities (266).

Craniosacral still point technique involves gently palpating the head or other body parts to the body's craniosacral rhythm. An uncontrolled pilot study of moderate quality suggests that it may offer temporary improvement in physically aggressive agitation until the intervention is ceased (267). Preliminary evidence was presented for one study of therapeutic touch. During the intervention the person with dementia's "energy imbalances" are identified and corrected "by the practitioner passing their hands several inches above the body" as opposed to simulated therapeutic touch which required those providing the placebo intervention to silently repeat mathematical calculations while moving their hands over the person (268). No significant difference was demonstrated for the incidence of physically aggressive behaviours between the therapeutic touch, simulated therapeutic touch and usual care groups after five days and the study analysis was flawed (268).

The only study in the behavioural/cognitive-behavioural interventions category provided moderate evidence of a reduction in the frequency of aggressive behaviours with individual behavioural therapy (269). Moderate evidence that bright light therapy may also be associated with decreased aggression (270) and modest evidence for multisensory stimulation in reducing the frequency of aggressive behaviours was reported (271).

The efficacy of music interventions is questionable. Three studies of moderate to strong quality reported that music interventions had no beneficial effects on levels of aggression (233, 272, 273), and verbally aggressive behaviours actually increased in one subgroup (273). A further music study of moderate quality reported increased aggression during the intervention period, which decreased during the control period (274).

The education/training category included two studies of staff education interventions, which showed limited efficacy in reducing aggression. While the intervention decreased the frequency of aggressive behaviours in one study of moderate quality, neither the intensity nor the overall severity of aggressive behaviours was reduced (251). The second staff education study provided strong evidence of no benefit for physically or verbally aggressive behaviours (275).

Psychosocial and environmental interventions are recommended as part of an individualised care plan. Strategies can also include adapting the living environment, structured activities for persons with dementia as well as providing training and support to family and paid carers (241). While the evidence in support of the psychosocial interventions is not strong, this should not prevent clinicians from considering these interventions on a case-by-case basis (241), where they are beneficial to the individual with dementia, enjoyable and culturally appropriate (276). Aggression in persons with dementia can occur as a consequence of many potential antecedents (see *Table 1.2, Module 1* for a list of contributory factors); the identification of triggers or underlying causes will assist in managing the behaviour.

One limitation of the literature presented occurs with studies examining single intervention techniques, such as music therapy or massage, for groups of persons with dementia, whereas good clinical practice suggests tailoring psychosocial interventions to individuals. For example, for one person alleviation of aggression may result from changing their personal care routine for; for another it may be prescribing analgesics for severe osteoarthritic pain prior to dressing; and for a third, it may be arranging outdoor walks with a carer or family member to alleviate feelings of imprisonment. Single-case designs have less impact academically and are underrepresented in this area.

*Please see Appendix 3 for interventions reported above.*

### *Biological interventions*

Although the adverse effects of pharmacological interventions raise concerns, situations can arise which place the person with dementia and/or others around them at risk, requiring an urgent response. Where necessary for safety, expert consensus recommends an atypical antipsychotic for physical aggression, not due to underlying psychosis, anxiety or depression (277). Pharmacological interventions are also suggested where symptoms appear to have a physical or iatrogenic aetiology, are unresponsive to psychosocial interventions or where residual symptoms are problematic (241, 250). Risperidone, quetiapine and olanzapine are

suggested (277) although evidence to support their use is limited in the recent literature. No first-line medication recommendations are provided for verbal aggression or aggression without a safety risk, indicating a lack of support for pharmacotherapy in management of this behaviour (277).

Traditionally, typical or conventional antipsychotics were the mainstay for the treatment of aggression in dementia, however as they are associated with a risk of significant adverse events (278) they have largely been replaced with atypical antipsychotics. Studies yielded mixed results for the efficacy of atypical antipsychotics. Three studies of moderate quality reported improvements in aggression with risperidone, olanzapine and quetiapine (278-280). One case study found no benefit with blonanserin (281).

The findings from two further studies of moderate quality with perospirone (currently unavailable in Australia) are conflicting: one showed reduced aggression (282), while the other reported decreased verbal outbursts only, with no significant reduction in physical threats and/or violence (283). Current guidelines recommend careful monitoring for adverse effects with the use of atypical antipsychotics (277). Their use has been associated with further cognitive decline and risk of somnolence, extrapyramidal symptoms, abnormal gait, oedema, urinary tract infections, metabolic syndrome, incontinence, falls, cerebrovascular adverse events and mortality (284) (see *Table 2.3, Module 2* for side effects associated with neuroleptics).

Primarily used for treating cognitive symptoms in dementia, ChEIs and memantine may have potential benefits in the management of aggressive behaviours. One study of strong quality showed no effect for physically or verbally aggressive behaviours with donepezil (285) while a further study provided modest to moderate evidence for its efficacy (286). Four studies of memantine, three of strong quality and one of

| STRATEGIES/OUTCOMES |
| --- |
| • *It is evident that Mr B's frustration, related to his inability to express his needs in English, is contributing to the aggressive behaviours.* |
| • *Some staff members also observed that Mr B can become anxious and resistant when he does not know what is about to happen.* |
| • *Staff have been relying on gestures and pointing to items in an attempt to communicate with Mr B. They were unaware of the range of language specific communication aids available to assist Mr B to express his needs. Training sessions were arranged with regard to the importance of using communication aids and how to use them effectively.* |
| • *Consultation with family members identified Mr B's preferred dialect and appropriate communication style. RACF staff was able to engage a professional interpreter or bilingual/bicultural health worker when conducting assessments or reviewing Mr B's care needs.* |
| • *Staff was made aware of the subtle signs in Mr B's nonverbal communication which may be indicators of his escalating anxiety or frustration. They were better able to deescalate situations before Mr B became aggressive.* |
| • *Since his admission to the RACF, staff and family members have noted that Mr B has become increasingly socially isolated. His children described Mr B as an outgoing man who previously had many friends and enjoyed the company of others.* |
| • *Mr B's inability to communicate effectively with others also results in his need for social contact not being met. He has become further isolated because other* |

moderate quality, showed reduced aggression (183, 287-289). While memantine is generally well-tolerated, some persons with dementia, particularly those with Lewy body pathology, may be susceptible to developing adverse effects which include increased aggression, de novo delusions, hallucinations or agitation (290-292).

No good evidence for use of anticonvulsants for aggression in dementia is available. Divalproex sodium demonstrated a reduction in aggression in a study of moderate quality (293) but valproate increased aggression in another study (294). Oxcarbazepine (a derivative of carbamazepine or Tegretol) showed no effects in a further study of moderate quality (295).

There is some suggestion that androgen levels in males are correlated with aggression in dementia and that antiandrogens may improve this symptom. One study of strong quality, which included eight males and nineteen females with possible or probable AD, and a further case study (male), reported positive results with cyproterone acetate (296, 297). Depending on the jurisdiction, it may be necessary to obtain consent from a guardianship tribunal or board, not just from the family member or person responsible, before administering hormonal therapy. For example, under the NSW Guardianship Act, use of oestrogens or antiandrogens in men with impaired decision making capacity who exhibit sexual disinhibition is regarded as "Special Treatment" and approval by Guardianship Tribunal (not merely by the "person responsible") is required.

*residents were fearful of his outbursts. An Italian gentleman, living in the self care units within the larger complex, was identified and he was willing to visit Mr B regularly.*

- *While visiting Mr B, the gentleman was able to share some of the interesting points of conversation with staff, allowing some social interaction and rapport building to occur between Mr B and RACF staff.*
- *When asked, the family reported that Mr B enjoyed listening to Italian opera, Italian radio and television as well as gardening and playing cards. The family provided some of Mr B's favourite Italian music and the Multicultural Aged Care Service was contacted for an Italian radio program guide as well as available audio and videotapes.*
- *Within the RACF, structured social activities were conducted in English and hence, Mr B had been largely excluded. The family identified special days which had always been culturally significant to Mr B and these were incorporated into the activity program. The family helped to make these times special with traditional food and by including other residents. Mr B was proud to be the centre of attention on these occasions.*
- *A mobility assessment was conducted by the physiotherapist to determine whether a walking stick was the most suitable mobility aid for Mr B and if a change was possible to reduce the inappropriate use of his current aid.*
- *Mr B was introduced to the RACF garden patch so he could continue his interest in vegetable gardening. While he was limited in what he could physically contribute, Mr B apparently enjoyed being around the garden.*

One moderate quality study of a sympatholytic agent, prazosin used for hypertension and benign prostatic hypertrophy, provided preliminary support for a significant reduction in total BPSD scores and improvement in agitation/aggression when compared to placebo. As statistical analysis was not performed on behavioural subscores, the degree of improvement in aggression is unknown (298). Lastly, three studies of moderate quality (299-301) and a

case series of five persons with dementia (302) provided some evidence that a traditional herbal medicine formulation Yokukansan (also known as Yi-Gan San) reduced aggression in persons with dementia.

The individual risk/benefit ratio for the person with dementia and the safety of others in the immediate environment must be carefully considered prior to the prescription of pharmacological agents. Where prescribed, the use of such agents should be time-limited, and the situation reviewed frequently (241). Additionally, individuals with different types of dementia may respond differently. Those with FTD may not respond to ChEIs (250), and those with dementia with Lewy bodies (DLB) are more vulnerable to the adverse effects of antipsychotics (250, 303, 304).

*Electroconvulsive therapy*
Traditionally used as treatment for mania, catatonia or treatment-resistant depression, electroconvulsive therapy (ECT) has recently been trialled in persons with BPSD. A case series (305) reports complete remission of aggression in five persons with dementia and clinical improvement in one following bitemporal ECT. As no control group was included, placebo effects are unknown and findings should be interpreted with caution. Moreover, the risk/benefit ratio should be considered as the literature suggests that ECT can be associated with retrograde and anterograde memory impairment as well as a slightly increased risk of death (306).

*See Appendix 4 for interventions reported above.*

**Limitations**
There is a paucity of sound research to guide clinicians and carers on the management of aggression in persons with dementia, with most studies offering only moderate evidence at best. Psychosocial intervention studies are limited in number, and many studies reported no effects, or conflicting results. The studies tend to have small sample sizes or report improvements on a symptom cluster which includes aggression, limiting the generalisability of their findings. (233, 289). While most trials failed to conduct long-term follow-ups, five studies completed short-term follow-up assessments between two and twelve weeks (233, 267, 268, 272, 275). Beneficial effects were not maintained after interventions ceased.

**Conclusions**
In summary, while aggression in dementia is relatively uncommon, it has significant consequences for both the person with dementia and others within the care environment. While reports on the outcomes of interventions, particularly psychosocial and environmental interventions are limited, some support was demonstrated for light massage, individual behavioural therapy, bright light therapy and *Montessori* activities. Expert consensus guidelines recommend the use of multidisciplinary, individualised and multifaceted care including psychosocial interventions and short-term pharmacological treatment only when necessary. Where pharmacological treatment is indicated, atypical antipsychotics and memantine provide some evidence for the treatment of aggression in dementia although the risk of adverse effects limits the use of antipsychotics.

# MODULE 4: Agitation

**Key messages**

- Agitated behaviours in dementia present as observable, non-specific, restless behaviours that are excessive, inappropriate and repetitive.
- In addition to the physical component of agitation in dementia, a psychological component involving strong and disabling emotions is proposed.
- Symptoms of agitation can overlap with aggressive behaviours and delirium can be misdiagnosed as agitation.
- Agitation is one of the most commonly occurring BPSD, with prevalence rates ranging from 9% to 96%. Not all cases are clinically significant.
- Individualised psychosocial interventions are recommended as a first-line approach in the management of agitation in dementia and short-term pharmacological intervention only when necessary.
- Music interventions provide the best evidence for the psychosocial management of agitation.
- The strongest evidence for pharmacological interventions is provided by trials of atypical antipsychotics; however, these are not recommended due to safety concerns.
- Where pharmacological management is required, ChEIs, memantine and antidepressants are alternatives.

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**Before you move on, have the following been done?**

1. A *risk assessment* to identity any immediate risks to the person with dementia or others within the care environment

2. A *comprehensive assessment* that is person centred and considers the following key aspects:
   - Referrer's description of behaviour
   - The behaviour
   - The person
   - The carer
   - The care environment

3. Any reversible causes of the behaviour(s) excluded and/or treated

(See *Module 1* for further details)

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## Agitation Summary

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

**Causes of agitation**
- Decreased frontal or temporal lobe metabolism, increased neurofibrillary tangle burden in the frontal lobe, and altered activity in the neurotransmitter systems.
- Interaction between individual and environmental factors may also play a role.

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

**Measuring agitation**
Current guidelines recommend the use of 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**). Other instruments include the 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 prevalence rates ranging from 9% to 96% however, not all cases are clinically significant.
- Prevalence rates also vary depending on the definition of agitation adopted, the instrument used to measure agitation and/or the population studied.
- More agitated behaviours have been reported in those with greater dementia severity, greater impairment of insight, faster rate of cognitive decline, poorer performance in activities of daily living and lower income.
- No difference in the prevalence rates of agitation have been reported for the different types of dementia.

**Effects of agitation**
Agitation is associated with:
- higher likelihood of psychiatric or medical comorbidity
- poorer health-related quality of life
- increased use of psychotropic medication
- increased use of physical restraint
- greater burden on family and RACF carers
- premature RACF placement

**Management of agitation**

Episodes of agitation may be associated with underlying physical symptoms, pain, discomfort, medication effects or specific environmental stimuli. Where the person with dementia and/or others are not at risk and reversible causes have been eliminated, consider psychosocial and/or environmental interventions as a first option.

*Psychosocial and environmental interventions*

- Psychosocial intervention studies were primarily conducted in residential settings.
- The majority of the studies fell within the music interventions category and these provided the best evidence for the psychosocial management of agitation.
- Most intervention studies reported positive results but the quality of the evidence varies.
- Individualised care based on psychosocial management is recommended.
- The lack of scientific evidence for psychosocial interventions should not prevent clinicians from considering these interventions on a case-by-case basis.

*Biological interventions*

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

**Limitations**

- Many of the 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.
- Short-term follow-up data is available in several studies, but none of the studies conducted long-term follow-ups.

**Conclusions**

- Expert consensus guidelines recommend the use of individualised psychosocial interventions as a first-line approach in the management of agitation in dementia and short-term pharmacological intervention only when necessary.
- Music interventions provide the best evidence for the psychosocial management of agitation.
- Where pharmacological management is required, ChEIs, memantine and antidepressants may be considered as alternatives to atypical antipsychotics as these are not recommended due to safety concerns.

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

Agitation is one of the three major neuropsychiatric syndromes of dementia, and it generally refers to behaviours such as restlessness and pacing, aberrant motor activities (e.g. excessive fidgeting or hand wringing), and/or disruptive vocalisations (244). Other non-specific disruptive behaviours are also indiscriminately classified as agitation and this may primarily arise from the lack of consensus around the conceptualisation of agitation. A critical appraisal of the literature and concept analysis identified five common attributes of agitation in dementia: excessive, inappropriate, repetitive, non-specific, and observable (307). In addition to the physical component of agitation in dementia, an underlying psychological aspect which incorporates strong and disabling emotions is proposed (257, 308).

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**PRESENTATION**

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

*Clinical scenario adapted from Professor Lynn Chenoweth, with permission*

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Sundowning is a related clinical phenomenon, which refers to the appearance or exacerbation of a cluster of disruptive behaviours occurring in the late afternoon or early evening. The literature appears divided on the existence of sundowning with some studies suggesting there is limited clinical evidence to support its existence, while others report peak agitation in the late afternoon or early evening (309). Various aetiologies of sundowning have been proposed, including unmet biopsychosocial needs, fatigue (310), diurnal mood variations (309), sleep disturbances (311) and inadequate daylight exposure (312).

**Causes of agitation**

The neurobiological underpinnings of agitation are not well understood. Recent research suggests decreased frontal or temporal lobe metabolism (313), increased neurofibrillary tangle burden in the frontal lobe (314), and altered activity in the neurotransmitter systems (315-317) may play a role in the expression of agitation. Agitation is also a product of the interaction between individual and environmental factors including premorbid personality, communication difficulties, medical comorbidities, pain and/or underlying distress arising from unmet biopsychosocial needs such as a lack of sensory stimulation or social interaction (98).

**Differential diagnosis**

No diagnostic gold standard for agitation exists. On occasion agitation can conceptually and symptomatically overlap with aggression, although it has been suggested that aggressive behaviours are generally intentional, violent, intense and harmful as well as lacking the repetitiveness and non-specificity of agitated behaviours (307). Hyperactive delirium can

also be misdiagnosed as agitation (318). Similar to delirium, agitation can arise from potentially reversible organic factors such as pain, infection, metabolic conditions, neuropsychiatric conditions, medication side-effects, substance intoxication/withdrawal, dietary issues arising from specific intolerances and/or toxins (319). Differing aetiologies, and hence management strategies, necessitate differentiating between agitation, aggression and delirium, and identifying the underlying issues.

**Measuring agitation**

In line with the inconsistencies in the nosology of agitation, numerous instruments have been developed to assess different aspects of agitated behaviours. Current guidelines recommend the use of the following scales for the measurement of agitation in dementia (1):

- The Cohen-Mansfield Agitation Inventory (**CMAI**) is a carer-rated questionnaire that quantifies the frequency and disruptiveness of 29 agitated behaviours over a two-week period. Scores can be further computed for three specific types of agitated behaviours: physically aggressive behaviours, physically non-aggressive behaviours and verbally agitated behaviours (258).
- The Pittsburgh Agitation Scale (**PAS**) assesses the presence and severity of agitation symptoms in four behaviour groups: aberrant vocalisation, motor agitation, aggressiveness and resisting care. It is based on relatively short periods of direct observation and offers greater flexibility to suit different clinical needs (320).
- The agitation/aggression and aberrant motor behaviour subscales of the Neuropsychiatric Inventory (**NPI**) are completed during a clinical interview with the carer, in which they rate the frequency and severity of the person with dementia's agitated/aggressive behaviours as well as their own subsequent distress (6, 7). The reliability and validity of the NPI, overall is well established (178) however, individual NPI symptom domains can be more clinically relevant than the total NPI score (179).
- The NPI-Clinician (**NPI-C**) version has since revised the original subscale, allocating agitation to a discrete subscale with an expanded list of 14 items (7). The additional items gather information around unwanted requests for attention, repetitive questioning, restlessness, fidgeting, complaining hyperventilating, refusing medication, pacing, aggressively trying to get to a different place, crying with frustration and trying to enlist help inappropriately.

Other rating scales which have also been widely used to measure agitation in research and clinical settings include:

- The NPI-Clinician (**NPI-C**) divides the Agitation/Aggression subscale from the original NPI into two separate subscales and includes a further 11 questions concerning agitated behaviours (7).
- The Agitated Behaviour Mapping Instrument (**ABMI**) is an observational tool that can be used to assess both the frequency of 14 agitated behaviours and the social and physical environment in which the behaviours occur across a three-minute period (321).
- The Brief Agitation Rating Scale (**BARS**) is a carer-rated scale that measures the frequency of 10 agitated behaviours over the previous two weeks (322).
- The Excited Component of the Positive and Negative Syndrome Scale (**PANSS-EC**) is a simple tool that rates agitation from not present to extremely severe on five

items: excitement, tension, hostility, uncooperativeness and poor impulse control (323, 324).

The literature suggests that informant ratings converge to a moderate extent with ratings based on direct observations (325). While observation-based assessments may be more time consuming to administer, they are less prone to bias when compared to carer-rated instruments relying on retrospective reporting (326).

**Prevalence of agitation**

Agitation is one of the most commonly occurring BPSD with symptoms reported in 9% to 96% of persons with dementia. Variance in prevalence arises from the different definitions of agitation, the instrument used for assessment and/or the population studied (e.g. community dwellers or nursing home residents). Although agitation is observed in the majority of those with dementia, the level of disruption is not always clinically significant (327). Increased agitation in dementia has been associated with greater dementia severity (328-330), greater impairment in insight (331), faster rate of cognitive and functional decline (332, 333), poorer performance in activities of daily living (ADLs) (328) and those with a lower income (334). The majority of studies report no difference in the prevalence of agitation between the different types of dementia, suggesting that agitation is not related to any disease-specific neuropathology.

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*ASSESSMENT*

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

- *Pain/discomfort/illness/infection*
- *Medication interactions, dosage*
- *Overstimulation (noise, people, activities)*
- *Lack of attention to culturally-relevant needs*
- *Overextending her capabilities by expecting too much of her*
- *Stopped her from what she is doing or wanting to do*
- *Altered routines, new staff, particular staff and/or family members*
- *Unfamiliar/altered/deprived physical environment*
- *Reduced stress threshold*

*Assessing the situation*

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

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**Effects of agitation**

Agitation is often viewed as one of the most challenging and persistent behaviours manifesting in persons with dementia. It is linked to poorer outcomes such as a increased likelihood of neuropsychiatric or medical comorbidity (328, 335), poorer health-related quality of life (336, 337), increased use of psychotropic medication (335, 338), increased use of physical restraints (335) and increased burden in family and RACF carers (328, 338). Further, agitation can precipitate admission to a RACF (339).

**Results**

A systematic literature review to set criteria (see *Appendix 7*) yielded 32 psychosocial and environmental and 33 biological intervention studies with outcomes relevant to agitation in dementia. Psychosocial interventions were grouped into four broad categories: therapeutic activities, music, multi-sensory and miscellaneous. Pharmacological interventions were grouped into four categories: ChEIs and/or memantine, atypical antipsychotics, antidepressants and other pharmacological agents.

**Management of agitation**

It is important for the clinician to attempt to determine the potential triggers behind the agitated behaviours for the individual with dementia. Episodes of agitation may be linked with specific environmental stimuli, incidents or people. Interventions targeting the cause will likely assist in reducing the behaviour. Where underlying physical symptoms, pain, discomfort and or medication effects are prompting agitated behaviours, treatment of these may reduce the agitated behaviours. *Appendix 1* provides suggested questions to facilitate comprehensive behavioural assessment. 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***

Psychosocial and environmental intervention studies were primarily conducted in residential settings, with the music category incorporating the greatest number of studies. The majority of the music intervention studies involved group music therapy and were of moderate quality, with most reporting positive effects (340-342). Benefits were not maintained on withdrawal of the music intervention (342) and two studies of moderate and strong quality found no benefit for group music (273, 343). Moderate evidence is provided for the efficacy of music concerts (272), music with hand massage (344), and individualised/preferred music (345, 346). Two case studies in music therapy showed improved agitation in patients with frontotemporal dementia (FTD) (347).

The therapeutic recreation category is diverse and comprises brief psychosocial therapy (348), activities using a range of standardised stimuli (349), indoor gardening (350) and the Closing Group therapeutic recreation program (351). Moderate evidence in support of these interventions was presented.

The touch therapies category is also heterogeneous and includes therapeutic touch (268, 352), acupressure (265, 353) and healing touch (354). Moderate support is reported for these interventions with the exception of therapeutic touch. During the intervention the person with dementia's "energy imbalances" are identified and corrected "by the practitioner passing their hands several inches above the body" as opposed to simulated therapeutic touch which required those providing the placebo intervention to silently repeat mathematical calculations while moving their hands over the person (268). No significant difference was demonstrated for the incidence of verbally agitated behaviours between the therapeutic touch, simulated therapeutic touch and usual care groups after five days (268). While reductions in physically non-aggressive behaviours were reported, the study analysis was flawed (268). The other therapeutic touch study involved actual contact with the person with dementia's neck and shoulders. This is a good quality study although results showed only a trend toward decreasing restlessness (352).

Sensory interventions include bright light therapy and aromatherapy. There is moderate to strong evidence to show that bright light therapy does not decrease and may even aggravate agitation (355, 356). Marked improvement in agitation and aberrant motor behaviours was reported with aromatherapy in the form of lavender oil inhalation (357), but massage with Melissa oil showed no beneficial effects (358). Both aromatherapy studies were of moderate quality.

Some positive results were reported for models of care in NH, with significant reductions in agitation reported with "Treatment Routes for Exploring Agitation" in a single case study and a study of moderate quality (359, 360). The evidence for the effects of person-centred care on agitation is mixed, with one study of moderate quality reporting improvements only at follow-up but not immediately post-intervention (37).  The evidence for the effects of staff training is also mixed, with two studies of strong quality reporting conflicting results (361, 362).

The reminiscence-based, exercise, animals and environmental interventions categories each included one study. No definite conclusions could be drawn from the exercise study of moderate quality, as it reported contradictory results on two outcome measures (363). A case series with four patients receiving animal-assisted therapy, as well as two studies of moderate quality involving simulated family presence and a "wander garden" reported fewer agitated behaviours (364-366).

Overall, interventions that attempt to address the unmet biopsychosocial needs of the person with dementia showed some beneficial effects. Professional consensus recommends using psychosocial interventions as part of an individualised care plan. Strategies could also include adapting the living environment, allowing persons with dementia to participate in structured activities as well as providing training and support to family and paid carers (241). While the evidence in support of the psychosocial interventions is not strong, this should not prevent clinicians from considering these interventions on a case-by-case basis (241), where they are beneficial to the individual with dementia, enjoyable and culturally appropriate (276). Agitation in persons with dementia can occur as a consequence of many potential antecedents (see *Table 1.2*, *Module 1* for a list of contributory factors); the identification of triggers or underlying causes will assist in managing the behaviour.

*Please see Appendix 3 for interventions reported above.*

### *Biological interventions*
Expert consensus guidelines suggest pharmacological interventions should only be used as a second-line approach for agitation, typically when symptoms appear to have a physical or iatrogenic aetiology, are unresponsive to psychosocial interventions or where residual symptoms are problematic (241, 250).

Traditionally, typical antipsychotics have been the mainstay for the treatment of agitation in dementia,  however as they are associated with an elevated risk of significant adverse events (278) they have largely been replaced with atypical antipsychotics. There is strong evidence for the efficacy of olanzapine in reducing agitation (367). Studies of moderate to strong quality have shown improvements in agitation levels with the use of risperidone (278, 368, 369). The evidence for aripiprazole (370, 371), clozapine (372), and amisulpride (373)

is moderate, while the evidence for quetiapine is mixed (374, 375). In spite of the evidence for efficacy, current guidelines do not recommend the use of atypical antipsychotics due to safety concerns. Their use has been associated with further cognitive decline and greater risk of somnolence, extrapyramidal symptoms, abnormal gait, oedema, urinary tract infections, incontinence, falls, cerebrovascular adverse events and mortality (284) (see *Table 2.3, Module 2* for side effects associated with neuroleptics).

| STRATEGIES/OUTCOMES |
| --- |
| • *When asked, the family reported that when she was rubbing the table Mrs W had told them that she was trying to finish her paintings in time for the for the art exhibition.*<br>• *When she was touching items on the other residents' walls Mrs W was reportedly checking that her paintings had been hung, ready for the exhibition.*<br>• *Showing Mrs W the artwork in lounge and dining rooms as well as along the corridors of the RACF appeared to provide her with some reassurance that her paintings were ready for the exhibition.*<br>• *Mrs W responded positively to being given large sheets of paper and (safe) art materials to do new paintings.*<br>• *Staff hung Mrs W's new artwork around her room and the RACF and praised her efforts to other residents and visitors, in her presence.*<br>• *These strategies provided staff with opportunities to interact positively and meaningfully with Mrs W as well as praise her work.*<br>• *Mrs W enjoyed being asked to show her art to others during planned art discussion activities.* |

Primarily used for treating cognitive symptoms in dementia, ChEIs may play a role in the management of agitation, although the evidence is mixed. While rivastigmine showed positive effects in studies of moderate to strong quality (376, 377), the findings for donepezil are inconsistent across studies of strong quality (285, 378). Strong evidence is provided for memantine in one study of agitation in Alzheimer's disease (AD) (183) and in three patients with FTD (379). A further study looked at agitation in AD as part of an agitation/aggression, delusions and hallucinations cluster. Strong support was provided for this cluster of symptoms, however it is not possible to determine if agitation in isolation showed an effect (289). Similarly, a recent RCT of strong quality also reported reductions of this cluster of "core" symptoms in patients with moderate to severe AD with clinically significant agitation, but improvements were not found on specific measures of agitation (380). Other benefits of memantine, such as improved overall BPSD as well as cognition, were however demonstrated in this study (380).

Analgesics (including paracetamol, morphine, buprenorphine and pregabaline) administered individually to a stepwise protocol was also shown to reduce agitation as pain was effectively managed in one study of strong quality (169). Antidepressants may target the underlying neurotransmitter system deficits and/or frontal lobe dysfunction in agitation. Studies with mirtazapine (381) and citalopram (382) provided moderate and strong evidence respectively for their efficacy in decreasing levels of agitation.

Anticonvulsants have doubtful efficacy in reducing agitation in dementia. The number of trials completed is small and findings are inconsistent. Divalproex sodium or sodium valproate (Epilim) demonstrated a limited reduction in agitation in a case series with 20 patients and one study of moderate quality (293, 383) but increased agitation in another study (294). Oxcarbazepine showed no effects in a study of strong quality (295).

Underlying disruption to circadian rhythms may contribute to agitation in dementia, but studies of moderate quality with exogenous melatonin yielded contradictory results. Melatonin failed to reduce agitation in one study (384) while both nocturnal activity and agitation improved in another (385). It is not possible to determine if the treatment effect was due to concurrent therapy with another pharmacological agent also used in the study.

Some evidence suggests that cannabinoid receptor agonists may improve agitation in dementia. Nabilone reportedly reduced agitation and resistance to care in a single case study (386) and dronabinol appeared to have beneficial effects on agitation, aberrant motor behaviours and nocturnal agitation in a study of moderate quality (387). Sympatholytic agents, including alpha- and beta-blockers, may also offer benefits for agitation. There is strong evidence for prazosin (298) and another single case study similarly showed positive effects for propranolol (388).

A study of strong quality found that ApoE ε4 allele carriers benefited from the effects of omega-3 fatty acids on agitation in dementia (115). Lastly, a case series reported positive effects of a traditional Japanese medicine, Yokukansan on agitation in five patients with FTD (302).

While symptomatic, pharmacological treatment is never a substitute for good quality care (326), the individual risk/benefit ratio of pharmacological agents must be considered. Where prescribed, their use should be time-limited and the situation reviewed frequently (241). Additionally, individuals with different types of dementia may respond differently to pharmacological agents. Those with FTD may not respond to ChEIs (250). Those with dementia with Lewy bodies (DLB) are more vulnerable to the adverse effects of antipsychotics (250, 303, 304).

*Please see Appendix 4 for interventions reported above.*

**Limitations**

Many of the intervention studies have methodological and sampling issues (343, 375) which impact on outcomes and/or potentially limit the generalisability of the results. Additionally, a definitive diagnosis of agitation in dementia can be difficult due to overlapping symptoms of aggression, sundowning and other BPSD. One of the studies conducted a long-term follow-up at 6 months post-intervention (362), but data from short-term follow-ups (between one hour and 4 months post-intervention) are available in several studies (37, 268, 272, 342, 344, 352, 356, 361, 384).

**Conclusions**

In summary, agitation is one of the most common and challenging behaviours in dementia and it is associated with poor health and quality of life outcomes. While intervention studies for the management of agitation in dementia are relatively plentiful in the literature, many of the psychosocial studies are of limited quality. Expert consensus guidelines recommend the use of multidisciplinary, individualised and multifaceted care including psychosocial interventions as a first-line approach and short-term pharmacological intervention only when necessary. Music interventions provide the best evidence for the psychosocial management of agitation in dementia. Where pharmacological treatment is indicated, atypical antipsychotics appear to provide the best evidence. As these are not recommended for long-

term treatment due to the associated risks, memantine or citalopram may warrant a trial. ChEIs and other antidepressants are other viable alternatives. Despite some positive reports for anticonvulsants, melatonin, cannabinoids, alpha- and beta-blockers and omega-3, the evidence is too limited or mixed for any recommendations to be made.

# 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 BPSD.
- Multicomponent interventions provide the best evidence for psychosocial management of anxiety in dementia. This group includes interventions which target environmental, biological and psychosocial factors contributing to anxiety.
- The need for a multidisciplinary, individualised and multifaceted approach is emphasised.
- Where anxiety is secondary to another psychological disturbance in dementia the primary problem should be treated.
- Of the medications reviewed, the cholinesterase inhibitors (ChEIs) have the largest patient numbers treated in whom anxiety was a secondary measure, hence providing the best evidence of improvement in anxiety symptoms.
- Benzodiazepines and antidepressants may be of some benefit.
- Selective serotonin reuptake inhibitors (SSRIs) are suggested where long-term management is required.
- Symptomatic pharmacological agents when required for treatment of anxiety, should be time limited, closely monitored, reviewed, reduced and/or discontinued when indicated and prescribed with appropriate psychosocial interventions.
- When symptoms of anxiety occur with other BPSD, medication which may also address other symptoms should be considered in an attempt to avoid polypharmacy.

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**Before you move on, have the following been done?**

1. A *risk assessment* to identity any immediate risks to the person with dementia or others within the care environment

2. A *comprehensive assessment* that is person centred and considers the following key aspects:
   - Referrer's description of behaviour
   - The behaviour
   - The person
   - The carer
   - The care environment

3. Any reversible causes of the behaviour(s) excluded and/or treated

(See *Module 1* for further details)

# Anxiety Summary

## 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, insomnia and/or palpitations associated with autonomic hyperactivity
- behaviours such as avoidance, hand wringing, pacing, requesting assistance or restlessness

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

## Measuring anxiety
Scales employed to measure anxiety in dementia include the Rating Anxiety in Dementia (**RAID**) scale, the anxiety subscale of the Neuropsychiatric Inventory (**NPI**) and 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 BPSD occurring as a symptom in 8% to 71% of persons with dementia and as a disorder in 5% to 31%.
- The incidence of clinically relevant anxiety is higher in those with frontotemporal dementia and vascular dementia than in those with Alzheimer's disease (AD).

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

## Management
Individual triggers for anxiety, where identifiable, should be taken into account and not purely the management of symptoms. Where the triggers and frustrations for the individual 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 maintain anxiety at a manageable level.

### Psychosocial and environmental interventions

- Psychosocial intervention trials were primarily conducted in residential settings.
- The music interventions group incorporated the greatest number of studies. This was followed by behavioural/cognitive-behavioural interventions.
- Multicomponent interventions provide the best evidence for the psychosocial management of anxiety in dementia. This group includes a therapeutic day hospital program and the "Closing Group" intervention which targets environmental, biological and psychosocial factors contributing to anxiety and agitation.
- The need for a multidisciplinary, individualised and multifaceted approach to managing anxiety in dementia is emphasised.

### Biological interventions

- ChEIs have demonstrated beneficial effects on anxiety and their use may reduce neuroleptic and benzodiazepine use.
- Benzodiazepines may be of some benefit and evidence for antipsychotics is mixed, however expert consensus guidelines recommend against the long-term use of benzodiazepines or traditional antipsychotics in this group.
- Antidepressants may have a potential part to play in anxiety in dementia but evidence is limited.
- In the case of prominent anxiety in mild-moderate dementia, SSRIs are suggested for long-term management.
- Some limited evidence for traditional herbal medicine, Ginkgo biloba extract and sodium valproate is also presented for anxiety in dementia.
- Where possible, the use of symptomatic, pharmacological agents, when required for treatment of anxiety should be time limited, closely monitored, reviewed, reduced and/or discontinued when indicated and prescribed with appropriate psychosocial interventions.

## Limitations

- There is a lack of sound research to guide clinicians and carers on the management of anxiety in persons with dementia.
- Diagnosis of anxiety in dementia can also be difficult due to underlying symptoms of depression and/or agitation.

## Conclusions

- Recognised expert guidelines are limited in the area of managing anxiety in dementia.
- Therapeutic activities provide the best evidence for psychosocial management. Environmental factors may also have a part in reducing anxiety symptoms.
- The need for a multidisciplinary, individualised and multifaceted approach is stressed.
- Where pharmacological treatment is in the best interest of the person with dementia, ChEIs provide the best evidence although short-term use of benzodiazepines and antidepressants may play a part in the treatment of anxiety in dementia.
- SSRIs are suggested for long-term management.

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

Anxiety in the person with dementia may present with facial expressions of worry, distress or fear, complaints of somatic symptoms, agitation, irritability, restlessness and/or requests for reassurance, often related to forgotten information (277, 389). Anxiety in dementia has been described as principally an internal state defined by:

- thoughts of worry, anguish, apprehension and/or vigilance
- emotions such as fearfulness, unease or dread
- physical sensations of muscle tension, tremor, fatigue, nausea, hyperventilation/shortness of breath, headache, insomnia and/or palpitations associated with autonomic hyperactivity
- behaviours such as avoidance, hand wringing, pacing, requesting assistance or restlessness (390)

Ballard and colleagues (391) propose three main categories of anxiety in dementia: anxiety related to depression, anxiety in the context of psychosis or interpersonal situations. Anxiety in dementia can become exacerbated to the point of phobias and panic attacks (392) and frequently presents comorbidly with depression (389), further compounding management. Anxiety is at times used interchangeably with agitation when agitation presents as the motor manifestation of anxiety (390). It has been suggested that agitation is a manifestation of anxiety that the person with dementia can no longer express verbally (393).

**Causes of anxiety in dementia**

Higher rates of anxiety in those with dementia have been associated with unmet needs in RACFs (140), most commonly mental health, social and psychological needs, including lack of company and daytime activities. Anxiety can occur in response to the person with dementia's reduced capacity to make sense of their environment (394) and has been associated with staff competence to provide care in residential settings (395).

A person with dementia may experience an exaggerated anxiety response around

| PRESENTATION |
| --- |
| *Mrs Y is an 86 year old Vietnamese lady who lives with three generations of her family. She migrated to Australia after the Vietnamese war under the Family Reunion Scheme. When she arrived in Australia, the family noticed that Mrs Y had some cognitive difficulties which ultimately led to a diagnosis of dementia, by the local GP.* |
| *Extended family members live in the same street and visit socially but they do not provide care. Mrs Y does not speak, read or write English. Mrs Y's daughter is her primary carer and over past months she has become increasingly concerned about the degree of her mother's anxiety. Mrs Y reportedly has strong spiritual beliefs but since she started wandering during church services, she no longer attends with her family.* |
| *A culturally specific in-home service has recently been cancelled and the family has largely become isolated from the Vietnamese community. The granddaughter reports that many of those in the community lack an understanding of dementia and/or BPSD and the family is concerned that others will think their mother is "crazy".* |
| *Adapted from the DBMAS Best Practice Guidelines for People with Dementia from a Culturally and Linguistically Diverse (CALD) Background who have Changing Behaviours (2007).* |

changes to a familiar routine or environment, separation from their primary carer, being rushed, overstimulation and/or fatigue. Concern around making errors, failing at simple tasks, forgetting information, not recognising others, having difficulty participating in conversation and/or being able to find the toilet can also trigger significant anxiety. Anxiety in the early stages of dementia can also arise from the diagnosis itself and subsequent fears for their future.

**Differential Diagnosis**

Presentation of anxiety is not always typical in those with dementia and medical comorbidities. Differential diagnosis can be confounded by overlapping symptoms of anxiety and depression (389, 396). Validated diagnostic criteria for anxiety in AD include restlessness, irritability, muscle tension, fears and respiratory symptoms in the context of excessive anxiety and worry (389).

**Assessment of Anxiety**

No standardised measure of anxiety in dementia exists (397). The personal nature of the core symptoms of anxiety such as worry may mean that assessment based on behavioural observations or informant report alone may be inadequate (398). The following scales have been widely used:

- The anxiety subscale of the Neuropsychiatric Inventory (**NPI**) is completed during an interview with the carer, in which they rate the frequency and severity of the person with dementia's anxiety, as well as their own subsequent distress (6, 7). The reliability and validity of the NPI, overall is well established (178) however, individual NPI symptom domains can be more clinically relevant than the total NPI score (179).
- The revised NPI-Clinician (**NPI-C**) has expanded the anxiety subscale to include additional items around feeling threatened, facial expression, worries over health, tearfulness, fear of abandonment, repeated questioning, distractibility and overconcern (7).
- The Rating Anxiety in Dementia scale (**RAID**) rates symptoms of anxiety according to information from all available sources. It includes four subscales: worry, apprehension and vigilance, motor tension and autonomic hyperactivity (390, 392).
- The Behavioral Pathology in Alzheimer's Disease Scale (**BEHAVE-AD**) anxieties and phobias subscale also includes four anxiety items: anxiety regarding upcoming events, other anxieties, fear of being left alone and other phobias (184, 399).
- The Hamilton Anxiety Rating Scale (**HAM-A**) includes 14 items and classifies anxiety as mild, mild to moderate or moderate to severe (400).
- The Geriatric Anxiety Inventory (**GAI**) is a 20-item self-report or clinician-administered scale that measures dimensional anxiety in elderly people. It has sound psychometric properties in assessing anxiety in psychogeriatric populations (401).

**Prevalence**

Anxiety is more frequent in those with dementia than in those who are cognitively intact (111, 402, 403). Anxiety is one of the most commonly occurring BPSD (108, 404) occurring as a symptom in 8% to 71% of persons with dementia (395, 398) and as a disorder in 5% to 31% (391, 398, 405). The incidence of clinically relevant anxiety is higher in those with frontotemporal dementia (FTD) and vascular dementia (VaD) than in those with AD (403)

and it has been reported as the most common BPSD in dementia with Lewy bodies (DLB) (330).

Consensus is lacking with regard to the prevalence of anxiety during different stages of dementia (392, 403, 406, 407). Occurrence has been reported to increase as cognitive function decreases (134, 403, 408, 409). Others purport the theory that anxiety tends to increase as cognition declines in the early stages of dementia but decreases in later stages with diminishing cognition (406, 410, 411). Likewise, a higher incidence of anxiety disorder has been reported in those with mild dementia and insight (331, 392, 405). This raises the question of whether an awareness of one's declining cognition and functioning leads to anxiety (412) or is it the case that those in the early stages of dementia are better able to express their anxiety (398). Anxiety in AD has also been associated with a history of hypertension (413), physical ill-health (392) and earlier age of onset (403).

| *ASSESSMENT* |
| --- |
| *In order to reduce the presenting symptoms of anxiety, potentially contributing factors must be identified:*<br>• *Illness/infection/discomfort/pain*<br>• *Eliminate depression*<br>• *Medication review: interactions, dosage, recently prescribed, adverse effects*<br>• *Lack of attention to culturally-relevant needs*<br>• *Unfamiliar or altered physical environment*<br>• *Unrealistic expectations causing Mrs Y to overextend her capabilities*<br><br>*Assessing the situation*<br>• *Encourage Mrs Y to report her concerns as far as she is able*<br>• *Directly observe for any environmental aspects that may contribute to the symptoms*<br>• *With the family's consent, communicate with staff from the recently ceased community service as to any incidents that provoked Mrs Y's anxiety*<br>• *Consult Mrs Y's family with regard to her life history and for further information around potentially relevant factors such as war experiences*<br>• *Consult close family members to identify possible triggers for the symptoms* |

**Effects of anxiety**

Anxiety in dementia is linked to earlier residential care placement (414, 415), other problematic behaviours (396, 416, 417), overestimation of disease severity (403), impaired social function (418), poorer quality of life (336, 419, 420) and higher carer burden due to increased dependence (145, 416, 418, 421).

Excess anxiety may lead to the person with dementia "shadowing" or searching for carers, both formal and informal. This in turn can result in wandering behaviours and increased carer stress and feelings of guilt. According to the Progressively Lowered Stress Threshold (PLST) model of care (94), symptoms of anxiety indicate escalation to more intense and troubling behaviours which further impede function and comfort.

**Results**

A systematic literature review to set criteria (see *Appendix 4*) yielded 17 psychosocial or environmental and 20 biological intervention studies with outcomes relevant to anxiety in dementia. Psychosocial interventions were grouped into four broad categories: therapeutic activities, music, multi-sensory and miscellaneous. Pharmacological interventions were grouped into seven categories: ChEIs, memantine, typical and atypical antipsychotics, antidepressants, psychostimulants and other medications. BPSD overall is associated with increased carer burden (422, 423) and depressive symptoms (424), however no evidence

was found for a link between higher carer anxiety and anxiety in the person with dementia. Others also report a lack of research in this specific area (425, 426).

## Management

Individual triggers for anxiety, where identifiable, should be taken into account and not purely the management of symptoms (427). Acute expressions of anxiety in persons with dementia can occur as a consequence of many potential antecedants (see *Table 1.2, Module 1* for a list of contributory factors). Anxiety can escalate to the point of overwhelming the person with dementia until a catastrophic reaction ensues. Where the triggers and frustrations for the individual can be identified, minimised and/or avoided, anxiety may be reduced or prevented. *Appendix 1* provides suggested questions to facilitate comprehensive behavioural assessment.

Keeping the environment uncomplicated, maintaining structure and routine, reducing the need to make decisions (394), avoiding overstimulation, providing opportunities to succeed and reinforcing retained skills may help to maintain the individual with dementia's anxiety at a manageable level. Likewise, redirection and reassurance may disrupt the emotional cycles perpetuating the anxiety (428).

### *Psychosocial and environmental interventions*

Psychosocial and environmental intervention trials were mainly conducted in residential settings. The music group incorporated the greatest number of studies followed by *models of care* and behavioural/cognitive-behavioural interventions; the majority of them report positive outcomes. Moderate to strong evidence of benefit was found for a preferred music intervention (429) and individual, receptive music therapy (430); however, a good quality study of live music programming found no benefit for anxiety

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**STRATEGIES/OUTCOMES**

- *Establish who is able to provide information on Mrs Y's behalf and who is the main decision maker within the family and liaise directly with them. Ensure that they are included in all discussions and/or decisions.*
- *The family was hesitant to provide information due to language barriers and fear of how the information will be used. They are concerned that they may be perceived as unable to cope which could result in Mrs Y being removed from the family home. The family was reassured that services are available to support them to continue to care for Mrs Y in the family home.*
- *Mrs Y's granddaughter is the only family member who speaks English. Access to a professional interpreter who speaks the same dialect as Mrs Y and her family was offered, where appropriate and possible.*
- *Mrs Y's family has been reluctant to accept formal services due to community expectations that they should care for their aged relatives. They do not want to be judged by members of the local community as unable to care for Mrs Y.*
- *Information about dementia and BPSD was provided in Vietnamese. The information in written or DVD format could be shared with the extended family and others.*
- *The family was linked with a Vietnamese agency that was able to provide further culturally safe support and information.*
- *The family has been reluctant to continue prescribed medication as they are unfamiliar with western medical practices. Mrs Y's doctor was informed that she was no longer taking the prescribed medication. The family was provided with information around the purpose of medication and how long*

(273). The beneficial outcomes observed with music therapy promoting nonverbal communication were found to be similar to placebo (431).

The *models of care* group includes three studies of moderate to strong quality. The multifaceted *GentleCare* program builds a "prosthesis of care" based on the concept that those with dementia are provided with external support to compensate for cognitive and functional losses (432). The *GentleCare* program (433) and a study of "emotion-oriented care" reported reduced anxiety in those with dementia (434); while the multi-level activity-based "Enriched Opportunities" program did not (435). Reduced anxiety was also reported in two multicomponent interventions, which included a psychotherapeutic day hospital program (436) and the "Closing Group" intervention which attempted to eliminate biological, environmental and psychosocial factors contributing to anxiety and agitation in dementia (351), providing moderate evidence for its efficacy.

> *Mrs Y needs to take it before the anxiety symptoms may be reduced.*
> - *When asked, the family was able to suggest activities which could be encouraged, such as those that Mrs Y previously found pleasurable, engaging, comforting and /or related to her spiritual beliefs.*
> - *Mrs Y's family was provided with strategies to avoid triggering her anxiety and to help ease her symptoms during acute periods of escalation.*
> - *When extended family members were made aware of the situation they were willing to assist. Mrs Y was able to resume attendance for part of the church service with others helping to supervise her.*
> - *The possibility of Mrs Y attending a CALD day respite centre with others from a Vietnamese background was investigated.*

Moderate support for reduced anxiety was demonstrated for *Montessori* based, individually meaningful activities (437). A study of moderate-intensity group exercise provided moderate evidence for reduce anxiety (438). The evidence, however, for the efficacy of multi-sensory interventions is far from convincing as two studies provide moderate to strong evidence of no benefit (439, 440).

Evidence in the form of case studies/series or open trials supports psychotherapy and CBT interventions (397, 441, 442). Such therapies, often delivered individually or in small groups, are largely relevant to mild dementia although case studies have also demonstrated some positive outcomes in persons with moderate dementia (443, 444). No improvement in anxiety symptoms was reported for psychotherapy or psychoeducation in a small study of moderate quality (445).

Further support is evident for psychotherapy and CBT for anxiety in dementia, particularly where carers are actively involved (150, 443, 444, 446-448). The following learning techniques for persons with dementia are outlined as strategies which can compensate for deficits during CBT (444):
- focus on only one or two themes per session
- present new concepts as concretely as possible
- use reflective listening to be sure that information communicated by the person with dementia is understood
- ask the person with dementia to repeat key information to ensure understanding

- involve the person with dementia actively in retaining information
- use written materials to present information
- involve carers and family.

Such interventions are necessarily delivered to individuals or small groups. While they enrich the literature, interventions which are trialled with small numbers or reported as case studies only, inevitably rate lower on quality.

The need for a multidisciplinary, individualised and multifaceted approach to managing anxiety in dementia is emphasised (139, 435, 443, 448-450). The relationship between the physical environment and the mental well-being of persons with dementia has been previously identified (451-453). Although home-like environments with single bedrooms have been linked to lower rates of anxiety (454), research into the relationship between environmental variables and anxiety in dementia is limited (398). Interestingly, a qualitative study by Qazi and colleagues (427) considered perspectives on anxiety in dementia from the person with dementia, family carers and staff members. Engagement in meaningful activity, person-centred care and relationships were among the most significant areas of concern reported. The majority saw identifying and minimising precipitants to the anxiety as the first step in management and pharmacological options as a last resort.

Suggested strategies for anxious behaviours (455):
- Identify triggers and intervene early
- Develop appropriate communication e.g. reassuring, speaking slowly
- Distract and divert attention to something pleasant
- Use gentle touch judiciously
- Non-threatening postures
- Calm environment
- Don't argue or attempt to reason
- Avoid restraint

*See Appendix 3 for interventions reported above.*

### *Biological interventions*

Primarily used for treating cognitive symptoms in dementia, ChEIs have demonstrated beneficial effects on anxiety and their use may reduce neuroleptic and benzodiazepine use (109, 180, 182, 237, 456-463). Of all the medications reviewed, the ChEIs have the largest patient numbers treated in whom anxiety was measured. In spite of this, rarely are they trialled with BPSD as a primary trial outcome in those with well-defined neuropsychiatric symptoms at baseline (459). Overall, studies show no clear indication that any one ChEI is superior (315, 464). The only evidence found for improvement in anxiety for memantine was a small case series of three patients with FTD (379).

Although benzodiazepines may be of some benefit in the management of anxiety in dementia (465), expert consensus guidelines (277) recommend against the long-term use of benzodiazepines or traditional antipsychotics in this group. In the case of prominent anxiety in mild-moderate dementia, the experts suggested SSRIs for long-term management. A benzodiazepine or atypical antipsychotic is proposed for treatment of short-term anxiety, where indicated, until an SSRI takes effect (277). Likewise, others report ample evidence of

side effects from the benzodiazepines to recommend against their use in those with dementia and anxiety (466-469).

Antidepressants may have a potential part to play in anxiety in dementia but evidence is limited (469). The antidepressant mirtazapine has an anxiolytic property when prescribed for depression in dementia (113, 381, 470) and likewise, milnacipran, a selective serotonin and noradrenaline reuptake inhibitor (SSNRI) (471). Trazodone has also been shown to provide some benefit in the management of anxiety in dementia (465). At this time milnacipran and trazodone are unavailable in Australia.

The evidence found for antipsychotics is mixed. Risperidone significantly improved symptoms of anxiety in dementia when compared to haloperidol (369). A further small trial of quetiapine and haloperidol showed improvement in anxiety for both (472). Aripiprazole improved anxiety in the treatment of psychosis (473) although it is not possible to determine if anxiety improved independently of the effect on psychosis. Blonanserin, a novel $D_2$ and 5-$HT_{2A}$ receptor antagonist, (281) proved nonsignificant on overall BPSD in a small trial, while anxiety scores were reduced. Although not currently available in Australia, tandospirone, a 5-$HT_{1A}$ partial agonist, has also shown improvement in a study of moderate quality (474). A short trial, of moderate quality, for sodium valproate in hospital patients indicated nonsignificant results for aggression in different types of dementia but did show improvement in anxiety (475).

Three small trials of traditional Asian herbal medicine indicated improvement in BPSD scores on the NPI, including anxiety (299, 301, 476). Although numbers included in these studies were small, they were all of moderate quality. A larger study of the same herbal formulation which was rated as strong showed significant benefit for total NPI scores but not anxiety (477). A large study which trialled Ginkgo biloba extract for BPSD (478) was also of moderate quality. Drug-placebo differences of four points on the NPI, in favour of Ginkgo biloba, were reported for anxiety although statistical significance was not calculated.

Wherever possible, the use of symptomatic, pharmacological agents, when required for treatment of anxiety should be time limited, closely monitored, reviewed, reduced and/or discontinued when indicated and prescribed in conjunction with appropriate psychosocial interventions (277). As always, the potential benefits to the person with dementia must be weighed against the side effects of pharmacological treatments (see *Table 2.3, Module 2* of side effects associated with neuroleptics). Further, when symptoms of anxiety occur with other BPSD, medication which may also address other symptoms should be considered in an attempt to minimise polypharmacy (465).

*See Appendix 4 for interventions reported above.*

**Limitations**
Research into anxiety in dementing disorders is sparse (397, 404, 427, 443, 455). The management of BPSD overall may be better served by grouping symptoms that tend to occur together (108, 118, 134, 136, 137, 479). Anxiety has been linked to depression as part of an affective syndrome in dementia (135, 404, 406, 408, 480). Pharmacological trials have shown benefits on behavioural syndromes where evidence was lacking for individual symptoms (481, 482).

There is a paucity of sound research to guide clinicians and carers on the management of anxiety in persons with dementia (398, 427, 443) and little evidence is presented of benefits being maintained after interventions cease. Predictably, those experiencing the disabling features of anxiety and dementia may be unwilling to participate in research. Diagnosis of anxiety in dementia can also be difficult due to underlying symptoms of depression and/or agitation.

**Conclusions**

In summary, anxiety is common in dementia with significant and disabling consequences. Recognised expert guidelines are limited in the area of managing anxiety in those with dementia. Reports on the outcomes of interventions are limited in number and quality. Multicomponent interventions provide the best evidence for psychosocial management of anxiety in dementia. Environmental factors may also have a part in reducing anxiety symptoms. The need for a multidisciplinary, individualised and multifaceted approach is stressed. Where pharmacological treatment is in the best interest of the person with dementia, ChEIs provide the best evidence although short-term benzodiazepines and antidepressants may have a role to play in the treatment of anxiety in dementia.

## MODULE 6: Apathy

**Key messages**

- Apathy is one of the most challenging and prevalent behavioural symptoms of dementia.
- It is associated with increased disability and carer frustration as well as reduced quality of life, rehabilitation outcomes and survival after nursing home admission.
- Despite a lack of methodological rigour, it is apparent that psychosocial interventions have the potential to reduce apathy.
- Therapeutic recreation, particularly when provided individually, has the best available evidence for effectiveness in dementia. This is a heterogeneous group which includes "question-asking reading", small group, individual/tailored, *Montessori* based and kit-based activities.
- The evidence for the efficacy of pharmacotherapy for apathy in dementia is limited and the research quality modest.
- The best evidence was found for cholinesterase inhibitors (ChEIs).
- Some evidence exists for memantine, but less evidence of efficacy for stimulants, calcium antagonists and antipsychotics.
- No evidence was found to support the use of antidepressants or anticonvulsants.

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**Before you move on, have the following been done?**

1. A *risk assessment* to identity any immediate risks to the person with dementia or others within the care environment

2. A *comprehensive assessment* that is person centred and considers the following key aspects:
   - Referrer's description of behaviour
   - The behaviour
   - The person
   - The carer
   - The care environment

3. Any reversible causes of the behaviour(s) excluded and/or treated

(See *Module 1* for further details)

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## Apathy Summary

### What is apathy and what does it look like in dementia?
- Apathy can describe an internal state of lack of interest or a state of behavioural inaction.
- The apathy spectrum includes reduced initiative, interest, motivation, spontaneity, affection, energy, enthusiasm, emotion and persistence as well as blunted affect.
- Synonyms for apathy include passivity, abulia and amotivation.
- Apathy occurring in the course of dementia is frequently accompanied by one or more neuropsychiatric symptoms.

Lack of motivation is evidenced by diminished goal-directed behaviour, goal-directed cognition and emotion, relative to previous functioning levels and not attributable to intellectual impairment, emotional distress or diminished consciousness. Emotional distress is typically absent. Symptoms should cause clinically significant functional impairment not attributable to physical disabilities, motor disabilities or direct physiological effects of a substance.

### Causes of apathy
Apathy is a major clinical feature of dementia with subcortical and frontal pathology such as dementia with Lewy bodies (DLB), Huntington's disease, Binswanger's disease, frontotemporal dementia (FTD) and vascular dementia (VaD). Apathy in Alzheimer's disease (AD) has also been significantly related to older age and depression.

### Differential diagnosis
Apathy in dementia may be misdiagnosed as depression and should also be differentiated from medication effects.

### Measuring apathy
Scales designed to specifically measure apathy include the Apathy Evaluation Scale (**AES**) and the Apathy Inventory (**AI**). The Neuropsychiatric Inventory (**NPI**) and the Neuropsychiatric Inventory-Clinician (**NPI-C**) include an apathy subscale.

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

### Effects of apathy
- Apathy is associated with increased disability and frustration, worsening functional impairment and poorer quality of life for both those with dementia and carers, with family life and relationships often disrupted.
- Families not recognising an apathetic state may become increasingly resentful as they misperceive the person as lazy.
- Morbidity and mortality may be indirectly related to apathy as residents in long-term care tend to be less noticed by care staff and receive fewer direct care hours.

**Management of apathy**

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

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

*Psychosocial and environmental interventions*

- The benefit of therapeutic recreation for apathy in dementia is apparent although this is a heterogeneous group. This includes *question-asking reading*, small group, individual/tailored, *Montessori* based and kit-based activities.
- Some positive results were reported for music, exercise, multi-sensory stimulation, pet therapy and special care units.
- There is limited evidence of sustainability of effect once interventions cease.

*Biological interventions*

- ChEIs have demonstrated beneficial effects on non-cognitive symptoms such as apathy. Overall, studies show no clear indication that any one ChEI is superior.
- Limited evidence exists for improvement in apathy with memantine and no sound evidence of benefit was found for traditional antipsychotics.
- Atypical antipsychotics may have some beneficial effect although it is not possible to determine if improvement in apathy occurs independent of the effect on psychosis.
- Good evidence indicates that antidepressants do *not* significantly improve apathy in persons with dementia.
- Modest efficacy has been demonstrated for psychostimulants although side effects are a concern.

**Limitations**

- Few quality studies are available for the management of apathy in dementia.
- Research into the management of apathy is, particularly, hampered by the difficulties of recruiting and retaining numbers to ensure sufficient power.

**Conclusions**

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

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

Apathy represents a form of executive cognitive dysfunction (483) which overlaps with other psychological and behavioural aspects such as mood, personality and cognitive functioning (484). Apathy can describe an internal state of lack of interest or a state of behavioural inaction (485). The apathy spectrum includes reduced initiative, interest, motivation, spontaneity, affection, energy, enthusiasm, emotion and persistence as well as blunted affect (109, 486). The nosology of apathy is blurred and it has received little attention in the scientific literature in spite of its prevalence (487-489).

Despite an increasing literature indicating that apathy is an independent syndrome (490), there is no structured definition for this construct. The International Classification of Diseases (ICD-10, 491) makes no mention of apathy and the Diagnostic and Statistical Manual of Mental Diseases (DSM-IV, 492) uses the term to refer to a subtype of personality change due to a general medical condition only. Apathy is widely recognised by clinicians and carers however, as a syndrome of decreased motivation, initiation and persistence as well as social disengagement and emotional indifference or absence.

Synonyms for apathy include passivity, abulia and amotivation. Apathy can be a symptom of many neuropsychiatric disorders or a syndrome per se (493, 494). At a symptomatic level Marin (495) defines apathy as "loss of motivation due to disturbance of intellect, emotion or level of consciousness" and at syndromal level as primary motivational loss or "loss of motivation not attributable to emotional distress, intellectual impairment or diminished level of consciousness". Individuals with apathy "do less, think less and feel less" (496). Stuss proposes three subtypes of apathy: emotional, cognitive and behavioural defined on the basis of the anatomical regions and psychological mechanisms involved (497).

**Causes of apathy**

Apathy is a major clinical feature of dementia with subcortical and frontal pathology such as DLB (330, 498, 499), Huntington's disease (500-505), Binswanger's disease (506, 507) and VaD (508, 509). Apathy in AD has also been significantly related to older age and depression (510). AD with a stroke prior to onset is also associated with an increased risk of apathy (413).

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> **PRESENTATION**
>
> *Mrs P had been an efficient homemaker and loving mother of four. After her husband died, it became evident to the family that he had been significantly compensating for Mrs P's functional losses. Her son and three daughters managed to support Mrs P in the family home, with the assistance of community services, for a year following Mr P's death. When she was admitted to a RACF, Mrs P presented as physically well for her years. Her MMSE score was 19/30. She responded positively to family visits and outings. Staff reported that Mrs P was a lovely lady who was "no trouble". Mrs P's family visited regularly and would invariably find her sitting alone and unoccupied in her room. Items of interest that they left for her remained untouched and they repeatedly complained to staff that their mother "does nothing" and speaks to no one between family visits. Staff did their best to stay out of the way of Mrs P's family members when they visited.*

Broadly speaking, increased risks for developing apathy include older age (413, 511) and greater severity of cognitive impairment (413). Apathy occurring in the course of dementia is frequently accompanied by one or more neuropsychiatric symptoms (327), which may fluctuate during the course of the disease, unlike cognition which worsens steadily (179, 459). The often impoverished physical and social environment of residential care can further inhibit motivation, as can sensory impairments (489).

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ASSESSMENT

In order to reduce the presenting behaviour,
potentially contributing factors must be
identified:
• Pain/discomfort/illness/infection may be
  demotivating Mrs P
• Medication interactions, dosage
• Impaired hearing and/or eyesight
• Exclude underlying depression, grief
  reaction
• Lack of stimulation
• Unfamiliar/altered/deprived physical
  environment
• Reduced ability to initiate activities for
  herself
• Activities offered not of
  interest/unfamiliar/too difficult so Mrs P's
  default response is to decline attempts by
  staff to include her
• Mrs P's premorbid personality; how readily
  did she join in group activities in the past?

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

Diagnostic criteria for apathy were initially proposed by Marin (495, 512). Lack of motivation is evidenced by diminished goal-directed behaviour, goal-directed cognition and emotion, relative to previous functioning levels and not attributable to intellectual impairment, emotional distress or diminished consciousness. These criteria have been adapted over time (513, 514). Recent modifications propose that diminished motivation must be present most of the time for at least four weeks and a minimum of one symptom should be evident from two of the behavioural, cognitive and emotional domains (515, 516). Additionally, symptoms should cause clinically significant functional impairment and not be attributable to physical disabilities, motor disabilities or direct physiological effects of a substance.

Apathy is related to but distinct from depression (486, 517-519) and dysphoria (483, 520, 521). Although the overlap in symptoms can pose difficulties in differentiating the two and apathy is commonly misdiagnosed as depression, individuals with apathy present as compliant or passive whereas those with depression are deliberately avoidant (522). Further, unlike depression, apathy is not typically associated with insomnia, impaired attention or feelings of hopelessness, anxiety and/or sadness.

The use of antipsychotic/neuroleptic and antidepressant medications, which can induce side effects such as fatigue, lethargy, listlessness and reduced response to stimuli, can initiate, maintain or imitate apathetic behaviours (523). SSRIs have also been reported to induce an amotivational or apathy syndrome and which is reversible when the dose is ceased or reduced (524-527).

**Measuring apathy**

Apart from scales specifically designed to rate apathy such as the Apathy Evaluation Scale (AES, 528) and the Apathy Inventory (IA, 529), a number of neuropsychiatric or behavioural scales such as the Neuropsychiatric Inventory (NPI; 6, 530) include items that rate apathy (531).

- The **AES** is recommended for the specialist assessment of apathy symptoms in dementia (1, 528). The 18-item rating scale has reasonable to good psychometric properties and it is available in clinician, informant and self-rated versions. Assessment is based on the person with dementia's interests, activities and daily routine.
- The **IA** is a rating scale for the global assessment of apathy. Separate assessment of dimensions of the apathetic syndrome: emotional blunting, lack of initiative and lack of interest as well as the person with dementia's awareness of these symptoms are also included (529).
- The apathy subscale of the **NPI** is completed during an interview with the carer, in which they rate the frequency and severity of the person with dementia's apathetic symptoms as well as their own subsequent distress (6).
- The NPI-Clinician (**NPI-C**) has expanded the apathy/indifference subscale to include three additional items around reduced participation, interest in new events and emotional expression (7).

While specific scales differentiate components of apathy such as motivation, interest and behaviour, omnibus neurobehavioural scales do not. This may be important as different components of apathy appear to become more prominent over time in the older population generally (511) and at different stages in those with dementia. Assessment of apathy in dementia is further complicated by the need to distinguish between diminished behaviour due to loss of motivation and loss of ability secondary to cognitive impairment (487, 512).

**Prevalence**

The frequency of apathy in neurological disorders ranges from 0% to 92% (532) with the highest prevalence reported in progressive supranuclear palsy (533-535), FTD (536-539) and severe AD (410). In studies using the NPI (6), apathy occurred in up to 70% of individuals with AD (496, 519, 540-542). Apathy tends to appear early in dementia (329, 543-547), increases with dementia severity (118, 530), tends to persist (541), and is consistently reported globally (92, 111, 134, 204, 329, 548). The prevalence of apathy in mild cognitive impairment (MCI) ranges from 11.1% to 39.8% (327, 496, 549, 550) which is intermediate between rates in elderly normal controls and AD (551, 552) and predicts a higher rate of conversion to AD (496, 549, 550, 553-555).

**Effects of apathy**

Apathy is associated with increased disability and frustration as well as poorer quality of life in persons with dementia and carers alike (136, 141, 540, 556-559). The degree of carer distress may be dependent on the premorbid personality of the person with dementia, expectations of the carers and the living situation. For example, family members are more likely to be distressed by seeing a premorbidly active person become apathetic whereas apathy in a RACF setting is much easier for staff to tolerate as apathetic residents make few demands. Families not recognising an apathetic state may become resentful as they

misperceive the person with dementia as lazy (494, 558, 560, 561), increasing the risk of relationship breakdown. Responses to issues of personal safety and risk may likewise be impaired.

The potential for apathy to prevent those affected from seeking assistance, to be misdiagnosed with depression or to become noncompliant with treatment further exacerbates the degree of dysfunction (560). Apathy is significantly related to reduced independence in ADLs above and beyond dementia severity (509, 562-564), survival duration after RACF admission (565) and poor outcomes in rehabilitation (552, 566). Those with dementia, living alone may be unable to reliably initiate activities of daily living and hence, be at risk of self-neglect. The person with dementia and apathy may retain capacity but not self-initiative and hence may undertake activities in groups that they are unable to do alone (567). Morbidity and mortality may also 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 (523, 568). Additionally, behavioural deficits influence staff-resident interactions and quality of care (569) as well as staff frustration and job satisfaction.

Apathy is underrecognised (483) and difficult to treat, not least because persons with dementia have poor insight into their condition. It thus imposes high levels of economic, social and physical burden and distress on partners and carers (270, 570-572), compounding disability in those with dementia (327) and frequently leading to earlier admission to a RACF than for those who are similarly impaired without apathy (411).

### Results

A literature search to set criteria (see *Appendix 7*) yielded a total of 38 psychosocial and environmental as well as 20 biological intervention studies with outcomes relevant to apathy in dementia. Psychosocial and environmental interventions were grouped into four broad categories: therapeutic activities, music, multi-sensory and miscellaneous. Biological treatment studies were likewise grouped into seven categories: ChEIs, memantine, typical antipsychotics, atypical antipsychotics, antidepressants, psychostimulants and other medications.

### Management of apathy

Recognised guidelines for the management of apathy do not exist (573) yet response to treatment may have important implications in delaying institutionalisation, alleviating carer burden and in turn improving quality of life for those with dementia. Indications for treatment of apathy are unclear. These differ from other psychiatric conditions such as depression because patient distress rarely applies to those with apathy and in dementia; apathy typically worsens with time rather than remitting. Additional confounds such as depression, medication effects, metabolic disorders, environmental differences as well as concurrent acute and/or chronic illnesses should be considered. *Appendix 1* provides suggested questions to facilitate comprehensive behavioural assessment.

Acknowledging individuality, personal history and previous interests may forecast individual strategies for engaging those with apathetic behaviours (573-575) as well as variations in response (576). Person-centred care (38), likewise seeks to view the person as a whole, incorporating the individual's personal and social psychology in developing a management

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

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

***Psychosocial and environmental interventions***

Studies of psychosocial and environmental interventions were largely conducted in residential settings. The therapeutic recreation group incorporated the greatest number of studies and some benefit for apathy in dementia is demonstrated. Four strong quality studies demonstrated positive results for (577-580) apathy for activities which were tailored or individualised. A further five studies provide moderate support for small group, individual, cooking and *Montessori* method interventions (437, 581-584).

Positive results were reported for music with three strong studies demonstrating support for live or active music therapy (181, 585, 586) and a further four studies of moderate quality (587-590) showing reduced apathy with singing or dancing, rhythmical instruments and live music. A moderate quality study of reminiscence music therapy (591) and a strong quality study of 30 music sessions over 15 weeks (431) found no significant improvement in apathy although some evidence is reported for improvement of depressive symptoms.

Strong evidence was shown for reduced apathy with reminiscence therapy (592) and moderate evidence for integrated support for persons with dementia and their carers (593). A study which assessed response to a reminiscence video of growing up in the 1920s-30s found moderate evidence for improvement in some aspects of responsive behaviour (594). However, two studies of strong quality showed only a nonsignificant trend toward reduced apathy with cognitive-communication stimulation (595) and an improvement similar to that observed in the placebo group with life story reminiscence therapy (596).

Although the evidence is less impressive overall, multisensory stimulation (MSS) showed reduced apathy in one strong quality study only in the severe dementia group within one of the two samples (439). Two further studies provide moderate support for multi-sensory behaviour therapy (597) and MSS integrated into 24-hour care (440) while another provides modest evidence for improved positive behaviours over a year (598). Animal therapies also showed benefits in three studies of moderate quality for a therapeutic *robocat* (599) and dog therapy (600, 601) as well as one study which provides limited evidence for live cats compared with toy cats (602).

The models of care group includes moderate support for reduced apathy with a dementia unit providing *Gentlecare* (433) and modest support for continuous activity programming (603). The multifaceted *Gentlecare* program builds a "prosthesis of care" based on the concept that those with dementia are provided with external supports to compensate for cognitive and functional losses (432). One study of integrated support for persons with dementia and their carers and another study of continuous activity programming provide moderate and modest evidence of improvements in apathy respectively (593, 603). Two further studies of emotion-oriented care demonstrated strong evidence of no beneficial effect for apathy (434, 604). The only study in the multicomponent interventions group showed moderate evidence of reductions in the level of apathy in a psychotherapeutic day hospital

program (436). The evidence for the efficacy of exercise interventions is far from convincing with moderate evidence for cued exercise to music found in one study (605) and strong evidence of no benefit for *walk and talk* sessions in another (606).

Only five of the above studies reported follow-up between four weeks and one year after interventions ceased (439, 589, 592, 595, 596). Of these studies, two showed that positive effects for, or a nonsignificant trend toward (595), reduced apathy were maintained (589). A biopsychosocial approach to managing apathy recognises that there are multiple contributors to apathetic behaviours. In order to engage persons with dementia and maintain interest and/or involvement, psychosocial activities should ideally be matched to the individual's interests and retained skills (601, 607-609). This is consistent with our findings.

*See Appendix 3 for interventions reported above.*

### Biological interventions

Primarily used for treating cognitive symptoms in dementia, ChEIs have demonstrated beneficial effects on non-cognitive symptoms such as apathy, depression, anxiety and purposeless motor behaviours (109, 456-459), although they are not established treatment for all types of dementia. Of all medications reviewed, the ChEIs and/or memantine report the largest numbers for apathy with 14 studies. Four of six good quality studies of donepezil provide strong evidence for reduced apathy (180, 460, 461, 610-612) and a further three good quality studies reported positive outcomes for galantamine (182, 613, 614). Strong evidence of reduced apathy is provided in two studies of rivastigmine and a third provides moderate evidence (615-617). A post hoc analysis of secondary NPI data, from earlier RCTs of donepezil and memantine provides good evidence of a nonsignificant trend in favour of memantine in reducing apathy (618). ChEIs have rarely been tested in persons with dementia who exhibit well-defined neuropsychiatric symptoms at baseline and/or apathy as a primary trial outcome (459, 619) Overall, studies show no clear indication that any one ChEI is superior.

No sound evidence of reduced apathy was found for the traditional antipsychotic perphenazine (620). A good quality study of the atypical antipsychotic olanzapine showed improvement (621) however, a case study of blonanserin did not (281). While atypical antipsychotics may have a beneficial effect, it is not possible to determine if improvement in apathy occurs independent of the effect on psychosis. Good evidence indicates that the antidepressants citalopram and trazodone did not significantly improve apathy (620, 622).

Psychostimulants are known to influence anatomic substrates that regulate wakefulness and executive function. Limited efficacy for methylphenidate was found in a study of moderate quality (623) however, side effects such as tachycardia and psychosis are a concern. No evidence of benefit was reported in a trial of moderate quality for the anticonvulsant, sodium valproate (624). Moderate evidence of a significant improvement in apathy was shown in two studies of a traditional Asian herbal medicine, Yokukansan.

Few pharmacological trials have examined apathy, considering its prevalence and burden on carers. Even fewer report apathy as a primary outcome; the majority of studies are open-label and the overall quality of research is modest. Despite an increased number of available

medications, there is as yet no sound evidence that pharmacological treatments work well for apathy in dementia (619).

| STRATEGIES/OUTCOMES |
|---|
| • *When asked, the family reported their distress at seeing Mrs P "wasting away". They feel she is often unnoticed by staff and as a consequence, receives less care and contact time than other residents.* |
| • *Family members are also feeling increasingly guilty as Mrs P's functioning and quality of life appear to be diminishing further since her admission to RACF. Family was provided with information with regard to the changes anticipated with the progression of dementia, particularly after a change in environment, which may be contributing to Mrs P's behaviour.* |
| • *Staff members felt that they have tried to help Mrs P by escorting her to the craft activities or weekly bingo games however, she "refused" to join in.* |
| • *One part-time member of staff has found that Mrs P became quite animated when included in simple housekeeping tasks but other staff see this as her exploiting Mrs P's good nature.* |
| • *Some staff have limited knowledge of dementia, believing that Mrs P chooses to isolate herself from others. They are unaware that apathy is a behavioural symptom of dementia. Education was provided around BPSD and Mrs P's potentially retained skills which relate to her role as a homemaker. More staff members are willing to support Mrs P to participate in tasks that she apparently feels more confident to attempt.* |
| • *Staff encouraged Mrs P to talk about her family and the things that were important to her in her younger years.* |
| • *Family members have a better understanding of the need to assist Mrs P to engage with items of interest that they bring in for her.* |

*See Appendix 4 for interventions reported above.*

**Limitations**

The potential confounds of studying apathy in dementia are numerous: a lack of standardised, assessment guidelines for diagnosing apathy; difficulties in differentiating it from and overlap with depression, fatigue syndromes and parkinsonism (625-628); underreporting of apathy (629); and similar symptoms secondary to medications such as psychotropics and beta-blockers (523). Further, dementia severity likely influences the success of interventions trialled yet many studies treated participants as a homogenous group. The degree to which findings can be generalised across the stages of dementia is largely unknown (630).

Many studies comprise small sample sizes and methodological shortcomings such as a wide range of definitions and terminologies for apathy. There is no evidence to guide the clinician as to how the different components of apathy (i.e. emotional, cognitive and behavioural) (497) which may appear at different phases of the dementia, respond to interventions. Further, there is scant evidence of sustainability of effect once interventions cease. Distal outcomes of apathetic behaviours such as time to residential care placement, effects on carers and complications of immobility are also neglected.

**Conclusions**

Apathy is a major source of carer distress and frustration for those living at home (631). As a negative symptom however, apathy tends to pose less overt disruption and economic consequences in residential care settings relative to the more agitated and aggressive BPSD (632, 633). Improved quality of life and care, through reduced apathy, is more difficult to recognise and quantify. Targeting apathy

may alert carers at home or in RACFs to an additional problem that would not normally demand their attention. The secondary benefits of successful interventions may be better evident in social gains or maintenance of functional abilities.

While a "one size fits all" approach to managing apathy in dementia may be inappropriate, individualised programs require additional resources. The benefits to care providers and organisations must ultimately outweigh implementation costs. It is apparent that psychosocial and environmental interventions are warranted (206, 483, 569, 634-637) but there is a paucity of sound research to guide clinicians and carers. Many interventions are the subject of a limited number of studies (638) and others such as remotivation therapy (575), structured daily routine, art therapy, psychomotor therapy, humour therapy (639) and validation therapy (640) are not represented.

Apathy is complex and multifaceted and further rigorous research is needed (604, 641, 642) including the investigation of integrative approaches (558). Psychosocial interventions have the potential to reduce apathy in dementia. Of these, therapeutic recreation has the best available evidence for effectiveness particularly when these activities are provided individually.

Of the pharmacological treatments reviewed, ChEIs provide the best evidence of improvement in apathy (619). For many with dementia, stabilisation of apathy levels may be a positive result as the natural history of apathy is progression with dementia severity (643). There is some evidence for benefits of memantine and mixed evidence for benefits of atypical antipsychotics on apathy. As antipsychotics can have serious adverse effects they are not recommended primarily for the treatment of apathy (644). There is modest evidence of benefit with stimulants but potential adverse effects limit their use.

The threshold for initiating pharmacotherapy varies with the setting and with those providing care. It has been argued that early initiation of ChEI treatment in dementia is preferable (645) and may prevent emergence of behavioural changes (109, 182). Evaluating the success of interventions should be attended with one of a variety of scales (531). There are no data to guide clinicians on how long pharmacotherapy should be continued for treatment of apathy but as apathy increases with severity of dementia a positive response suggests long-term therapy is indicated.

A lack of quality research is not necessarily indicative of a lack of efficacy (635). Stabilisation of apathy, in the face of disease progression may indicate that the intervention is beneficial even without evidence of improvement. Apathy, as part of the spectrum of behavioural disturbances in dementia, remains underdiagnosed and difficult to treat. Initial therapy should aim at alleviating intercurrent/underlying illnesses, addressing unsuitable physical/environmental factors and trialling appropriate psychosocial therapies. Only once all these measures have been attempted should pharmacological interventions be employed. Of those reported, the best evidence is for the use of ChEIs.

*We gratefully acknowledge the work done by Dr Karen Berman and colleagues in their excellent review of the pharmacological treatment of apathy* (619).

# MODULE 7: Depression

**Key messages**

- Depression in dementia presents as unhappiness, withdrawal, inactivity, fatigue, tearfulness or loss of interest. Other symptoms may include sleep or appetite disturbances; low self-esteem, negativity or hopelessness; or suicidal ideation.
- Depression in dementia needs to be differentiated from apathy, anhedonia, sleep disturbance, delirium or the underlying dementia.
- Depression is a commonly occurring BPSD, with prevalence clustering around 30%.
- Depression may be a presenting feature of dementia and it is one of the most challenging BPSD to diagnose and treat.
- Psychotic depression and suicidal depression requires urgent psychogeriatric review.
- Individualised psychosocial interventions are recommended as a first-line approach, or in combination with medication where indicated.
- Support is demonstrated for selected psychosocial and environmental interventions, with exercise and behavioural approaches providing the best evidence.
- Where medication is indicated, expert consensus guidelines recommend the use of antidepressants as a first-line approach for non-psychotic depression in dementia and combination therapy with cholinesterase inhibitors (ChEIs) as a second-line approach.

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**Before you move on, have the following been done?**

1. A **risk assessment** to identity any immediate risks to the person with dementia or others within the care environment

2. A **comprehensive assessment** that is person centred and considers the following key aspects:
   - Referrer's description of behaviour
   - The behaviour
   - The person
   - The carer
   - The care environment

3. Any reversible causes of the behaviour(s) excluded and/or treated

(See *Module 1* for further details)

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## Depression Summary

**What is depression and what does it look like in dementia?**
- unhappiness
- withdrawal
- inactivity
- fatigue
- tearfulness
- loss of interest
- sleep disturbance
- appetite disturbance
- low self-esteem
- negativity
- hopelessness
- suicidal ideation

**Causes of depression**

Degenerative changes in the brain associated with dementia can lead to depression. Family history may be a contributing factor.

**Differential diagnosis**

It is essential to differentiate depression in dementia from delirium, apathy, anhedonia, sleep disturbance or impaired concentration.

**Measuring depression**

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

**Prevalence of depression**
- Depression is one of the most commonly occurring BPSD, with prevalence rates clustering around 30% and a range of 9% to 96%.
- Variance in prevalence arises from differing definitions, diagnostic tools used or populations assessed.
- Persons with vascular dementia (VaD) tend to have higher rates of comorbid depression compared to other dementia subtypes.

**Effects of depression**

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

**Management of depression**

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

*Psychosocial and environmental interventions*
- Psychosocial and environmental interventions were primarily conducted in residential settings.
- The exercise category incorporated the greatest number of intervention studies.
- Exercise and behavioural approaches provide the best evidence for the psychosocial management of depression in dementia.

*Biological interventions*
- Pharmacological intervention studies for the management of depression in dementia are limited in number and quality.
- Expert consensus guidelines recommend the use of antidepressants as a first-line approach for non-psychotic depression in dementia, and combination therapy with ChEIs are recommended as a second-line approach.
- The evidence for the efficacy of antidepressants is mixed.
- There is moderate evidence for the efficacy of ChEIs in alleviating depressive symptoms in dementia.
- Combination therapy of an antidepressant and an antipsychotic is the recommended treatment for psychotic depression.
- The literature on and the evidence for brain stimulation interventions for depression in dementia are limited.

**Limitations**
- There is a paucity of sound research to guide clinicians and carers on the management of depression in persons with dementia.
- A number of intervention studies reported mixed findings or failed to find any effects.
- Few studies conducted long-term follow-ups to determine the sustainability of intervention effects.

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

## Depression Module

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

Depression in dementia can present as unhappiness, withdrawal, inactivity, fatigue, tearfulness and loss of interest contributing to excess disability (646, 647). Other symptoms which may also manifest in depression are disturbed sleep, poor appetite, low self-esteem and energy, negativity, hopelessness and to a lesser extent, suicidal ideation or thoughts. Severity of depression can vary from mild through moderate to severe (648). There is some support for a relapsing-remitting course in depression of dementia (126).

### Causes of depression

Dementia is associated with brain changes that can lead to depression (277), for example Alzheimer's disease and Lewy body pathology, monoamine neurotransmitter alterations, cerebrovascular disease and/or neuroinflammation (649) and an overlap in the underlying neural substrate of Alzheimer's disease (AD) and depression is reported (647). Genetic factors may also contribute to depression in dementia. Polymorphisms of dopaminergic and serotonergic gene pathways have been shown to be associated with the manifestation of mood syndromes (650). Depression, particularly late-onset, frequently presents prior to a diagnosis of dementia or in the early stages of the disease (647, 648, 651-654) providing further support for this association.

Depression in the early stages of dementia may be related to an awareness of the losses and prognosis associated with the diagnosis, however evidence suggests this accounts for only a small percentage of cases (647). While consensus is lacking, a family history of major depressive disorder may also contribute to depression in dementia (655, 656).

> ### *PRESENTATION*
>
> *Mr L was born in Poland. After he migrated to Australia, he married, had three children and ran his own business until he retired. Mr L's wife describes him as patriarchal, determined and of strong character. He currently lives with his wife in a retirement village and their children visit regularly and provide support. Mrs L is finding it increasingly difficult to encourage her husband to attend family events and the local dementia day centre. When he does attend the day centre, Mr L can become aggressive with staff, volunteers and other attendees when attempts are made to include him in activities. Mrs L reports that her husband has become increasingly sad over recent months and even tearful at times which is out of character for him. When she mentioned her concerns to their GP, he explained to her that Mr L's symptoms, particularly the apathetic behaviours, can occur with the progression of dementia and they should just monitor his symptoms for now.*
>
> *Adapted from the DBMAS Best Practice Guidelines for People with Dementia from a Culturally and Linguistically Diverse (CALD) Background who have Changing Behaviours (2007).*

### Differential diagnosis

It is important to determine if the presenting problem is depression as it can be mistaken for apathy, delirium or the underlying dementia. Apathy can also cause symptoms which overlap with depression such as loss of interest, low energy, withdrawal and lack of motivation. Apathy can be distinguished by a lack of emotion rather than typical depressive cognitions, emotions and behaviours such feelings of sadness, tearfulness or complaints about futility of life. Apathy can also be a symptom of depression which further compounds

diagnosis. There is some suggestion that apathy may be an early marker of depression in dementia (510). Hypoactive delirium can be "quiet" in older people who may appear withdrawn and be mistakenly diagnosed as depressed.

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**ASSESSMENT**

*In order to reduce Mr L's presenting psychological symptoms, potentially contributing factors must be identified:*
- *Pain/discomfort/illness/infection*
- *Medication review: interactions, dosage, adverse effects, recently prescribed*
- *Overstimulation (noise, people, activities)*
- *Lack of attention to culturally-relevant needs and historical issues*
- *Overextending his capabilities by expecting too much of him*
- *Altered routines, new day centre staff, particular staff, other day centre attendees and/or family members*
- *Unfamiliar/altered/threatening physical environment*
- *Reduced stress threshold*

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

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Many symptoms of dementia overlap with those of depression. For example, disturbed sleep, anxiety, agitation, changes in eating behaviours or decreased engagement in hobbies and interests may be mistakenly attributed to depression. Pathological crying (i.e. sudden onset of crying episodes in the absence of an underlying emotional change) may be mistaken for depression (657). Differential diagnosis is often difficult and a therapeutic trial may help decide if depression is accounting for the symptoms.

**Measuring depression**

The assessment of depressive symptoms in dementia must be comprehensive and include a risk assessment for possibility of self-harm. The overlap of symptoms with possible underlying medical conditions and the dementia itself requires a sound knowledge of medical and psychiatric causal factors. It is important to determine when consultation with other disciplines is indicated. Depression in dementia may remain undiagnosed and untreated if depressive symptoms are not differentiated from apathy, anhedonia, sleep disturbance and/or the impaired concentration of dementia (277).

Neither the DSM-IV nor the ICD-10 provides clear definitions for BPSD (1, 647). The National Institute of Mental Health (NIMH) provides a provisional criteria for depression of AD which specifies that depressive symptoms be present for at least 2 weeks, represent a change from previous functioning and not occur as a result of a medical condition other than AD or non-mood related dementia symptoms such as weight loss due to difficulties with food intake (277, 646, 658).

Expert consensus (1, 277) recommends the Cornell Scale for Depression in Dementia (CSDD, 659) and for the assessment of less severe cases and for use in community, the Geriatric Depression Scale (**GDS**, 2). The depression/dysphoria subscale of the

Neuropsychiatric Inventory (**NPI**, 6) and the Hamilton Depression Rating Scale (HAM-D, 660) are also widely used for the assessment of depression in dementia.

- The **CSDD** is a 19-item clinician-rated tool. Assessment is based on a semi-structured interview with an informant as well as signs and responses to interview questions from the person with dementia (659).
- The **GDS** is a short self-report scale specifically designed for rating depression in the elderly. The 30-, 15-, 10- or 4-item versions can be read aloud and yes/no responses only are required with regard to the previous week (2).
- The **HAM-D** is a clinician-rated tool consisting of 17 items requiring graded responses according to the severity of symptoms over the past week (660).
- The depression/dysphoria subscale of the **NPI** is completed during an interview with the carer, in which they rate the frequency and severity of the person with dementia's depressive symptoms as well as their own subsequent distress (6).
- The NPI-Clinician (**NPI-C**) has expanded the dysphoria subscale of the NPI to include six additional questions around facial expression, pessimism, irritability, eating habits, feelings of guilt and loss of enjoyment (7).

**Prevalence of depression**

Depression is one of the most commonly occurring psychological symptoms of dementia (92, 479, 661) with a significantly higher prevalence in those with AD than in the general elderly population (647). Although prevalence ranges from 9% to 96% (394, 455, 648, 662-665), it reportedly clusters around 30% (666, 667). Rates for depressive symptoms or a minor depressive disorder in persons with dementia are reportedly 50%, and for a major depressive disorder rates are between 15% and 20% (668). Variance in prevalence arises from the differing definitions of depression, difficulty in accurately diagnosing depression in dementia, populations assessed, variability in carer stress influencing reporting and the use of a range of assessment tools, some of which are not designed for assessment of those with comorbid dementia (658).

Depressive symptoms in dementia tend to increase in prevalence as cognition declines and then decrease when cognitive functioning is severely impaired (406, 409, 664, 665, 669). It is possible that the decrease in the prevalence of depression over time occurs, in part, as the person with dementia becomes progressively less able to interpret and/or report their mood. With the progression of dementia, assessment of depressive symptoms increasingly relies on observation (665). Moreover, family history of mood disorders in first-degree relatives, personal history of emotional problems or depression, female gender, poor self-reported health, a recent major loss and younger age have been associated with a higher risk for depression in dementia (670, 671).

Depression is more prevalent in VaD, DLB, and PDD than in AD (111, 672), and is reported to be more persistent in the multi-infarct subtype than the subcortical subtype of VaD (673). The depressive symptoms in VaD are also qualitatively different from those manifested in AD, with a greater frequency of neurovegetative symptoms (e.g. changes in eating habits, changes in weight or feelings of fatigue) reported in VaD (674). Concomitant BPSD, particularly irritability, physical aggression, anxiety, agitation and psychosis are reportedly high among persons with dementia and depressive symptoms (254, 389, 416, 479, 675-679)

and it is important to consider all of the presenting symptoms when developing a management plan. It has been suggested that treating depression in dementia may be one means of preventing and managing physically aggressive behaviour (254).

**Effects of depression**

Depression may be a presenting feature of dementia and it is one of the most challenging BPSD to diagnose and treat. Despite the high prevalence of depression in RACF residents with dementia, it is frequently underdiagnosed and undertreated (647, 678). Depression in dementia is associated with increased carer depression and burden, transition from dementia-specialised assisted-living facilities to nursing homes, earlier RACF admission, higher likelihood of suicide, increased mortality, greater disability in activities of daily living, medical comorbidity, social withdrawal and reduced quality of life (145, 420, 424, 647, 661, 664, 678, 680-683). Furthermore, multiple unmet needs have been reported in RACF residents with dementia and depression, which may in turn lead to an increase in other BPSD (140).

**Results**

A systematic literature review to set criteria (see *Appendix 7*) yielded 22 psychosocial and environmental as well as 12 biological intervention studies with outcomes relevant to depression in dementia. Psychosocial and environmental interventions were grouped into four broad categories: therapeutic activities, exercise, music, special care programming and therapeutic activities. Biological interventions were grouped into two categories: antidepressants and cholinesterase inhibitors (ChEIs).

**Management of depression**

While depression in dementia is largely attributed to brain changes and genetic factors, it is nonetheless important to identify potentially reversible factors that may be contributing to the low mood. Untreated physical symptoms such as those related to infection, constipation and/or chronic pain may be exacerbating the depressive symptoms. Likewise delirium and apathy should be excluded. *Appendix 1* provides suggested questions to facilitate comprehensive behavioural assessment. As the course of depressive symptoms in dementia can be relatively transient, evaluation and follow-up of initial symptoms is indicated prior to commencing antidepressant treatment (126, 131). Where antidepressant medication is prescribed, the person with dementia and their family may need an explanation as to the period of time required before any potential benefits are evident.

***Psychosocial and environmental interventions***

Psychosocial and environmental intervention trials were primarily conducted in residential settings and the exercise category incorporated the greatest number of studies. Strong evidence was demonstrated for reduced depression scores with a three-month exercise and behavioural management program (Reducing Disability in AD) and the effect was maintained at 24-month follow-up (684). A further study showed moderate evidence for a reduction in depressive symptom severity with a chair-based group exercise program (438). In contrast, three exercise intervention studies provided moderate to strong evidence of no significant effect on depressive symptoms (363, 685, 686). One of the studies included a mixed group of elderly with 52% diagnosed with dementia (685).

Strong evidence was demonstrated for a behavioural/cognitive-behavioural intervention comprising persons with dementia's engagement in pleasurable events, carers' problem solving and environmental adaptation strategies (687). Beneficial effects were reported on completion of the nine-week intervention and maintained at six-month follow-up (687). A further study of strong quality found no benefit for a cognitive-behavioural family intervention (688). A good quality study demonstrated a small but significant reduction in depressive symptoms for bright light therapy alone however, bright light with melatonin showed no benefit and melatonin alone was deleterious (689). A further bright light study of moderate quality showed a reduction in depressive symptoms which were not clinically significant (270). The degree of benefit found for light therapy may be dependent on climate and exposure to sunlight which is possibly less relevant in the Australian setting.

Moderate support was demonstrated for a health promotion course for those with early dementia (690), although no benefit was found for a trial of psychoeducation and psychotherapy in a group newly diagnosed with dementia (445). Moderate evidence is also reported for a life review/storybook program (691). Activities tailored to match the person with dementia's capabilities showed no significant benefit in a study of strong quality (578). Mixed findings were reported in a study of strong quality for a multicomponent insomnia intervention which comprised treatment and education, as improvements were reported on one measure of depression but not another (692). No benefit was found for a multimodal intervention which comprised exercise, CBT and a support group (693).

| STRATEGIES/OUTCOMES |
| --- |

- *When asked, the family reported that Mr L experienced the harshness of wartime Europe as a teenager, prior to his migration to Australia. He has rarely spoken of these experiences with his wife or family.*
- *Mrs L is aware, however that soon after he migrated her husband applied to bring his parents and younger brother to Australia on compassionate grounds. This was not possible and the family did not survive the war.*
- *With the progression of dementia, Mr L has become more inclined to focus on unpleasant memories and express feelings of guilt around the traumatic experiences of his youth.*
- *Mrs L reports that she is finding the situation increasingly stressful as she now becomes anxious when readying Mr L for the day centre, unsure of what his response will be when the bus arrives to collect him. She is also concerned that the loss of her limited respite hours, when Mr L refuses to go, is reducing her tolerance for his symptoms.*
- *Mr L underwent further medical assessment and a medication review. When his GP was made aware of the full extent of his symptoms, Mr L was prescribed a trial of antidepressant medication. It was explained to the family that it may be two weeks before potential benefits are evident and he may initially experience side effects that will hopefully resolve.*
- *Mr L was referred to a psychogeriatrician for further assessment and management of his post traumatic stress symptoms.*
- *Staff reported that hostility and aggression towards others at the day centre was typically reserved for those from other European backgrounds. They suggested that Mr L mistakenly identified some of the other men attending the centre as German. The group composition of attendees to the centre on other days of*

Modest evidence was demonstrated for the efficacy of the "Enriched Opportunities Program", a multi-level, activity-based model of care, in reducing depressive symptoms (435). No positive effects on levels of depression were found for psychiatric case management or psychogeriatric consultation in a study of strong quality (694); Dementia Care Mapping in a study of modest quality (695); advanced illness care teams in a moderate quality study (696) or collaborative care in a study of strong quality (697). The latter study, however, showed a significant reduction in BPSD overall on total NPI scores which was maintained at six months' follow-up.

Music intervention studies reported conflicting findings. A study of strong quality of music therapy promoting the nonverbal expression of emotions reported significant reductions in levels of depression (431). However, another strong quality study involving the same intervention showed that while there was a reduction in depressive symptoms in the intervention group, it was similar to that in the placebo group (181). A group music study of moderate quality showed no reduction in depression for persons with dementia, however total NPI scores and carer distress did decrease (340).

In summary, strong support is demonstrated for selected psychosocial

> *the week was examined and it was determined that it was possible to trial Mr L on a day when fewer men from European backgrounds and more women were present.*
> - *Many of the day centre staff have little knowledge of dementia, BPSD or post traumatic stress symptoms and/or their management. Training was provided to enable staff to develop strategies which may assist in managing and supporting Mr L when he is at the centre.*
> - *While the day centre is small, it tends to bustle with high levels of activity and noise which can cause Mr L additional distress. Opportunities were created for Mr L to spend some time in a quiet area where additional individual time was provided for activities he previously enjoyed such as listening to his favourite music and/or browsing books on his favourite artists/artworks.*
> - *Additional information was provided to the day centre regarding Mr L's likes/dislikes, food preferences and daily routine as well as cultural and/or religious occasions that are important to him.*
> - *Not only has Mr L been apathetic with regard to outings, he has been expressing some increased anxiety around leaving his familiar home environment. A bilingual/bicultural staff member from the day centre was already transporting another lady who was unable to travel on the bus. She was recruited to collect Mr L also and he responded well to her additional attention.*

and/or environmental interventions. An increasing number of psychosocial interventions have been reported as effective in managing depression in dementia (698) and these positive findings are in line with expert consensus recommendations for psychosocial interventions tailored to the needs and the life contexts of the individual with depression in dementia (277, 699). The National Institute for Clinical Excellence Guidelines (NICE, 700) indicate that cognitive behavioural therapy, which includes carer participation may be helpful in the treatment of those with depression in dementia.

*See Appendix 3 for interventions reported above.*

### Biological interventions

Pharmacological intervention studies for the management of depression in dementia are limited in number and quality. While expert consensus guidelines recommend the use of antidepressants as the treatment of choice for nonpsychotic depression in dementia (277), the evidence for their efficacy is limited. Two smaller studies provided moderate to strong evidence for the efficacy of sertraline (701, 702) although three other larger studies of strong quality did not. Two of these studies, which included greater numbers of participants, examined the efficacy of sertraline and/or mirtazapine found no difference in outcome compared to placebo (661, 663, 703). Sertraline was associated with more adverse events than placebo (661). Strong evidence indicates no significant difference between placebo and fluoxetine (704), or between placebo and venlafaxine (705) in the reduction in depressive symptoms.

Adding a ChEI to antidepressant treatment is recommended as a second-line option (277) although no studies for combined therapy were evident in the recent literature. ChEIs in isolation demonstrated improvements in depressive symptoms in two prospective, open-label studies of moderate quality with galantamine (706) and rivastigmine (707). The recommended first-line treatment of choice for psychotic depression in dementia is an antidepressant with an antipsychotic while electroconvulsive therapy (ECT) is recommended as a second-line option (277). These are recommended in individuals without dementia, but no trials in those with psychotic depression and dementia have been reported in the recent literature.

A study of moderate quality reported that repetitive transcranial magnetic stimulation combined with cognitive training yielded no improvements in depression (708). Literature on ECT for those with dementia and depression is limited but it has been reported as effective and well tolerated. It is usually reserved for severe or urgent (e.g. danger from malnutrition, suicidality), treatment resistant or psychotic depression. One study provided moderate evidence of significant reductions in depressive symptoms at six weeks after cessation of treatment with ECT (709). Additional cognitive losses occurring as a side effect reportedly recovered (672, 694).

While depression is a common feature in dementia, few studies support the effective pharmacological treatment of depression in this group (111, 277, 647, 658, 663, 710). Wherever possible, the use of symptomatic, pharmacological agents, when required for treatment of depression should be time limited, closely monitored, reviewed, reduced and/or discontinued when indicated, and prescribed with appropriate psychosocial interventions. As always, the potential benefits to the person with dementia must be weighed against the side effects of pharmacological treatments. Further, when symptoms of depression occur with other BPSD, medication which may also address the other symptoms should be carefully considered in an attempt to avoid polypharmacy (465).

*See Appendix 4 for interventions reported above.*

### Limitations

There is a paucity of sound research to guide clinicians and carers on the management of depression in persons with dementia. A number of the intervention studies either reported mixed findings or failed to demonstrate beneficial effects of the interventions and thus cannot

be recommended. There is also a lack of long-term follow-up to determine the sustainability of the benefits after interventions ceased. Of the seven psychosocial intervention trials which reported follow-ups conducted between one month and 21 months post-intervention (181, 684, 685, 687, 688, 692, 697), only four indicate that effects were maintained (181, 687, 688, 692).

**Conclusions**

In summary, depression in dementia has significant consequences. Reports on the outcomes of interventions are limited in number and quality. Exercise and behavioural approaches provide the best evidence for psychosocial management of depression in dementia. A multidisciplinary, individualised and multifaceted approach, tailored to the needs and the life contexts of persons with dementia is recommended (699). Where pharmacological treatment is in the best interest of the person with dementia, some evidence is provided for antidepressants and ChEIs. Although studies indicate that recent group data are disappointing, individuals with depression in dementia may have positive outcomes.

# MODULE 8: Disinhibited behaviours

## Key messages

- Disinhibition in dementia present as those behaviours associated with a reduced capacity to edit immediate impulsive responses.
- Disinhibited behaviours of a sexual nature are particularly challenging.
- Disinhibited behaviours can be caused by frontal lobe pathology, substance use or be secondary to 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 behaviours for that person or inappropriate behaviours due to impairments in impulse control and moral judgement.
- Disinhibition is relatively uncommon, occurring in 2% to 25% of persons with dementia.
- Management of disinhibited behaviours requires the identification of potentially modifiable factors.
- Behavioural-based strategies may be used to discourage the inappropriate behaviours and psychoeducation/psychotherapy may be provided to support family carers or RACF staff.
- Atypical antipsychotics may be of some benefit, but their use is not recommended due to safety concerns. Cholinesterase inhibitors (ChEIs) and selective serotonin antagonist reuptake inhibitors (SSRIs) may be safer alternatives.
- Given the limited evidence available in the literature, disinhibited behaviours must be considered and managed on a case-by-case basis.

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**Before you move on, have the following been done?**

1. A *risk assessment* to identity any immediate risks to the person with dementia or others within the care environment

2. A *comprehensive assessment* that is person centred and considers the following key aspects:
   - Referrer's description of behaviour
   - The behaviour
   - The person
   - The carer
   - The care environment

3. Any reversible causes of the behaviour(s) excluded and/or treated

(See *Module 1* for further details)

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**Disinhibited behaviours Summary**

**What are disinhibited behaviours and what do they 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 and the impact on others.
- As sexual disinhibition in dementia is particularly problematic, the literature tends to focus on this area.
    - These behaviours can include:simulating sexual acts
    - requesting unnecessary genital care
    - attempts at intercourse, rape
    - sexual aggression
    - propositioning others
    - grabbing, groping
    - sexual remarks
    - masturbation in public
    - exhibitionism
    - fondling, frotteurism
    - chasing others for sexual purposes

Attempts to classify sexually inappropriate behaviours tend to differentiate between those that are misplaced in social context and those would be considered inappropriate in most contexts.

**Causes of disinhibition**
- Frontal lobe pathology
- Drugs, alcohol
- Secondary to delirium
- Secondary to a cerebral event
- Secondary to psychiatric syndromes such as mania or psychosis

**Differential diagnosis**

In the case of sexual disinhibition, it is important to determine if the presenting behaviour is actually normal sexual behaviour for the person with dementia presenting inappropriately as impulse control, judgement and/or moral values become increasingly impaired.

**Measuring disinhibited behaviours**

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

**Prevalence of disinhibited behaviours**
- Disinhibition is a relatively uncommon BPSD.
- Symptoms reportedly occur in 2% to 25% of persons with dementia.
- Reports are inconsistent with regard to prevalence ratios in males and females.

**Effects of disinhibited behaviours**

Disinhibited behaviours in dementia can be associated with negative behaviours, hallucinations or delusions, frustration and subsequent, agitation and/or aggression. Disinhibited behaviour may also provoke an aggressive response from others. Urinary tract infections, physical trauma and/or sexually transmitted infections are potential consequences of sexually disinhibited behaviours and promiscuity.

**Management**

The initial challenge for the clinician is to determine which of the underlying, individual factors driving the behaviour are potentially modifiable. Interventions reported are related to sexual disinhibition.

*Psychosocial and environmental interventions*

Suggested interventions and strategies are provided in the following areas:
- supportive psychotherapy or education of family carers and/or RACF staff
- identifying potential triggers, social cues and early indicators
- modifying environmental aspects, clothing and RACF staff roles
- providing distraction, redirection and modified learning techniques
- activities to occupy the person's hands and increased, positive contact with family
- avoiding overreaction or knee-jerk responses that induce shame or humiliation

*Biological interventions*

- No randomised controlled trials (RCTs) are currently available.
- Case studies/series for sexual disinhibition were located in the following pharmacological categories: anticonvulsants, hormonal agents, antipsychotics – atypical, antidepressants, cholinesterase inhibitors (ChEIs) and a $H_2$-receptor antagonist.
- 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.
- Although antipsychotics may be of some benefit, expert consensus guidelines recommend against their long-term use; ChEIs or SSRIs may provide a safer option.
- The potential benefits to the person with dementia and the safety of others must be weighed against the potential side effects of pharmacological treatments.
- It is crucial to obtain informed consent from person or from proxy and in some cases, from official bodies such as Guardianship Tribunal for the use of hormonal agents.

**Limitations**

In spite of the challenges evident, sound research to guide clinicians and carers in the management of disinhibited behaviours in dementia is extremely lacking. Evidence for interventions based solely on case studies cannot be considered robust.

**Conclusions**

A major dilemma arises in attempts to allow the person with dementia's sexual expression while protecting the safety, rights and dignity of all. The limited evidence available suggests that individual situations must be managed on a case-by-case basis.

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

Disinhibition is not typically a presenting feature of dementia, however when it presents it can be one of the most challenging BPSD for those providing care (711-714). Disinhibition has been described as a coarsening of the personality and a loss of mature demeanor (715) which typically occurs with reduced capacity to edit immediate impulsive responses. Disinhibition in dementia has been reported as consisting of four independent subsyndromes: abnormal motor behaviour, hypomania, egocentrism/loss of insight and poor self-care (716). Socially disinhibited behaviours in dementia can include (7, 530):

- loud, insulting or hurtful comments about others
- urinating in public
- anti-social behaviour
- finding humour where others don't
- acting impulsively
- discussing personal or private matters in public
- exhibiting vulgar or deviant behaviour
- use of language considered inappropriate to the context
- emotional inappropriateness
- uncontrolled eating
- demanding attention
- taking things from others
- low frustration tolerance and impatience

When disinhibited behaviours present with a sexual resonance, they tend to be more problematic. Sexually disinhibited behaviours in dementia have been defined as "sexual behaviours that are inappropriate, disruptive, and distressing and that impair the care of the patient in a given environment" (717). These can include:

- touching of the genitals in public, exhibitionism
- sexual remarks, propositioning others
- grabbing, groping, reaching inside the underwear of vulnerable others
- masturbation without shame in the presence of others
- simulating sexual acts
- requesting unnecessary genital care
- unwelcome cuddling, fondling, frotteurism or manipulating others' clothing
- chasing others for sexual purposes
- attempts at intercourse or other sexual acts, rape
- aberrant sexual behaviour such as sexual aggression
- publicly reading pornographic material

In light of the substantial difficulties encountered in managing disinhibited behaviours of a sexual nature, it is not unexpected that this is largely the focus of the literature related to disinhibition in dementia. Terminology in the literature for sexually disinhibited behaviours includes sexual voracity, sexual misdemeanours, inappropriate sexual behaviour (ISB), hypersexuality, sexual misbehaviour, paraphilias, sexual aggresssion and compulsive sexual behaviour (263, 714, 718-721).

While social, moral, cultural, ethical and medico-legal factors inevitably influence attempts to classify sexually inappropriate behaviours, a number of classifications have been proposed (722, 723). Nagaratnam and Gayagay propose the following (724):
- Hand-holding, kissing, fondling, cuddling
- Manipulating clothing, touching breasts, genitals
- Sexually related comments and use of obscene words, propositioning
- Eroticism, exhibitionism, masturbating openly, sexual acts

More recently, de Medeiros and colleagues (725) suggest just two types of sexually inappropriate behaviours:
- Intimacy seeking: normal behaviours such as kissing and hugging that are misplaced in social context
- Disinhibited: rude and intrusive behaviours such as lewdness, fondling and exhibitionism that would be considered inappropriate in most contexts

### Causes of disinhibition
Disinhibition, particularly sexually disinhibited behaviours, in dementia has been associated with impairment of frontal subcortical circuits (713), focal brain lesions (714, 724, 726) and Kluver-Bucy syndrome (722), defined as a collection of symptoms arising from bilateral destruction of temporal lobe tissue (727). Social factors such as the lack of a usual sexual partner and lack of privacy can also contribute to sexual disinhibition (728).

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

Where disinhibited behaviours present as a sudden behavioural change in the person with dementia, comorbid psychosis, delirium and/or cerebral event should be excluded (729). Those with dementia may also be more vulnerable to the disinhibiting effects of alcohol (717, 729). Adverse effects of medications have been linked to sexual disinhibition and hypersexuality with the use of benzodiazepines (717, 730), donepezil (731), fluvoxamine (732) and levadopa in Parkinson's disease (PD) (733, 734).

### Differential diagnosis
Disinhibition exhibited in dementia may be an exacerbation of the person's premorbid personality. In the case of sexual disinhibition, it is important to determine if the presenting behaviour is actually normal sexual behaviour for the person with dementia, in an abnormal context (735) rather than inappropriate sexual behaviour. No agreed definition exists for the point at which a behaviour becomes "abnormal", hence judgement must be made on the basis of what is normal for the individual in a particular situation (728). Sexual impulses previously controlled by judgement or moral values can become increasingly evident with the progression of dementia (736).

Ageism biases and stereotypic views may influence perceptions of sexual expression in those with dementia (737-741) and those living in residential aged care facilities (RACFs)

have little or no opportunity for "normal" sexual expression (724, 729, 742-744). Sexually ambiguous behaviour such as undressing in front of others and/or in an inappropriate place (713) or attempting to remove irritating clothing, e.g. tight or soiled underwear, may be mistakenly deemed sexually inappropriate. Urinating in inappropriate places can occur when the person with dementia is unable to remember where the toilet is or find their way to the bathroom.

Additionally, misinterpretation of the intentions of carers and/or staff, an unmet need for human contact, attention or affection (744) in combination with diminished insight, judgement and/or awareness of their surroundings and others, may trigger these behaviours in a person with dementia. The potential effects of explicit television content (729, 745) and underdressed visitors and/or staff should also be considered. Misidentification of others as their long-term spouse (717) can be particularly problematic if the person with dementia is recalling their spouse when they were much younger. The crucial task for the clinician is to attempt to understand what the behaviour means for the individual with dementia.

**Measuring disinhibited behaviours**
While no standardised measure of disinhibition in dementia or validated scales for measuring sexual behaviour in dementia are available (746), the Disinhibition Scale has been validated in persons with dementia (716).
- **The Disinhibition Scale** consists of 26 questions each for the patient and the carer. Behaviours are rated over the preceding four weeks with item scores ranging from no abnormal behaviour to extreme abnormal behaviour. Items are grouped into four domains:
  - Abnormal motor behaviors (e.g., hyperactivity, wandering)
  - Stereotyped routines (e.g., motor routines, obsessive ideas and rituals)
  - Psychosis (delusions, hallucinations)
  - Hypomanic behavior (e.g., pressured speech, euphoria, hypersexuality, grandiose ideas, inappropriate social behaviour)
  - Poor self-care (e.g., poor hygiene, poor insight into own deficits, distractibility, poor awareness of danger)

The following scales include items relevant to disinhibition:
- The disinhibition subscale of the Neuropsychiatric Inventory (**NPI**) is completed during an interview with the carer, in which they rate the frequency and severity of the person with dementia's disinhibition, as well as their own subsequent distress (6).
- The NPI-Clinician (**NPI-C**) expands the original disinhibition subscale by a further eleven items including disrobing, social judgement, demanding attention, insulting others and eating behaviours. An item relevant to sexual aggression has also been added to the aggression subscale (7).
- The Behavioral Syndromes Scale for Dementia (**BSSD**) evaluates five syndromes of dementia, one of which is disinhibition (137). The global disinhibition syndrome rating encompasses a broad range of behaviours including those associated with impulsivity and sexual disinhibition. Assessment is based on the previous week with ratings ranging from absent to extreme.
- The Challenging Behaviour Scale (**CBS**) includes items on swearing, urinating in public, stripping, inappropriate sexual behaviour and deviant behaviour (747).

Ratings are based on the frequency and severity of behaviours over the past eight weeks. While this scale shows promise there is insufficient evidence to recommend it at this time (1).

- The CERAD Behaviour Rating Scale for Dementia (**BRSD**) includes an item for socially inappropriate behaviour (748).

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**ASSESSMENT**

*In order to reduce the presenting behaviours that are potentially placing 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.*
- *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 what may trigger the behaviour*
- *Ask staff who know Mr A if they can assist in identifying possible triggers for the behaviour*
- *Consult Mr A's life history as well as behaviour and clinical charts for further information with regard to triggers.*
- *Assess the immediate environment for possible triggers.*
- *Consult family members to identify possible triggers which may be unknown to staff and not previously documented*

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**Prevalence of disinhibited behaviours**

Disinhibition is not one of the most commonly occurring BPSD (134, 408) with symptoms reportedly occurring in 2% to 25% of persons with dementia (124, 137, 709, 716, 722, 728, 749-752), particularly in those with frontotemporal dementia (FTD) (147, 728). While sexually disinhibited behaviours can be extremely challenging, they do not occur frequently in dementia (717). Decreased libido and sexual activity are reportedly the more characteristic changes (715). Reports are inconsistent with regard to prevalence ratios in males and females with some indicating that sexual disinhibition occurs equally in both sexes (722, 728, 753) and others reporting it more commonly presents in males (714, 754).

Variance in prevalence arises from the different definitions of disinhibition, settings, measurement tools and the duration of assessment. The BSSD scale, for example broadly defines sexual disinhibition as sexually motivated behaviours only and excludes instances such as undressing in an inappropriate place (137). The NPI includes a broader definition of disinhibited behaviours such as acting impulsively and talking openly about very personal or private matters (6).

Underreporting of problematic behaviours of a sexual nature, by family carers, is likely (713). This may be due to embarrassment or shame (755, 756), social taboos (740, 742), a sense of spousal duty and/or loyalty to the person with dementia (756). In a residential setting a "victim" may also be impaired to the extent that they are unable to report the incidents (757). The cultural and religious background of carers may further influence perceptions of disinhibited behaviours and willingness to report (758).

Although sexually inappropriate behaviour has been reported in MCI (713), the prevalence of disinhibition tends to rise as cognition and functioning in ADLs diminish and dementia

increases in severity (134, 137, 408, 409, 716, 722). This may be associated with executive dyscontrol, particularly where frontal subcortical circuits are impaired (713).

**Effects of disinhibited behaviours**
Disinhibited behaviours may provoke an angry or aggressive response from others such as other RACF residents and/or families as well as members of the public, depending on the context. Sexually disinhibited behaviours in dementia are linked to earlier admission to RACFs (717, 719), other problematic behaviours, poor quality of life (336) and increased carer burden (756, 759). RACF staff members have described sexual behaviours as the most challenging BPSD (713, 760, 761).

Within a RACF, the need may arise for staff to determine the capacity of residents with dementia to pursue a sexual relationship and guidelines in this area are lacking (762).

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Guidelines to assist in the assessment of a person with dementia's competency to participate in a sexual relationship (adapted from 762):
- **Person with dementia's awareness of the relationship**
    - Is he/she aware of who is initiating sexual contact?
    - Does he/she believe that the other person is his/her spouse/partner and thus acquiesces out of a 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?
- **Person with dementia's ability to avoid exploitation**
    - Is the behaviour consistent with formerly held beliefs and values?
    - Does he/she have the capacity to say no to any uninvited sexual contact?

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Disinhibited behaviours in dementia may be associated with negative symptoms, particularly apathy (716), hallucinations or delusions (745), frustration and subsequent, agitation and/or aggression (711, 763). Urinary tract infections, physical trauma and/or sexually transmitted infections are potential consequences of sexual disinhibition (764). Acute expressions of disinhibited behaviours in persons with dementia can occur as a result of a number of potential antecedents (see *Table 1.2, Module 1* for a list of contributory factors).

**Results**
A systematic literature review to set criteria (see *Appendix 7*) with hand searching yielded no psychosocial and environmental or biological intervention trials with outcomes relevant to social and/or sexual disinhibition in dementia. One psychosocial case study relevant to sexual disinhibition was identified. Case studies/series and one open-label trial for sexual disinhibition were located in the following pharmacological categories: anticonvulsants, antiandrogen agents, oestrogens, antipsychotics – atypical, antidepressants, ChEIs and an $H_2$-receptor antagonist. One RCT of aggressive behaviours in dementia included sexual aggression.

**Management**

Management of disinhibition should commence with an assessment of possible precipitating factors: medications (714), comorbid physical condition, stroke or seizure disorder (726), comorbid psychiatric condition or environmental triggers. *Appendix 1* provides suggested questions to facilitate comprehensive behavioural assessment.

With regard to sexual disinhibition, a problem-solving approach which deals with these BPSD as "behaviours" rather than clouding the issue with moral judgements is recommended (756). Supportive psychotherapy (745) and/or education of family carers and/or RACF staff around sexuality issues in dementia (713, 740, 742, 744, 765) may provide assurance that the disinhibited behaviours occur secondary to cognitive impairment (745). As no literature was located for interventions relevant to general disinhibition, the following largely relate to sexually disinhibited behaviours although some principles may apply to both.

*Psychosocial and environmental interventions*

Observing for triggers and/or early indicators of sexual disinhibition, such as humour with sexual undertones, may allow unwelcome behaviours to be diverted prior to them escalating (713). Strategies for modifying the inappropriate behaviours include redirection of sexual expression to an appropriate time and place (745), modifying cues which are misinterpreted, firmly identifying the behaviour as unacceptable, attempting to reorientate the person with dementia as to who they are directing the inappropriate behaviour toward, same sex staff attending personal hygiene and/or reallocating seating assignments in a communal dining and/or lounge area (713, 726).

Other psychosocial interventions suggested include activities to keep the person with dementia's hands occupied, increased affectionate contact with family and pets to compensate for loss of companionship as well as modified clothing that fastens at the back or an activity/modesty apron and/or provide screening or privacy when public masturbation occurs (713, 761, 766). The need for a multidisciplinary, individualised and multifaceted approach to managing disinhibited behaviours in dementia is emphasised.

A single case study reported providing an assisted-living resident with a large, stuffed toy animal as a distraction (752). As a result, the resident "inappropriately grasped and fondled" the toy and disrupted other residents and/or staff less often. Previous unsuccessful attempts at managing the behaviour included isolation, antipsychotic medications and divalproex. This outcome may be deemed partially effective where others are protected from the disinhibited behaviours and the resident with dementia was spared the adverse effects of pharmacological interventions.

The relevant literature includes a single report of an elderly RACF resident with cognitive impairment engaging a sex worker in his room, on a regular basis (767). When this was no longer possible due to objections from numerous sources, his sexually disinhibited behaviours became problematic.

Other BPSD have shown improvement with modified learning techniques to compensate for cognitive deficits in dementia (444). Strategies include immediacy of reinforcement, using written materials to present information, involving carers and family as well as adapting positive reinforcers to suit the degree of dementia. Developing a consistent, neutral and

simple response to propositions and avoiding knee-jerk overreactions which prompt a shame response and leave the person with dementia feeling "bad" may help. Avoid confrontation as it may provoke a catastrophic reaction and do not reinforce negative behaviour by paying it undue attention (745, 766).

*See Appendix 3 for interventions reported above.*

### Biological interventions

Where indicated, the choice of pharmacological agent is frequently determined by the urgency and risks associated with the disinhibited behaviour (709). The person with dementia's comorbidities and/or concomitant medications as well as their tolerance for any potential medication side effects, their sexual history and the outcomes of previous attempts at managing the behaviour (735) should also be taken into account.

No RCTs of pharmacological treatment for sexually disinhibited behaviours are currently available in the literature (711, 717, 735). One RCT which trialled oestrogen therapy for aggression in dementia included a measure of sexual aggression (728). Although a significant reduction in overall physical aggression was reported, no benefit was found for sexually aggressive behaviours. Case studies and an open label trial provide some evidence for the use of:

- anticonvulsants
  - gabapentin (768)
  - carbamazepine (Tegretol) (769)
  - divalproex (752)
- antiandrogen agents
  - Synythetic hormone progesterone: medroxyprogesterone acetate (770-772)
  - leuprolide (721) sometimes used as a better alternative to antiandrogens
- oestrogens
  - diethylstilbestrol (767) (This drug is no longer manufactured due to reported carcinogenic properties. It is included here as support for the concept.)
  - conjugated oestrogens (735, 773)
- $H_2$-receptor antagonist/antiandrogen: cimetidine (Tagamet) (718, 735)
- antidepressants
  - Tricyclic antidepressant: clomipramine (774)
  - SSRIs: citalopram (Cipramil) (775, 776), paroxetine (Aropax)(777)
  - Serotonin antagonist and reuptake inhibitor: trazodone (778)
- antipsychotics - atypical
  - quetiapine (Seroquel) (764, 779)
  - olanzapine (Zyprexa) (720)
- ChEIs: rivastigmine (Exelon) (780)

Five of the included case studies report that benefits were maintained for between two months and one year, from the time of starting treatment although it is not possible to determine if the behaviours would have extinguished during that period without medication. Studies were primarily focussed on males. There is some suggestion that androgen levels in males are correlated with generalised physical aggression in dementia and antiandrogens may improve these symptoms. A study, of eight males and 19 females with possible or

probable AD and aggressive behaviours, as well as a further case study (male) report positive results with cyproterone acetate (296, 297). Further research is required to determine if these findings are relevant to sexual aggression and/or disinhibition.

The prescription of hormonal therapy can be controversial as it can be viewed as feminisation or chemical castration of males (726). Depending on the jurisdiction, it may be necessary to obtain consent from a guardianship tribunal or board, not just from the family member or person responsible before administering hormonal therapy. For example under the NSW Guardianship Act, use of oestrogens or antiandrogens in men with impaired decision making capacity who exhibit sexual disinhibition is regarded as "Special Treatment" and approval by Guardianship Tribunal (not merely by the "person responsible") is required.

An open-label trial of geriatric outpatients referred for problematic sexual behaviours included 17 individuals with a diagnosis of dementia (709). SSRIs were suggested as a first-line option for sexual aggression with physically assaultive behaviour, where nonpharmacological treatment was deemed unsuitable or ineffective. Where behaviours were unresponsive to SSRIs, oestrogen therapy was suggested as a second-line approach although potential side effects were a concern. Where behaviours remained unresponsive or a more rapid response was required, and antiandrogen therapy was not medically contraindicated, this was suggested as a third line approach. A double-blind RCT in 13 females and two males with dementia which investigated the effectiveness of conjugated oestrogens on aggression, showed no benefit over placebo for sexual aggression (728).

Although antipsychotics may be of some benefit in the management of sexual disinhibition in dementia, expert consensus guidelines (277) recommend against their

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**STRATEGIES/OUTCOMES**

- *Direct observation suggested possible triggers for the behaviour were related to the presence of specific female staff members and a very sociable female resident who was seated at Mr A's table in the dining room. The female resident was happy to change her seating to join a friend at another table.*
- *RACF staff reported that Mr A was possibly misidentifying their intentions during personal hygiene tasks as these also provoked a sexual response at times. Change in rosters enabled two male staff members to cover Mr A's personal care needs between them, on most occasions.*
- *A review of Mr A's current medication did not suggest any association with the behaviour.*
- *When asked, the family reported that Mr A and his wife had been openly affectionate and apparently a close couple until her death in the past year. Mr A had reportedly become increasingly less aware of social boundaries since that time.*
- *Family members provided items of special interest from Mr A's home that helped to keep him occupied during periods of reduced environmental stimulation. They also increased their visits to provide him with additional appropriate human contact.*
- *Consultation with staff members indicated that some were shocked and repulsed by Mr A's disinhibited behaviours and were unaware that these BPSD can occur during the course of dementia.*
  *Staff education was provided around causes of disinhibition, "normal" sexual expression in older people, diminished privacy issues, strategies to avoid provoking and/or manage unwanted sexual behaviours as well as potential consequences of overreaction and shaming the resident.*
- *Opportunities for staff to debrief and*

long-term use. ChEIs or SSRIs may provide a safer option.

SSRIs reportedly have an antilibidinal and anti-obsessive effect (728), although no evidence is provided that any one SSRI is superior. Further, a comparison trial for the treatment of the paraphilic disorders (not dementia) found no significant differences in the efficacy of fluvoxamine, fluoxetine, and sertraline (781). Wherever possible,the use of symptomatic, pharmacological agents, when required for treatment of disinhibited behaviours should be time-limited, closely monitored, reviewed, reduced and/or discontinued when indicated and prescribed with appropriate psychosocial strategies.

> *validate their personal reaction to Mr A's behaviour in a safe and enabling environment were provided.*
> - *Behavioural and environmental measures reduced Mr A's disinhibited behaviours.*
> - *Increased staff awareness of the underlying issues increased staff confidence and ability to implement successful strategies for dealing with the behaviours.*
> - *Close monitoring of Mr A's behaviour continued with a view to trialling pharmacological interventions if the safety of others was jeopardised.*

The potential benefits to the person with dementia and the safety of others must be weighed against the side effects of pharmacological treatments (see *Table 2.3, Module 2* for side effects associated with neuroleptics). Where disinhibition occurs with other BPSD, medication which may also address other symptoms e.g., agitation or aggression should be considered in an attempt to avoid polypharmacy (465).

*See Appendix 4 for interventions reported above.*

**Limitations**

Sound research to guide clinicians and carers in the management of disinhibited behaviours in persons with dementia is lacking and reports of interventions are limited to sexually disinhibited behaviours. Reports on the outcomes of interventions are extremely limited and evidence for interventions based solely on case studies cannot be considered robust. Case studies frequently outline a "trial and error" approach to pharmacological management of sexually disinhibited behaviours with most reporting several failed medication trials prior to showing an effect (711). It is impossible to determine if the disinhibited behaviours would have run their course and resolved in the meantime.

**Conclusions**

In summary, disinhibition in dementia can have significant and disabling consequences. Recognised expert guidelines are limited in the area of managing disinhibition, particularly where sexual behaviours are involved. A major dilemma arises in attempts to allow the person with dementia sexual expression while protecting the safety, rights and dignity of all. The evidence suggests that individual situations must be managed on a case-by-case basis. Modifying environmental factors may have a part in reducing symptoms and the need for a multidisciplinary, individualised and multifaceted approach is stressed. Where pharmacological treatment is in the best interest of the person with dementia or necessary for the safety of others, the reported medications may have a role to play in managing disinhibited behaviours in dementia although sound evidence is lacking.

# MODULE 9: Nocturnal disruption

**Key messages**

- Symptoms of nocturnal disruption vary with dementia subtypes and can present as part of a range of sleep related symptoms associated with the person with dementia's night and daytime behaviours.
- Nocturnal disruption can be caused by physical factors or be inherent to the type of dementia e.g. tends to occur more frequently in dementia with Lewy bodies (DLB).
- Differential diagnosis requires eliminating delirium, comorbid medical and/or psychiatric conditions, substance abuse, physiological effects of medications, parasomnias and other primary sleep disorders.
- Nocturnal disruption occurs in 20% to 82% of persons with dementia.
- The impact on the health of person with dementia and their carer can be significant.
- Management requires identifying the potentially treatable factors contributing to the nocturnal disruption such as pain, hunger, thirst, infection and/or poor sleep hygiene.
- The NITE-AD intervention, a multi-component intervention with a carer sleep hygiene education component provides the best evidence for psychosocial management of nocturnal disruption.
- Where pharmacological treatment is indicated, ChEIs and atypical antipsychotics provide the best available evidence. The use of antipsychotics is not recommended due to safety concerns and the use of ChEIs may be problematic due to the potential adverse effects of sleep disturbance and nightmares.
- Sleep disturbances can occur secondary to depression, anxiety, agitation and/or pain. Pharmacotherapy for the underlying condition may be helpful.

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**Before you move on, have the following been done?**

1.  A *risk assessment* to identity any immediate risks to the person with dementia or others within the care environment

2.  A *comprehensive assessment* that is person centred and considers the following key aspects:
    - Referrer's description of behaviour
    - The behaviour
    - The person
    - The carer
    - The care environment

3.  Any reversible causes of the behaviour(s) excluded and/or treated

(See *Module 1* for further details)

## Nocturnal disruption Summary

**What is nocturnal disruption and what does it look like in dementia?**
Symptoms of nocturnal disruption vary with dementia subtypes, but may present as:
- increased early-morning awakenings
- nocturnal sleep fragmentation
- decreased total sleep time
- decreased sleep efficiency
- reverse day-night patterns
- decreased slow wave sleep
- excessive daytime sleepiness
- decreased rapid eye movement sleep
- nocturnal confusion
- increased daytime napping
- loss of normal sleep architecture
- increased sleep onset latency

**Causes of nocturnal disruption**
Nocturnal disruption can be caused by physical factors such as pain or adverse effects of medication. It can also be inherent to the type of dementia e.g. tends to occur more frequently in DLB. Other BPSD may become exacerbated at night due to reduced environmental cues.

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

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

**Prevalence of nocturnal disruption**
Nocturnal disruption occurs in 20% to 82% of persons with dementia. The occurrence of nocturnal disruption in dementia increases with dementia severity, negative ApoE ε4 allele status, anxiety, depression, reduced exposure to environmental cues and poor sleep hygiene. Other factors related to poor health contribute to nocturnal disruption in the general population and may occur comorbidly with dementia.

**Effects of nocturnal disruption**
Nocturnal disruption in dementia is associated with poor sleep quality, depressive symptoms, greater carer burden, earlier RACF placement, poorer cognitive functioning, more rapid cognitive decline, greater functional impairment, poor quality of life and/or wandering behaviours in persons with dementia as well as a higher risk of mortality.

**Management of nocturnal disruption**

It is important for the clinician to determine potentially treatable factors contributing to the nocturnal disruption. Management of underlying causes may require providing relief for pain, hunger, thirst and/or treating infection or adverse drug reactions. Carer education around sleep hygiene or assessing degree of 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 sensory or multicomponent categories.
- Evidence for bright light therapy is inconsistent.
- A study which looked at residential respite reduced carer stress but exacerbated sleep disturbances in persons with dementia.
- The NITE-AD intervention, a multi-component intervention which comprised carer sleep hygiene education, daily walking and increased daylight exposure reduced nocturnal disruptions, whereas other multi-component interventions showed improvement on daytime measures only.
- Although scientific evidence is lacking, traditional interventions such as such as warm milk, reassuring human contact, gentle massage and soothing music as well as adequate day time light exposure and physical activity to induce sleep may nonetheless contribute to management and should not be overlooked.

*Biological interventions*
- Limited high quality evidence is available for pharmacological management.
- Most studies examined the effects of ChEIs or atypical antipsychotics.
- Although some evidence is provided for atypical antipsychotics, current guidelines recommend against their use unless the BPSD is secondary to psychosis.
- Some evidence is reported for melatonin, dronabinol (a synthetic marijuana), Ginkgo biloba extract EGb 761 and Yi-Gan San.
- Two studies involving electrical stimulation interventions reported mixed results.

**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.

**Conclusions**
- Nocturnal disruption is a significant problem for persons with dementia and carers.
- Understanding the potential causes underlying nocturnal disruption will assist in managing the behaviour.
- The NITE-AD intervention provides the best evidence for psychosocial management of nocturnal disruption.
- Where pharmacological treatment is indicated, ChEIs and atypical antipsychotics provide the best evidence, but the use of antipsychotics is not recommended due to safety concerns. Further, sleep disturbance and nightmares are well known potential adverse effects of ChEIs.
- Sleep disturbances can occur secondary to depression, anxiety, agitation and/or pain. Pharmacotherapy for the underlying condition may be helpful.

**What is nocturnal disruption and what does it look like in dementia?**
Nocturnal disruption refers to circadian rhythm and sleep disturbances, which may arise from alterations of the circadian system or a misalignment between the circadian rhythm of the person and the activity schedule in their social and/or physical environment. The symptoms of nocturnal disruption vary according to dementia subtypes (539, 782-784) and may present with the following features (782, 785-787):

- increased sleep latency
- nocturnal sleep fragmentation
- increased early-morning awakenings
- decreased total sleep time
- decreased sleep efficiency
- decreased slow-wave and rapid-eye-movement (REM) sleep
- nocturnal confusion
- increased daytime napping and excessive daytime sleepiness
- other BPSD such as agitation, verbally disruptive behaviours, hallucinations and wandering may also be exacerbated nocturnally

The cause of nocturnal disruption is considered to be multifactorial. The 24-hour sleep-wake cycle is regulated endogenously by the suprachiasmatic nucleus (SCN) and the nocturnal secretion of melatonin, and exogenously by zeitgebers (environmental time cues) including daylight and physical activity (788, 789). In persons with dementia, there are often degenerative changes in the SCN, decreased levels of melatonin secretion and limited exposure to zeitgebers , particularly for those living in RACFs (789). Genetic factors may also play a role in familial circadian rhythm sleep disorders (790). Sleep apnoea is common especially in overweight snorers and may be exacerbated by dementia.

The *International Classification of Sleep Disorders, 2<sup>nd</sup> Edition* diagnostic criteria for circadian rhythm sleep disorder due to medical condition (791) are as follows:

- A chronic complaint of insomnia or excessive sleepiness related to alterations of the circadian timekeeping system or a misalignment between the endogenous circadian rhythm and exogenous factors that affect the timing or duration of sleep.
- An underlying medical or neurological disorder predominantly accounts for the circadian rhythm sleep disorder.
- Sleep log or actigraphy monitoring (with sleep diaries) for at least seven days demonstrates disturbed or low amplitude circadian rhythmicity.
- The sleep disturbance is not better explained by another current sleep disorder, mental disorder, medication use or substance use disorder.

**Causes of nocturnal disruption**
Nocturnal disruption can be caused by physical factors such as pain, discomfort, infection, adverse effects of medication or of their withdrawal although the person with dementia may be unable to articulate this. The behaviour can also be inherent to the type of dementia e.g. DLB. Other BPSD such as agitation, verbally disruptive behaviours, hallucinations and wandering may become exacerbated at night due to reduced environmental cues.

## Differential diagnosis

It is important to differentiate nocturnal disruption in dementia from parasomnias and other primary sleep disorders. While they can present comorbidly with dementia, these conditions may require specific medical attention. A thorough clinical assessment is essential to rule out sleep disturbance due to delirium, comorbid medical and/or psychiatric conditions, substance abuse or physiological effects of medications. The Mayo Sleep Questionnaire (MSQ) (792) is a brief carer-report instrument that can be used to screen for parasomnias and other primary sleep disorders including REM sleep behaviour disorder, periodic limb movements, restless legs syndrome, sleepwalking, sleep apnoea and sleep-related leg cramps. In residential care or clinical setting, it is generally more practical to rely on careful observations and unobtrusive recording of sleep times over 24 hours to provide a guide to the nature of the sleep disturbance (see below).

> **PRESENTATION**
>
> *Mr C is a recent admission to the RACF from hospital, following a medical crisis. He lived a chaotic lifestyle at home with no real routine and was dishevelled and underweight on admission. He did not have a regular sleeping pattern so was frequently awake at night. RACF staff reported that he had a disrupted sleep/wake cycle. When he was often awake late into the night, Mr C would wander into other resident's rooms while they are sleeping and turn on the lights and/or television. In the mornings, he did not wish to be disturbed by staff and Mr C has become increasingly resistant to their encouragement to eat breakfast or have a shower. He can ill afford to lose weight at this time. Because staff are busy, Mr C frequently falls back to sleep until 11am.*

Polysomnography (PSG) is an objective tool that reports physiological parameters relevant to sleep including electroencephalography, electro-oculography, electromyography, electrocardiography, airflow, respiratory effort and pulse oximetry (784). Although PSG may be used to rule out other sleep disorders with similar symptoms (793), it can be expensive and poorly tolerated (794) making it impracticable for most persons with dementia.

## Measuring nocturnal disruption

Current practice guidelines recommend the use of actigraphy and sleep log in the assessment of nocturnal disruption in dementia (793, 795).

- Actigraphy uses small computerised devices with accelerometers to continuously record limb movement over time. Some actigraphs include patient-activated event markers and ambient light sensors to record when lights are turned on/off. Actigraphy is an unobtrusive and naturalistic way to estimate sleep-wake patterns which may also be used as an outcome measure to assess treatment response (796). Limitations in distinguishing sleep from immobile wakefulness may result in underestimation of sleep onset latency and overestimation of total sleep time (796). Moreover, accuracy is reduced when sleep is fragmented (797) or in the event of a coexisting movement disorder such as Parkinson's disease, restless legs syndrome or periodic limb movement disorder (798).
- A sleep log is commonly used as an adjunct to actigraphy (784) to record subjective experiences of sleep and relevant events such as drug administration times. Sleep logs based on care staff observation have been shown to be reliable and useful where self-report is not feasible (799).

Questionnaires may also be used in the assessment of nocturnal disruption in dementia.

- The sleep disorders subscale of the 12-item Neuropsychiatric Inventory (**NPI**) is completed during an interview with the carer, in which they rate the frequency and severity of the person with dementia's sleep disruption or night-time behaviours as well as their own subsequent distress (6).
- The NPI-Clinician (**NPI-C**) version has added an additional question relevant to nocturnal disruption which asks if the person with dementia has experienced agitation or concern about being able to fall asleep or awakening at night (7).
- The Pittsburgh Sleep Quality Index (**PSQI**) is a self-rated questionnaire for assessing seven different aspects of global sleep quality: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of nocturnal sedation and daytime dysfunction over a one-month period (800).
- The Epworth Sleepiness Scale (**ESS**) is a brief self-rated questionnaire which can be used to assess excessive daytime sleepiness (801).

Both the PSQI and the ESS have been successfully administered in persons with dementia (783, 802) although the self-report nature of the instruments limits their usefulness in persons with moderate to severe dementia. At times carer- or self-report measures will disagree with more objective measures of sleep quality (803, 804).

**Prevalence of nocturnal disruption**

Nocturnal disruption commonly occurs in persons with dementia, with prevalence ranging from 20% to 82% (327, 805-807). Few studies report the differences in prevalence between dementia subtypes and findings are inconsistent. Two studies found no difference in prevalence rates between AD, VaD and FTD (808) or between AD and other dementias (327). Others suggest a higher prevalence of sleep disturbance in DLB when compared to AD (809), in temporal variant FTD compared to AD and behavioural/frontal variant FTD (539) and in AD compared to VaD (810). Variance in prevalence generally arises from differences in dementia severity and subtype of the persons sampled, the definition of nocturnal disruption (e.g. clinically significant sleep disturbance versus existence of any symptom of sleep disturbance) and/or the assessment instrument used.

The occurrence of nocturnal disruption has been reported to increase with dementia severity (799, 811, 812), negative ApoE ε4 allele status (813), anxiety (814), depression (815), limited exposure to environmental cues (93, 312, 692, 816) and poor sleep hygiene (692). Nocturnal disruption has also been associated with advanced age, poor health, heart disease, bodily pain, lower levels of physical activity (817, 818), incontinence and obesity (819) in the general population and these conditions frequently occur with dementia. A history of snoring and day time sleepiness should alert others to possibility of sleep apnoea syndrome.

**Effects of nocturnal disruption**

Nocturnal disruption is linked to significant detrimental effects in the person with dementia:
- poorer cognitive functioning (820)
- faster cognitive decline (821)
- greater functional impairment (814, 815, 820)
- reduced quality of life (822)
- increased wandering behaviour (823)

- increased agitation (824)
- depression (815)
- institutionalisation (312, 825, 826)
- higher risk of mortality (827).

While not always directly due to the disrupted sleep of the person with dementia, family carers experience poorer sleep quality, more depressive symptoms, increased burden (828) and greater distress (820, 822) in relation to this BPSD. When the person with dementia resides in a RACF, sleep disruption negatively affects other residents and staff (829).

## Results

A systematic literature review to set criteria (see *Appendix 7*) yielded 11 psychosocial and environmental and 16 biological intervention studies with outcomes relevant to wandering in dementia. Psychosocial and environmental interventions were grouped into four broad categories: therapeutic recreation, sensory, environmental and multicomponent interventions. Biological interventions were grouped into three categories: cholinesterase inhibitors (ChEIs), atypical antipsychotics and other medications.

## Management of nocturnal disruption

It is important for the clinician to determine potentially treatable factors contributing to the nocturnal disruption. *Appendix 1* provides suggested questions to facilitate comprehensive behavioural assessment. Management of underlying causes may require:

- relief from pain, hunger, thirst and/or the need to urinate
- cues to provide direction back to bed from the toilet
- management of evening fluid intake
- treatment of infection or adverse drug reactions
- carer education around sleep hygiene
- assessment of noise or environmental disturbance occurring at night close to the person with dementia in a RACFS

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**ASSESSMENT**

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

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

*Assessing the situation*

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

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## *Psychosocial and environmental interventions*

Psychosocial and environmental intervention trials were mainly conducted in residential settings, with most studies falling into the sensory and the multicomponent interventions

categories. Findings for bright light therapy intervention studies are inconsistent. There is moderate evidence that bright light therapy administered in the morning or all-day improves night-time sleep (830) but two other studies provide moderate to strong evidence that bright light therapy does not have any effect on nocturnal sleep or behaviours (270, 356). A further study reported circadian rhythmicity improvements when assessed by tympanic temperature but not by direct observations (831). Positive results were found in two studies of moderate quality for therapeutic recreation interventions; an outdoor activity program increased sleep duration (832) while indoor gardening reduced the frequency and duration of night-time awakenings and daytime napping and increased nocturnal sleep time and efficiency (350).

Support is mixed for multicomponent interventions which included combinations of bright light or outdoor exposure, increased physical activity, better sleep hygiene as well as reduced environmental noise and/or light during the night. Two strong studies employing the NITE-AD protocol, which included a carer sleep hygiene education component, daily walking and increased daylight exposure showed improvements in the frequency and duration of night-time awakenings and sleep percentage (160, 692, 833). Two studies provided moderate to strong evidence that these interventions improve only daytime activity measures (834, 835). Despite improving carers' quality of sleep, residential respite care was found to increase sleep onset latency and decrease stability of circadian activity rhythm in persons with dementia in a study of moderate quality (802).

Where nocturnal disruption prompts night wandering, safety may be an issue (see *Module 10* for information on technologically mediated devices). Traditional measures such as warm milk, reassuring human contact, gentle massage and soothing music may be considered although scientific evidence is lacking in these areas. Likewise, effective continence management and avoiding caffeine can promote better sleep.

*See Appendix 3 for interventions reported above.*

### *Biological interventions*
Limited RCTs of pharmacological treatment for nocturnal disruption are currently available in the literature. Open-label trials provide some evidence for the use of ChEIs for the treatment of nocturnal disruption. Primarily used for treating cognitive symptoms in dementia, ChEIs demonstrated beneficial effects on nocturnal disruption in three studies of moderate quality. Improvements in sleep disturbance were demonstrated for rivastigmine (377). Sleep and diurnal rhythm disturbances were also reduced in PDD and possible AD with or without cerebrovascular disease after taking galantamine (836, 837). One study of strong quality reported inconclusive results; REM sleep increased with donepezil but no effects were observed on any other sleep parameters (838). It is important to note that ChEIs can cause sleep disturbance and nightmares (839) so careful monitoring for adverse effects is indicated.

Two studies provide moderate evidence for the efficacy of quetiapine in reducing nocturnal disruption, with one showing improvements in sleep and diurnal rhythm disturbances (279) and the other reporting shorter wake bouts when compared to the haloperidol group (472). Two studies provide moderate to strong support for the use of risperidone to improve sleep and diurnal rhythm disturbances (278, 369). Although atypical antipsychotics may be of some benefit, their use is not recommended unless the sleep disruption is secondary to

psychosis (839). Their use has been associated with further cognitive decline and greater risk of somnolence, extrapyramidal symptoms, abnormal gait, oedema, urinary tract infections, incontinence, falls, cerebrovascular adverse events and mortality (284) (see *Table 2.3, Module 2* for side effects associated with neuroleptics).

Other pharmacological agents that have been investigated for the management of nocturnal disruption include melatonin, dronabinol (a synthetic marijuana), Ginkgo biloba extract EGb761 and Yi-Gan San. Two studies of moderate quality suggest no effect for melatonin on nocturnal sleep measures, with or without bright light therapy (384, 840) while a further study provided strong evidence that nocturnal disruption improved with melatonin alone or in combination with bright light therapy (689). Moderate support has been shown for the positive effects of Gingko biloba extract EGb761 (478), Yi-Gan San (301) and dronabinol (387) although as a cannabinoid, the use of dronabinol is restricted.

No studies were located for sedative-hypnotic medications even though hypnotics such as the benzodiazepines are commonly prescribed for sleep disturbance. These may help with sleep temporarily but are usually avoided as they the increase risk of confusion and falls and in the long term are addictive and lose their potency. If benzodiazepines are used as a "rescue medication" it is better to use shorter-acting hypnotics such as temazepam than longer-acting ones such nitrazepam or flunitrazepam. Other medications often prescribed are sedating antihistamines, anti-epileptic medications and antidepressants even though there is no empirical basis for their use. While these drugs can have hypnotic properties they also have important side effects. Analgesics clearly have a place where pain is obvious or suspected; as simple a

| STRATEGIES/OUTCOMES |
|---|
| • *After investigation via the hospital, Mr C's only surviving sibling was contacted. He reported that Mr C used to enjoy his garden and was very proud of his fig trees. Mr C would also spend time flicking through Greek newspapers and junk mail brochures from his letterbox.*<br>• *Mr C has had two recent relocations which will likely have increased his confusion. Providing familiar items may help him identify his space, making it more comfortable and appealing at night. Although Mr C's brother had not been close to him for some years, he was willing to bring some personal items to the RACF.*<br>• *It became evident that Mr C was further disrupted at night by activity around the nursing station and staff attending to the high level needs of the resident in the next room. He was moved to a quieter area of the RACF.*<br>• *The relative inactivity and darkness within the RACF environment at night, provides reduced cues and a small night light assisted with orientation.*<br>• *Keeping Mr C's daily routine as predictable as possible, given his previous lifestyle, provided some structure and ultimately, familiarity.*<br>• *Supporting staff through Mr C's transition to RACF and providing education around the factors contributing to his night-time wandering improved tolerance of the behaviour.*<br>*Staff members were able to chat to Mr C about his passion for gardening and source Greek newspapers for him to browse.*<br>• *A daily walk to RACF letterbox after multiple brochures (recycled by staff) were "delivered" became a positive activity.*<br>• *Better sleep hygiene minimised opportunities for sleep during the day and gradually helped to establish a* |

> *somewhat earlier and regular bedtime for Mr C.*
> - *While he was still awake later than other residents in the facility, the situation was more manageable and less disruptive to others.*

remedy as paracetamol 1 gram at night may be helpful and is well tolerated (see below).

Understanding the potential causes underlying the nocturnal disruption will assist in managing the behaviour. Sleep disturbances can be secondary to depression, anxiety, agitation and/or pain and pharmacotherapy for the underlying condition may be helpful. Paracetamol for musculoskeletal pain or gabapentin for neuropathic pain may be indicated (839) and earlier modules of this guide suggest interventions to address possible underlying BPSD.

Although benzodiazepine and non-benzodiazepine hypnotics are commonly prescribed for sleep problems, these can worsen confusion and increase the risk of falls in the person with dementia. The potential risk/benefit ratio for the individual with dementia must always be considered before prescribing pharmacological agents for nocturnal disruption. Symptomatic, pharmacological treatment of these BPSD should be time-limited, closely monitored, frequently reviewed and withdrawn when possible (179). Jurisdictions vary in their requirement for informed or proxy consent for regular prescriptions of psychotropic medications and local requirements should be checked.

While the literature available on the use of electrical stimulation to treat nocturnal disruption is limited, two studies of strong quality examined the effects in those with dementia. High-frequency cranial electrostimulation (841) and transcutaneous electrical nerve stimulation (842) showed no effect and a near significant effect on rest-activity rhythm, respectively. Interestingly, the latter trial showed selective improvement in "interdaily stability", a measure of the strength of coupling of the rest-activity rhythm to environmental time cues, in those *not* receiving concomitant treatment with ChEIs (842).

*See Appendix 4 for interventions reported above.*

### Limitations
Intervention studies, particularly those providing strong evidence, are limited in number and many report no benefit or mixed results. Few trials investigated the long-term effects of the interventions with only five studies conducting follow-up assessments at the conclusion of treatment-free periods ranging from five weeks to four months (160, 356, 692, 833, 841, 842). These factors all limit their clinical utility in the management of nocturnal disruption in dementia.

### Conclusions
In summary, nocturnal disruption is relatively common in dementia and it has significant consequences for persons with dementia and their carers. There are limited intervention studies available and most provide moderate evidence at best. The NITE-AD intervention, a multi-component intervention with a carer sleep hygiene education component provides the best evidence for the psychosocial management of nocturnal disruption in dementia, as it uses a multifaceted approach targeting several contributing factors. Traditional interventions to induce sleep can also contribute to management and shouldn't be overlooked.

Where pharmacological treatment is necessary, some evidence is provided for ChEIs and atypical antipsychotics but the long-term use of atypical antipsychotics is not recommended due to the associated risks. Further, sleep disturbance and nightmares are well known possible adverse effects of ChEIs. Despite the positive reports for melatonin, dronabinol, Ginkgo biloba or Yi-Gan San, the evidence is too limited or mixed for any recommendations to be made. Further evidence is needed before conclusions can be drawn regarding the efficacy of electrical stimulation.

# MODULE 10: Psychotic symptoms

**Key messages**

- Psychotic symptoms in dementia present as delusions or hallucinations indicative of a disturbance in the perception and/or appreciation of objective reality.
- Psychosis of dementia needs to be differentiated from schizophrenia, other primary psychotic disorders or delirium.
- Psychotic symptoms are some of the most commonly occurring BPSD, with prevalence rates ranging from 12.2% to 74.1%. Delusions are the most prevalent, followed by hallucinations and other psychotic symptoms (e.g. misidentification).
- Individualised psychosocial interventions are recommended initially, unless the psychotic symptoms are causing significant agitation, distress or safety concerns. Where medications are indicated, concurrent psychosocial interventions may be of benefit.
- The multifaceted care program *GentleCare*, which builds a "prosthesis of care" based on support to compensate for cognitive and functional losses, provides the best evidence for the psychosocial management of psychotic symptoms.
- Where pharmacological treatment is necessary, cholinesterase inhibitors (ChEIs) and memantine may provide a safer option than atypical antipsychotics.

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**Before you move on, have the following been done?**

1. A *risk assessment* to identity any immediate risks to the person with dementia or others within the care environment

2. A *comprehensive assessment* that is person centred and considers the following key aspects:
   - Referrer's description of behaviour
   - The behaviour
   - The person
   - The carer
   - The care environment

3. Any reversible causes of the behaviour(s) excluded and/or treated

(See *Module 1* for further details)

**Psychotic symptoms Summary**

**What are psychotic symptoms and what do they look like in dementia?**
Psychotic symptoms in dementia have been defined as a disturbance in the perception and/or appreciation of objective reality. Criteria for psychosis of dementia:

- delusions or hallucinations in the presence of dementia
- onset of psychotic signs and symptoms after onset of other dementia symptoms, and which are present at least intermittently for at least 1 month
- symptoms severe enough to disrupt patients' functioning, not better accounted for by another psychotic disorder, medical condition, or effects of a drug and not occurring during the course of a delirium

**Causes of psychotic symptoms**

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

**Differential diagnosis**
Psychosis of dementia can 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 and Schneiderian first-rank symptoms (i.e.
**ABCD**: **A**uditory hallucinations, **B**roadcasting of thought, **C**ontrolled thought (delusions of control), **D**elusional perception). It is also important to rule out delirium.

**Measuring psychotic symptoms**
Psychotic symptoms can be assessed using the delusions and hallucinations subscale 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)**.

**Prevalence of psychotic symptoms**
Psychotic symptoms occur in 12.2% to 74.1% of persons with dementia. Delusions are the most frequently reported psychotic symptoms, followed by hallucinations and other psychotic symptoms such as misidentification. 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 psychotic symptoms**
Psychotic symptoms have been associated with more rapid cognitive decline, impaired "real-world" functioning, lower quality of life, higher risk of comorbid BPSD, earlier residential care placement, higher healthcare costs and increased carer burden.

**Management of psychotic symptoms**

It is important to rule out delirium or potentially reversible causes, and to confirm that the claims of the person with dementia are not actually occurring. The presence of psychotic symptoms may be more distressing for the carers than for the person with dementia, and education and support may be indicated. Those who experience more distressing symptoms, particularly in DLB or PDD, may require more active treatment.

*Psychosocial and environmental interventions*
- All intervention studies were of moderate quality and primarily conducted in RACFs.
- Music interventions made up the largest group and these reported mixed results.
- The *GentleCare* protocol which comprised a non-pharmacological, prosthetic approach provides the best evidence of psychosocial management.
- No benefits were found for therapeutic activities or aromatherapy.
- Individualised care based on psychosocial management is recommended.
- The lack of scientific evidence for psychosocial interventions should not prevent clinicians considering these interventions on a case-by-case basis.

*Biological interventions*
- Where psychotic symptoms are a significant concern or a safety risk, pharmacological interventions may be indicated as a first-line approach.
- The majority of intervention studies focused on atypical antipsychotics, ChEIs or memantine and citalopram.
- Positive results were reported for ChEIs and memantine and they provide the best evidence for the pharmacological management of psychotic symptoms in dementia.
- The findings for atypical antipsychotics and antidepressants were mixed.
- Limited evidence of efficacy was reported for omega-3 supplements and a traditional Asian herbal formulation Yokukansan.
- No evidence was shown for other pharmacological agents trialled: tandospirone, dronabinol and Ginkgo biloba extract.
- A small case series reported some positive results for electroconvulsive therapy (ECT).

**Limitations**

Psychosocial intervention studies are limited and their quality is moderate at best. Treatment outcomes reported in studies are generally dependent on the severity of psychotic symptoms at baseline, which may vary across dementia subtypes. Three of the included studies report long-term follow-up and effects were not maintained.

**Conclusions**
- Expert consensus guidelines recommend the use of individualised psychosocial interventions in the management of psychosis where they are effective.
- Where distress or safety is an issue short-term pharmacological treatment may be indicated as a first line approach or concurrent with psychosocial interventions.
- Special care programming provided the best evidence for the psychosocial management of psychotic symptoms in dementia.
- Where pharmacological management is required, ChEIs and memantine may provide a safer option than atypical antipsychotics.

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

Psychosis, one of the three major neuropsychiatric syndromes of dementia, has been defined as a disturbance in the perception and/or appreciation of objective reality (843). The most common psychotic symptoms in persons with dementia are delusions and hallucinations (844). Published criteria for psychosis of dementia are (844):

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

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**PRESENTATION**

*Mr H is a 70 year old Aboriginal man from a remote community in the Northern Territory. He is dependent on his daughters for care, but they are currently unable to effectively meet his physical needs due to Mr H's considerable demands and their other family responsibilities. To ease the burden on the family, Mr H has recently started attending a day respite service. He is wary of care staff, particularly those who are from non-Aboriginal or Torres Strait Islander backgrounds, telling his family that they try to beat him and want to take him away from the community. His family also report that Mr H has recently been distressed by seeing "evil spirits" and feeling "snakes coming out of his eyes". At times Mr H has attempted to run away from staff at the day respite centre, which places him in considerable danger.*

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

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A delusion is a fixed false belief that is not culturally bound (492). Delusions in dementia are briefly described as paranoid, simple and non-bizarre (844). Subtypes of delusions common in dementia include delusions of theft, suspicion, abandonment, misidentification, danger, infidelity, and the delusion that "one's house is not one's home" (845-847). Because delusions in dementia can sometimes represent reality (e.g. a nursing home is not actually a person's home) and tend not to be fixed or incontrovertible, it has been suggested that they may not fit the DSM-IV definition (846).

An hallucination is a sensory experience that occurs in the absence of actual sensory stimulation (848). Hallucinations in dementia are most commonly visual, but can involve any sensory modality and hence be auditory, somatic, olfactory or tactile in nature (845). Recurrent visual hallucinations are a core feature in the diagnosis of dementia with Lewy bodies(DLB, 849) and Parkinson's disease dementia (PDD, 850). In those with DLB or PDD, visual hallucinations are generally complex, experienced daily, last for minutes, formed (i.e. not just colours and usually involving people or animals), and are often but not always experienced as unpleasant (851).

A lack of consensus exists as to whether delusions and hallucinations in dementia should be classified separately, or as part of the broader construct of psychosis of dementia (845). Delusions and hallucinations appear to have separate neuroanatomical bases (852). Of the

two, hallucinations may be more indicative of the presence of an overall psychotic syndrome (135, 853).

A further phenomenon known as misidentification may be a separate psychotic symptom, although it is frequently considered a type of delusion. Misidentification can be defined as a misperception of external stimuli with an associated belief or elaboration that is held with delusional intensity (854). Misidentifications can be differentiated from hallucinations by the presence of external stimuli. Examples are the belief that a familiar person is an imposter, that images on television are real, that the image in the mirror is a stranger or that there are phantom boarders in the house.

### Causes of psychotic symptoms

Psychotic symptoms can be caused by delirium, substance use as well as other general medical conditions such as infections or disturbances in the endocrine, hematologic and/or metabolic systems (844). Hallucinations can arise from potentially treatable factors such as misinterpretation of reality, sensory deprivation or vision loss, inappropriate sensory stimulation or depression (848, 855).

Age, gender, education, family history of dementia or psychiatric illness, age at onset of dementia and duration of illness are not consistently related to a risk of psychosis in dementia (845, 856). A history of intake of anticholinergic drugs (857) and the presence of extrapyramidal signs (858, 859) may be associated with a higher risk of psychosis in dementia.

### Differential diagnosis

While neither the DSM-IV nor the ICD-10 provides clear definitions for BPSD overall, hallucinations and delusions are defined as features of BPSD (1, p. 56). It is important to determine if the presenting psychotic symptoms can be attributed to schizophrenia or related primary psychotic disorders. Key features which can differentiate schizophrenia and psychosis of dementia include (844):
- past history of psychosis
- content of the delusion or hallucination
- presence of misidentification phenomena
- active suicidal ideation
- family history
- dosage and duration of any antipsychotic treatment
- Schneiderian first-rank symptoms (i.e. **ABCD**: **A**uditory hallucinations, **B**roadcasting of thought, **C**ontrolled thought (delusions of control), **D**elusional perception)

Delusions may resemble other phenomena such as confabulation and disorientation (847, 854). Hallucinations and/or delusions may be attributed to the person with dementia's religious/spiritual beliefs and/or cultural background rather than the dementia (848). It is also important to consider sensory impairment in assessing psychotic symptoms as lost hearing aids and/or glasses can contribute to misinterpretation of the environment.

**Measuring psychotic symptoms**

While no standardised measure of psychosis in dementia currently exists, assessment can be accomplished with good reliability and validity (845). The following scales have been widely used and have substantial overlap; nonetheless, each emphasises different aspects of psychosis (860, 861). The **NPI** and **BEHAVE-AD** are reportedly equivalent in detecting clinical improvement in response to treatment (861).

- The delusions and hallucinations subscales of the Neuropsychiatric Inventory (**NPI**) are completed during an interview with the carer, in which they rate the frequency and severity of the person with dementia's delusions and hallucinations, as well as their own subsequent distress (6, 7). The NPI includes six items concerning delusions and seven items relevant to hallucinations. The reliability and validity of the NPI overall is well established (178). The NPI-Clinician (**NPI-C**) version does not include any revised items for the delusions or hallucinations subscales (7).

- The Behavioural Pathology in Alzheimer's Disease scale (**BEHAVE-AD**) measures BPSD in persons with AD through informant interview, based on the preceding two weeks (184). It is appropriate for use in acute, community and residential care settings. The BEHAVE-AD contains seven items concerning delusions and five for hallucinations.

- The Consortium to Establish a Registry for Alzheimer's Disease Behavior Rating Scale for Dementia (**CERAD-BRSD**) contains two items relevant to delusions and one for hallucinations (748).

- The Columbia University Scale for Psychopathology in Alzheimer's Disease (**CUSPAD**) contains 11 items relevant to delusions and five for hallucinations. Psychotic features are identified with the use of a simple decision tree, making it suitable for use by trained, lay interviewers (126).

**Prevalence of psychotic symptoms**

Psychotic symptoms are some of the more commonly occurring BPSD (845) with reported prevalence between 12.2% and 74.1% of persons with AD (856). The prevalence of delusions ranges from 9.3% to 63% while hallucinations are reported less frequently at 4% to 41%. Other uncategorised psychotic symptoms such as misidentification reportedly occur in 3.6% to 38.9% of patients with AD (856).

Variation in prevalence rates is due to differences in populations studied (e.g. inpatients, outpatients, residential care or community samples), definition and assessment procedures, treatment with neuroleptic medications and diagnostic criteria for, dementia (845). The higher prevalence of hallucinations in individuals with DLB (330, 862) and PDD (863, 864), along with the reported lower prevalence of psychotic symptoms in FTD (865) and VaD (111), suggests that these symptoms are related to disease-specific neuropathology.

Psychotic symptoms tend to increase in the mild to moderate stages of dementia and then decrease in the later stages although some reports deviate from this pattern. Overall, psychotic symptoms in dementia appear to fluctuate with time, present episodically (126, 133, 845) and frequently recur once present (847, 856, 866-870).

## Effects of psychotic symptoms

Psychotic symptoms contribute substantially to poorer outcomes for persons with dementia and their carers. They are associated with increased carer burden (868, 871), earlier residential care placement (339, 872, 873), poorer quality of life (337) and physical health (853) as well as higher healthcare costs (874).

Psychotic symptoms collectively (856, 873, 875, 876) as well as in delusions in isolation (867) and hallucinations in isolation (877) have been associated with a more rapid cognitive decline in dementia. It has been proposed that psychotic symptoms may indicate a distinct disease subtype (136, 856). Psychotic symptoms are frequently associated with other BPSD (126, 870, 878) including aggression (871, 878) and more severe depression (853). Delusions and hallucinations are also associated with impaired capacity for "real-world" functioning (334, 879-881) even when the effects of diminished cognition are controlled although reports are inconsistent (867).

## Results

A systematic literature review to set criteria (see *Appendix 7*) yielded nine psychosocial and environmental, 30 biological intervention studies with outcomes relevant to psychosis in dementia. Psychosocial and environmental interventions were grouped into four broad categories: therapeutic activities, music, models of care and miscellaneous. Biological interventions were likewise grouped into four categories: cholinesterase inhibitors (ChEIs)/memantine, atypical antipsychotics, antidepressants and other pharmacological treatments.

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## ASSESSMENT

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

- *Exclude potentially reversible causes of the psychotic symptoms*
- *Misinterpretation of reality and/or the intentions of others*
- *Sensory deprivation/impairment or inappropriate sensory stimulation*
- *Illness/infection/delirium/depression*
- *Determine if a recent medical review has been attended*
- *An eye examination may exclude medical conditions which could account for Mr H's sensation of "snakes coming out of his eyes"*
- *Pain/discomfort may not be well managed.*
- *Medication review: interactions, dosage, recently prescribed, adverse effects, compliance*
  *Is pharmacological intervention indicated, possible and/or practical for treatment of psychotic symptoms?*
- *Lack of attention to culturally-relevant needs.*
- *Altered routines, unfamiliar people, reduced time spent with family and community*
- *Unfamiliar/ altered physical environment*
- *Reduced stress threshold*

*Assessing the situation:*

- *Consult with daughters to assist in identifying possible reversible causes for psychotic symptoms and/or underlying reasons for his distress, unknown to the respite centre staff.*
- *Encourage Mr H to express his concerns as far as he is able.*
- *Directly observe what may trigger the behaviours.*
- *Consult Mr H's life history and behavioural patterns for further information with regard to potential triggers for the hallucinations and delusions.*
- *Assess the immediate environment for possible triggers*

**Management of psychotic symptoms**

It is important to rule out a delirium as the reason for psychotic symptoms (for further information see *Module 1*) and to confirm that the claims made by the person with dementia are not actually occurring e.g., their valuables may actually have been stolen. Psychotic symptoms are not always distressing to the person with dementia. It is important for the clinician to determine what the symptoms mean to the individual and if the situation warrants treatment beyond supporting others in the care environment. While evidence of psychotic symptoms should always be investigated for potentially treatable causes, the presence of a *benign* hallucination is typically more distressing for family than for the person with dementia. Education and support for family and/or paid carers may be indicated (241). *Appendix 1* provides suggested questions to facilitate comprehensive behavioural assessment.

By contrast, those with dementia, particularly DLB or PDD, experiencing complex, unpleasant visual hallucinations may benefit from more active treatment. Even when the person with dementia retains insight into the fact that the hallucinations are not part of reality, their distress can be significant. Professional consensus recommends trialling psychosocial interventions, or where indicated in combination with medication, as part of an individualised care plan.

***Psychosocial and environmental interventions***

The nine psychosocial and environmental intervention studies were largely conducted in residential settings and most fell into the music category. All music therapy studies were of moderate quality and the findings were mixed. Two studies showed significant reductions in delusions but not hallucinations in the intervention group (181, 589) and a further study reported a reduction in hallucinations but not delusions (340). Another study found no positive effects for music on either delusional or hallucinatory symptoms (233). Two aromatherapy studies of moderate quality showed that neither massage with Melissa oil nor lavender oil inhalation reduced delusions or hallucinations (357, 358).

The *models of care* and *multicomponent* interventions categories each included one study of moderate quality. *GentleCare*, a multifaceted program which builds a "prosthesis of care" based on the concept that those with dementia are provided with external support to compensate for cognitive and functional losses (432) showed a reduction in both delusions and hallucinations (882). Residents' medications on admission to the program were not reported so improvement in symptoms may not be entirely due to the intervention program. By contrast, a multifaceted day hospital program which combined music, movement, psychodynamic group therapies, sociotherapy and family interventions program showed no significant improvement for psychotic symptoms (436).

While the evidence in support of the psychosocial interventions is not strong, this should not prevent clinicians from considering these interventions on a case-by-case basis (241), where they are beneficial to the individual with dementia, enjoyable and culturally appropriate (276). Psychosis, hallucinations and delusions in persons with dementia can occur as a consequence of many potential antecedents (see *Table 1.2, Module 1* for a list of contributory factors); the identification of triggers or underlying causes will assist in managing the behaviour.

*See Appendix 3 for interventions reported above.*

## STRATEGIES/OUTCOMES

- *Any one of Mr H's numerous comorbid illnesses may be causing discomfort or pain. Limited access to health services and transport within the community can preclude regular medical treatment. A medical review was arranged with the assistance of male family members.*

- *Mr H suffers from visual impairment due to bilateral cataracts which could potentially contribute to his misinterpretation of items in the environment. The feasibility of cataract surgery was a matter for a family case conference.*

- *When family provided relevant details of Mr H's history, it became evident that his past experiences as a member of the stolen generation and his ongoing fear of institutions may provoke anxiety around being taken out of his community for day respite. Community members initially attended the day respite centre with Mr H, for part of the day, to assist in his adjustment to the unfamiliar environment.*

- *English is not Mr H's first language and he had no opportunities for formal education as a child so communication with respite centre staff and other attendees is limited. Visual resources and pictorial language aids were developed and/or found with assistance of community members familiar with Mr H's first language. A language appropriate telephone interpreter was located but attempts to use the service with Mr H were largely unsuccessful.*

- *An older Aboriginal man who is a nearby neighbour to the respite centre was originally from the same community and had some knowledge of Mr H's first language. He was willing to assist with communication when he was available and regularly spend some time "yarning" with Mr H.*

- *Some staff members at the respite centre had little knowledge of dementia and BPSD and they became fearful of Mr H after he spoke of his psychotic symptoms.*

### *Biological Interventions*

Expert consensus guidelines suggest pharmacological interventions should be used concurrently with psychosocial interventions as first-line treatment when psychotic symptoms are very distressing and/or dangerous to the person with dementia or others (277, 883, 884).

Likewise, pharmacological treatment may be necessary when symptoms appear to have a physical or iatrogenic aetiology and are unresponsive to psychosocial interventions (241). A number of RCTs for pharmacological treatment of psychotic symptoms is currently available in the literature. Open-label trials and case studies also provide some support for potential alternatives to antipsychotics.

Primarily used for treating cognitive symptoms in dementia, ChEIs have demonstrated some beneficial effects in the management of psychotic symptoms. One study provided moderate evidence for improvement in delusional and hallucinatory symptoms with donepezil (286). Moderate support also exists for galantamine in reducing hallucinations in DLB (885) and in PDD (836) as well as reducing delusions in AD and VaD (837). Good evidence is provided for rivastigmine (376) and memantine for reduced psychotic symptoms (183, 289).

Atypical antipsychotics have largely replaced typical or traditional antipsychotics as the main treatment of psychosis, hallucinations and delusions in dementia, because of differences in the risk of significant adverse events (278). The evidence for atypical antipsychotics is mixed. Moderate to strong evidence was demonstrated for the efficacy of risperidone in reducing psychotic symptoms (278, 382, 886). Two studies provide strong support for olanzapine. The first found a reduction in delusions but not

> *Education was provided to improve management of clients with dementia.*
> - *The respite centre is located in different Country to Mr H's own, causing him distress when he forgets that he will be returning home later in the day. With a better understanding of dementia, staff at the centre provided Mr H with regular reassurance.*
> - *Limited experience and knowledge of dementia and BPSD within Mr H's extended family and community was increasing his daughters' stress and alienation. A visit to the community was attended to provide education and culturally appropriate information.*
> - *Family assisted the respite centre staff to plan appropriate activities, relevant to Mr H's interests and background.*

hallucinations (367) while the second showed improvements in hostile suspiciousness and total NPI (886). Dosage is important as olanzapine at 5mg daily and 7.5mg daily was more effective than the higher doses of 15mg daily.

Four studies of strong quality found no effect (374, 375, 886, 887) yet two further studies of moderate quality showed reduced psychotic symptoms for quetiapine (279, 472), although doses may have been too low to be effective. A landmark study (888) which compared olanzapine, quetiapine, risperidone and placebo for effectiveness and tolerability found no significant differences between groups in time to discontinuation. Results favoured olanzapine and risperidone with regard to time to discontinuation of treatment due to lack of efficacy but favoured placebo with regard to discontinuation because of side effects; no specific outcomes were reported for psychotic symptoms.

Strong evidence showed reduced delusions on aripiprazole (370, 473) and moderate evidence was reported for amisulpride (373). A case series of five patients receiving blonanserin showed no effect (281). Despite evidence of some benefits, current guidelines do not recommend the long-term use of antipsychotics due to safety concerns. Their use has been associated with further cognitive decline and greater risk of somnolence, extrapyramidal symptoms, abnormal gait, oedema, urinary tract infections, incontinence, falls, cerebrovascular adverse events and mortality (284) (see *Table 2.3, Module 2* for of side effects associated with neuroleptics).

Moderate to strong evidence is demonstrated for the efficacy of the antidepressant citalopram in alleviating psychotic symptoms (382, 889). Other pharmacological agents that have been trialled for the treatment of psychotic symptoms in dementia include tandospirone, dronabinol, Yokukansan (a traditional Asian herbal medicine also known as Yi-Gan San), omega-3 and Ginkgo biloba. Some support was provided for the efficacy of omega-3 supplementation (115) and studies of moderate quality largely showed no support for the use of Yokukansan (299, 476, 477) although one study demonstrated reduced delusions and hallucinations (301). No evidence of effect was shown for tandospirone (474), dronabinol (387) or Ginkgo biloba (478) in the management of psychotic symptoms.

Although no recent studies are available, haloperidol has been used for the management of psychotic symptoms in the past. A higher rate of extrapyramidal side effects and mortality than that of atypical antipsychotics has been demonstrated for haloperidol (890-893). Wherever possible, the use of symptomatic, pharmacological agents, when required for treatment of psychosis, hallucinations and delusions should be time-limited, closely monitored, reviewed, reduced and/or discontinued when indicated and prescribed with appropriate psychosocial interventions. As always, the potential benefits to the person with

dementia must be weighed against the side effects of pharmacological treatments (see *Table 2.3, Module 2* for side effects associated with neuroleptics). Further, when psychotic symptoms occur with other BPSD, medication which may also address other symptoms should be considered in an attempt to avoid polypharmacy (465).

Traditionally used as treatment for treatment-resistant or psychotic depression, mania or catatonia, electroconvulsive therapy (ECT) has recently been trialled in persons with dementia and BPSD. A case series showed complete remission in three patients presenting with psychotic symptoms after receiving bitemporal ECT (305). As the case series did not include a control or comparison group, placebo effects are unknown and findings must be interpreted with caution. Moreover, the individual risk/benefit ratio should be considered carefully before proceeding with ECT; while only one person in this case series reported mild cognitive decline the literature suggests that ECT is associated with retrograde and anterograde memory impairment as well as a slightly increased risk of death (306).

*See Appendix 4 for interventions reported above.*

**Limitations**

While current guidelines recommend using psychosocial interventions as a first-line approach to the management of psychotic symptoms in dementia, research studies in this area are limited in number and quality. Contradictory findings are evident possibly due to variance in psychotic symptoms across dementia subtypes. No sustainability of effects is evident in the only three studies which provided data on follow-up assessment up to four weeks after interventions were ceased (181, 233, 589).

**Conclusions**

In summary, psychotic symptoms in dementia have significant consequences for persons with dementia and their carers. Current expert consensus guidelines recommend the use of multidisciplinary, individualised and multifaceted care including psychosocial interventions as a first-line approach and short-term pharmacological intervention only where indicated. While quality evidence is limited, the special care protocol *GentleCare* (a nonpharmacological, prosthetic approach within a dementia unit) provides the best evidence for psychosocial management of psychotic symptoms. Where pharmacological treatment is necessary, ChEIs, memantine and citalopram may provide safer alternatives to antipsychotics although these may be indicated in the short term when psychotic symptoms are severe or causing distress provided informed consent has been obtained and potential side effects have been discussed.

# MODULE 11: Vocally disruptive behaviour

**Key messages**

- Differing definitions of vocally disruptive behaviour (VDB) yield varying prevalence rates and shape intervention studies and results.
- VDB causes distress within the RACF or home environment.
- Three key areas are suggested as causes for VDB and targets for intervention:
  - Discomfort (physical and or psychological/social isolation)
  - Operant conditioning of behaviour due to the increase in attention it attracts
  - Reduced-stress thresholds due to cognitive impairment
- The inclusion of "disruptive" in the definition is based on the perception of others.
- Therapeutic recreation provides the best evidence for the psychosocial management of VDB.
- Where pharmacological agents are indicated, the best available evidence is for risperidone however, the use of atypical antipsychotics is not recommended in this group.
- Evidence for benefits of cholinesterase inhibitors is limited.
- McMinn and Draper provide a practice guideline for the management of VDB, based on factors thought to contribute to VDB (see *Figure 11.1*).

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**Before you move on, have the following been done?**

1. A *risk assessment* to identity any immediate risks to the person with dementia or others within the care environment

2. A *comprehensive assessment* that is person centred and considers the following key aspects:
   - Referrer's description of behaviour
   - The behaviour
   - The person
   - The carer
   - The care environment

3. Any reversible causes of the behaviour(s) excluded and/or treated

(See *Module 1* for further details)

## Vocally disruptive behaviour Summary

**What is vocally disruptive behaviour and what does it look like in dementia?**
- Vocally disruptive behaviour (VDB) is also referred to as screaming and verbal agitation.
- VDB can be described as any vocalisation that causes stress within the person's environment. VDB can be intermittent or incessant and include vocalisations such as singing, screaming, abusive or verbally aggressive comments, perseveration, repetitive questioning, groaning and sighing.
- Theories propose that unmet needs, operant conditioning, environmental vulnerability and reduced stress-threshold in persons with dementia contribute to VDB.

**Causes of vocally disruptive behaviour**
Causes include physical and/or psychological discomfort or social isolation, combined with operant learning, in the context of reduced stress thresholds due to cognitive impairment.

**Differential diagnosis**
- Symptoms of VDB overlap with other agitated behaviours in dementia.
- VDB is disruptive whether or not the person with dementia has an awareness of their needs.
- The inclusion of "disruptive" in the definition is based on the perception of others.
- The same behaviour may be disruptive in one context and not in another.

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

**Prevalence of vocally disruptive behaviour**
Different definitions of VDB yield varying prevalence rates based on how inclusive they are and the setting e.g. residential care versus home. The prevalence of common VDB in persons with dementia include:
- cursing and/or verbal aggression from 10% to 48%
- repetitious sentences/questions from 3% to 31.1%
- screaming from 10% to 15%

**Effects of vocally disruptive behaviour**
VDB causes significant stress and/or distress within the RACF or home environment. It has been shown to cause concern, frustration, anxiety, anger and/or complaints from care staff, visitors, other residents and neighbours.

**Management of vocally disruptive behaviours**

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

*Psychosocial and environmental*
- The music interventions group included the greatest number of studies followed by behavioural/cognitive-behavioural interventions and models of care.
- The potential causes of the VDB may provide clues to the appropriate intervention.
- Therapeutic recreation provides the best evidence for psychosocial management.
- The need for a multidisciplinary, individualised and multifaceted approach is stressed.

*Biological interventions*
- The evidence for pharmacological treatments for VDB overall is limited.
- The best evidence is for risperidone, however, current guidelines recommend against the use of atypical antipsychotics in this group.
- Limited evidence for antidepressants and ChEIs is presented.

**Limitations**
- Numerous definitions of VDB mean differing prevalence rates.
- The high prevalence of case studies in the literature limits the evidence available.

**Conclusions**
- Recognised expert guidelines and reports on the outcomes of interventions are limited.
- Therapeutic activities provide the best evidence for psychosocial management.
- Results to date, for pharmacotherapy to treat VDB as the primary outcome, are disappointing. Where pharmacological treatment is indicated, risperidone provides the best evidence however, atypical antipsychotics are not recommended for safety reasons.
- Limited evidence for the use of galantamine and donepezil has been reported.

McMinn and Draper provide a practice guideline for the management of VDB, based on factors thought to contribute to VDB including discomfort, reduced-stress thresholds and operant conditioning (see *Figure 11.1*).

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

Vocally disruptive behaviour (VDB), also referred to as screaming (894) or verbal agitation (895), is commonly associated with dementia. It can loosely be described as any vocalisation (both verbal and non-verbal) that causes stress within the person's environment (896). Examples of VDB include singing, screaming, abusive or verbally aggressive comments, perseveration, repetitive questioning, groaning and sighing. VDB can be intermittent or incessant, with potential peak periods in the afternoon (897), possibly related to sundowning. The following classification of VDB has been proposed (898):

- Noise-making which appears purposeless and perseverative
- Noise-making which is a response to the environment
- Noise making which appears directed towards eliciting a response from the environment
- Chatterbox noise-making
- Noise making in the context of deafness
- Other noise making

**Causes of vocally disruptive behaviour**

It is proposed that VDB is caused by physical and/or psychological discomfort or social isolation, combined with operant learning, in the context of reduced stress thresholds due to cognitive impairment (899). This has been supported by the findings that depression, pain, discomfort, impairment in ADLs, mobility problems, impaired expressive communication skills, poor quality of relationships, reduced social interaction and cognitive impairment are associated with VDB (897, 900-902). VDB can also occur in response to visual and/or auditory hallucinations.

**Differential diagnosis**

Symptoms of VDB overlap with other agitated behaviours in dementia. Rather than differentiating VDB from other BPSD, it may be more appropriate to differentiate between the various factors contributing to the VDB. VDB is disruptive regardless of whether the person with dementia has an awareness of their needs or not. The potential causes of the VDB may provide clues to the appropriate choice of intervention. The inclusion of "disruptive" in the definition is based on the perception of others (899, 903) and is not necessarily inherent to the behaviour itself. It has been suggested that the situation may be compared with labelling the cries of a hungry

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

baby as "disruptive" (903). Further, the same behaviour may be disruptive in one context and not in another.

**Measuring vocally disruptive behaviour**

Scales specifically measuring VDB are limited:

- Whereas the original Neuropsychiatric Inventory (NPI, 530) did not include a subscale relevant to VDB, the revised NPI-Clinician (**NPI-C**, 7) includes an additional subscale for measuring aberrant vocalizations. This subscale contains 11 items that quantify vocalisations around making strange noises, yelling, repetitive requests, abusive language, verbally sexual advances, muttering to oneself, nonsensical conversation with others, angry noises and verbally manipulative requests.
- The Screaming Behavioral Mapping Instrument (**SBMI**) records nine types of VDB including: shouting, screaming or howling; constant requests for attention; repeating words; complaining or inappropriate verbalisations; cursing; verbal aggression; nonsense talk; hallucinations (talking to someone who is not there); and other disruptive verbal behaviours. If vocalisations manifest more than five times in the three-minute observation period, a rating of constant or extreme is recorded (904).
- The Typology of Vocalizations (**TOV**) scale measures the following criteria, rated on a five-point Likert scale ranging from never to constant or nearly constant (905):
    - Verbal (e.g. singing or yelling) or non-verbal (e.g. groaning or howling)
    - Meaning/reason/content (e.g. pain, hallucinations, ADL requests)
    - Timing (constant, random, apparent pattern)
    - Level of disruptiveness

The majority of scales measuring VDB include it as a subset of BPSD or agitation. The following are recommended (1):

- The Cohen-Mansfield Agitation Inventory (**CMAI**) includes six items relating to VDB: making strange noises; cursing or verbal aggression; screaming; repetitious sentences/questions; complaining; and constant requests for attention (258).
- The Pittsburgh Agitation Scale (**PAS**) includes a category which measures aberrant vocalisation on a scale from not present to most disruptive, typically based on observations over four to eight hours. The intensity and disruptiveness of the vocalisation within the environment, as well as the effort required to redirect the behaviour, determines the rating (320).

**Prevalence**

Different definitions of VDB yield varying prevalence rates based on how inclusive they are, and some studies focus only on the prevalence of specific types of VDB such as screaming. The instrument used to measure VDB influences prevalence rates, as does the target population. It is therefore difficult to estimate rates of VDB overall. The reported frequencies of various types of VDB in dementia populations are listed below. Increased age and female gender have also been associated with VDB (901).

*Table 11.1 Types and frequency of VDB*

| TYPES OF VDB | FREQUENCY |
|---|---|
| Complaining | 0% – 24.8% (906, 907) |
| Cursing and/or verbal aggression | 10% – 48% (906-909) |
| Fearful comments | 34% (910) |
| Negative comments | 3.8% (258) |
| Repetitious sentences/questions | 3% – 31.1% (906, 907) |
| Requests for attention/constant requests for attention | 0% – 36.2% (258, 906, 907) |
| Screaming | 10% – 15% (906, 907) |
| Strange or nonspecific vocalisations | 12.5% – 44% (258, 906, 907, 910) |

*Note: Some reported frequencies refer only to VDB manifested more than once per week.*

## Effects of vocally disruptive behaviour

By definition, VDB causes stress and/or distress within the RACF or home environment. These can manifest as concern, frustration, anxiety, anger and/or complaints from nursing staff, visitors, other residents and neighbours. Nursing staff may express a desire to distance themselves from residents exhibiting VDB (897). Further, the person with dementia and VDB may become victim to verbal and/or physical aggression from other residents who have reduced tolerance for the behaviour.

## Results

A systematic literature review to set criteria (see *Appendix 7*) yielded 22 psychosocial and environmental and 14 biological intervention studies with outcomes relevant to VDB in dementia. Psychosocial and environmental interventions were grouped into broad categories: music, multi-sensory, therapeutic activities and miscellaneous. Biological interventions were also grouped: cholinesterase inhibitors (ChEIs), memantine, antipsychotics – typical and atypical, antidepressants and other medications.

## Management of vocally disruptive behaviour

The initial step for the clinician in managing VDB is to attempt to understand the underlying factors provoking the behaviour, where possible. Where this is not achievable, management may involve minimising distress to the person with dementia and those around them. *Appendix 1* provides suggested questions to facilitate comprehensive behavioural assessment. The following theories may provide some insight into potentially reversible precipitants.

### *Psychosocial and environmental interventions*

Psychosocial and environmental intervention trials were primarily conducted in residential settings. The music category incorporated the greatest number of studies followed by behavioural/cognitive-behavioural interventions and models of care. The longest follow-up reported was nine weeks after cessation of the intervention with no evidence of reduced VDB at that time point (911). Theories propose that unmet needs, operant conditioning, environmental vulnerability and reduced stress-threshold in persons with dementia contribute to VDB (899). Psychosocial intervention studies tend to focus on these areas (609):

*1. Meeting unmet needs:*

- Pain
- Discomfort during routine care such as bathing, feeding or toileting
- Social isolation
- Boredom
- Low self-esteem
- Communication difficulties

The relationship between VDB and pain and/or physical discomfort has been demonstrated in studies showing reduced VDB when pain was minimised, comfort increased, opportunities for social interaction increased and/or attention or stimulation provided (349, 366, 904, 911-915). These studies were of moderate quality and largely come under the classification of models of care. Studies which conducted follow-up reported that benefits were not maintained (904, 911). Another study of moderate quality in the models of care category did not support this premise (916).

*2. Operant conditioning, learning and behavioural interventions:*

- VDB reinforced by increased attention
- Repetitive questioning related to memory deficits (i.e. forgetting the answer that has been provided previously)

The theory that VDB is inadvertently reinforced by the increased attention it attracts has been little researched. Case studies from the behavioural/cognitive-

| **ASSESSMENT** |
| --- |
| *In order to reduce the presenting behaviours, potentially contributing factors must be identified:*<br><br>• *Unreported pain/discomfort/infection*<br>• *Medication review: interactions, dosage, adverse effects*<br>• *Overstimulation (noise, people, activities)*<br>• *Altered routines, new staff, particular staff and/or family members prompting anxiety/distress*<br>• *Unfamiliar/altered/deprived physical environment*<br>• *Identification of potentially unmet needs*<br>• *Reduced stress threshold*<br><br>*Assessing the situation:*<br><br>• *Encourage Miss T to indicate her needs as far as she is able*<br>• *Directly observe what may trigger the behaviour*<br>• *Ask staff who know Miss T well if they can assist in identifying her needs or possible reasons for her VDB*<br>• *Consult Miss T's life history as well as behaviour and clinical charts for further information with regard to triggers for the VDB*<br>• *Assess the immediate environment for possible triggers*<br>• *Consult family members to identify potential triggers for VDB that are unknown to staff and not previously documented* |

behavioural interventions category have demonstrated that non-contingent attention and touch reinforcement for non-VDB behaviour have reduced VDB (917, 918). Further, there is moderate evidence for cued recall using index cards and message boards to manage repetitive questioning (919). A case study reporting cued recall with classical and operant conditioning (i.e. with a loud alarm or reinforcing quiet periods) was unsuccessful and thus did not support this premise (920).

*3. Environmental vulnerability and reduced stress-threshold interventions*

- Relaxation
- Reducing noise
- Impoverished environment
- Environment inappropriate for needs

The music, sensory and touch categories include studies of moderate to strong quality which are relevant here. Attempts at promoting relaxation through aromatherapy using lavender oil (357) as well as group singing and music therapy with and without hand massage were found to be effective (344, 921) or partially effective (922) in reducing VDB. Two therapeutic touch studies of moderate and strong quality showed no benefit (268, 352) and two further music studies of moderate quality found no reduction in VDB (343, 346).

Moderate support for an outdoor activity program has been demonstrated (832). A case study of environmental changes in combination with pharmacological and dental treatments, showed reduced VDB (914) although it was not possible to determine if changes to the environment improved VDB independent of the effects of other treatments.

*See Appendix 3 for interventions reported above.*

### Biological interventions

The evidence for pharmacological treatments for VDB is limited and primarily relies on case studies. The best evidence is for risperidone, which was found to reduce VDB in a high quality combined analysis of three double-blind RCTs (923) and in another high-quality double-blind RCT (369).

A further study of modest quality, and two case studies, also reported improvements in VDB (924, 925). In spite of the evidence

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**STRATEGIES/OUTCOMES**

- *Miss T has a long-term history of arthritis. Although she has been prescribed prn analgesia, medication charts indicated that Miss T currently receives pain relief irregularly and less frequently than when she was able to request it.*
- *Some RACF staff members had little knowledge of dementia and were unaware that pain can be a trigger for BPSD.*
- *A pain assessment indicated that Miss T may be experiencing frequent discomfort and/or pain, particularly in relation to personal care activities. Her analgesic medication was reviewed and non-pharmacological pain relief interventions, such as gentle heat, implemented.*
- *Miss T's shower was rescheduled to occur 30 mins after the morning dose of analgesia was administered.*
- *Continence aids were reviewed to source products that may reduce Miss T's need for frequent changes but still protect her skin.*
- *Resident room allocation throughout the RACF was reassessed and Miss T was relocated to a room where her VDB was less disruptive to other residents.*
- *Behavioural observation charts indicated that Miss T responded positively to gentle touching and stroking. A NH volunteer was trained to provide appropriate touch several times weekly.*
- *When Miss T's family were asked, they reported that they had felt anxious about touching Miss T, helpless to help her and distressed when they visited. Family members were trained and encouraged to gently touch or stroke Miss T's hands and arms.*
- *Willing family members subsequently developed an informal roster around the volunteer's visits to provide Miss T with maximum benefit. They reported that they now felt their visits were purposeful.*
- *Miss T's favourite music and aromatherapy were also trialled with mixed results.*
- *Overall, Miss T's VDB was substantially reduced and when she did call out, staff felt better able to provide strategies that may afford her some comfort.*

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for efficacy, current guidelines do not recommend the use of atypical antipsychotics in this group due to safety concerns (277). A study of moderate quality found that neither haloperidol nor oxazepam effectively reduced VDB (926).

The evidence for antidepressants is very limited. Citalopram combined with non-pharmacological interventions was found to reduce VDB in a case study (914), while an open pilot study of moderate quality showed no benefit (927). Additionally, trazodone with a L-tryptophan vitamin supplement (928) was found to be effective in a case study, although it was not possible to determine if the treatment effect occurred independent of the supplement.

Primarily used for treating cognitive symptoms in dementia, ChEIs may play a role in the management of VDB, although similar to other pharmacological treatments, the evidence is mixed. There was strong evidence showing positive effects for donepezil in reducing nonaggressive VDB; however, no benefit was found for aggressive VDB in the same study (285). Positive results but moderate evidence have been demonstrated  for galantamine (929).

Divalproex sodium (sodium valproate, Epilim) demonstrated initial improvements in VDB which were not maintained at 6 weeks (293), and positive results with moderate evidence are reported for xanomeline, a selective muscarinic receptor agonist which is still in development (930, 931).

Wherever possible, the use of symptomatic, pharmacological agents, when required for treatment of VDB, should be time limited, closely monitored, reviewed, reduced and/or discontinued when indicated, and prescribed alongside appropriate psychosocial interventions. As always, the potential benefits to the person with dementia must be weighed against the side effects of pharmacological treatments (see *Table 2.3, Module 2* for side effects associated with neuroleptics).

*See Appendix 4 for interventions reported above.*

**Limitations**
The many and varied definitions of VDB yield varying prevalence rates and shape how VDB is measured and treated. The different instruments used to measure VDB also affect evaluation of treatment interventions, particularly if the instrument is very limited in its measurement. Although evidence for interventions based solely on case studies cannot be considered robust, individually targeted interventions should not be disregarded.

**Conclusions**
If discomfort, reduced-stress thresholds and operant conditioning contribute to VDB, interventions focusing on these elements will likely be the most successful in reducing this disruptive behaviour. McMinn and Draper (896) suggest an approach where these factors are taken into account (*Figure 11.1*). Assessment of the person with dementia with the Typology of Vocalisation scale and a medical evaluation are recommended to determine possible aetiologies for the VDB (e.g. pain, depression, environmental stressors). An individualised care plan is then implemented based on treatment strategies that target each

of the key areas where relevant. Techniques with some (limited) evidence of benefit such as hand massage, music and operant conditioning may be trialled.

Additionally, the definition of VDB as being disruptive to others is perception-based (899, 903). Behaviours are not necessarily inherently disruptive and where behaviours are not harmful to self or others, not receptive to intervention and no specific underlying cause can be identified, changing the perceptions and understanding of VDB in others may be beneficial. Further, disruption can be reduced by changing the immediate environment of the person with VDB. Transferring them to an area where she or he may not be as disruptive, such as an appropriate garden or a soundproof room, may give others some relief. Using this strategy, supervision must be maintained, and the ethical question of isolating the person requires careful consideration in this situation.

In summary, various types of VDB are common in dementia, with significant and disruptive consequences. Recognised expert guidelines are limited in the area of managing VDB. Reports on the outcomes of interventions are limited in number and quality. Therapeutic recreation provides the best evidence for psychosocial management. The need for a multidisciplinary, individualised and multifaceted approach is stressed. Results to date for pharmacotherapy to treat VDB as the primary outcome are disappointing. Where pharmacological treatment is indicated, trials of risperidone provide the best evidence; however, current guidelines recommend against the use of atypical antipsychotics for VDB not underpinned by psychosis. Limited evidence for galantamine and donepezil in the management of VDB in dementia has been reported.

*Figure 11.1 Practice Guidelines for Vocally Disruptive Behaviour in persons with dementia. Additional information referred to in this figure can be obtained from McMinn and Draper (896). Reprinted by permission of the publisher Taylor & Francis Ltd, http://www.tandf.co.uk/journals*
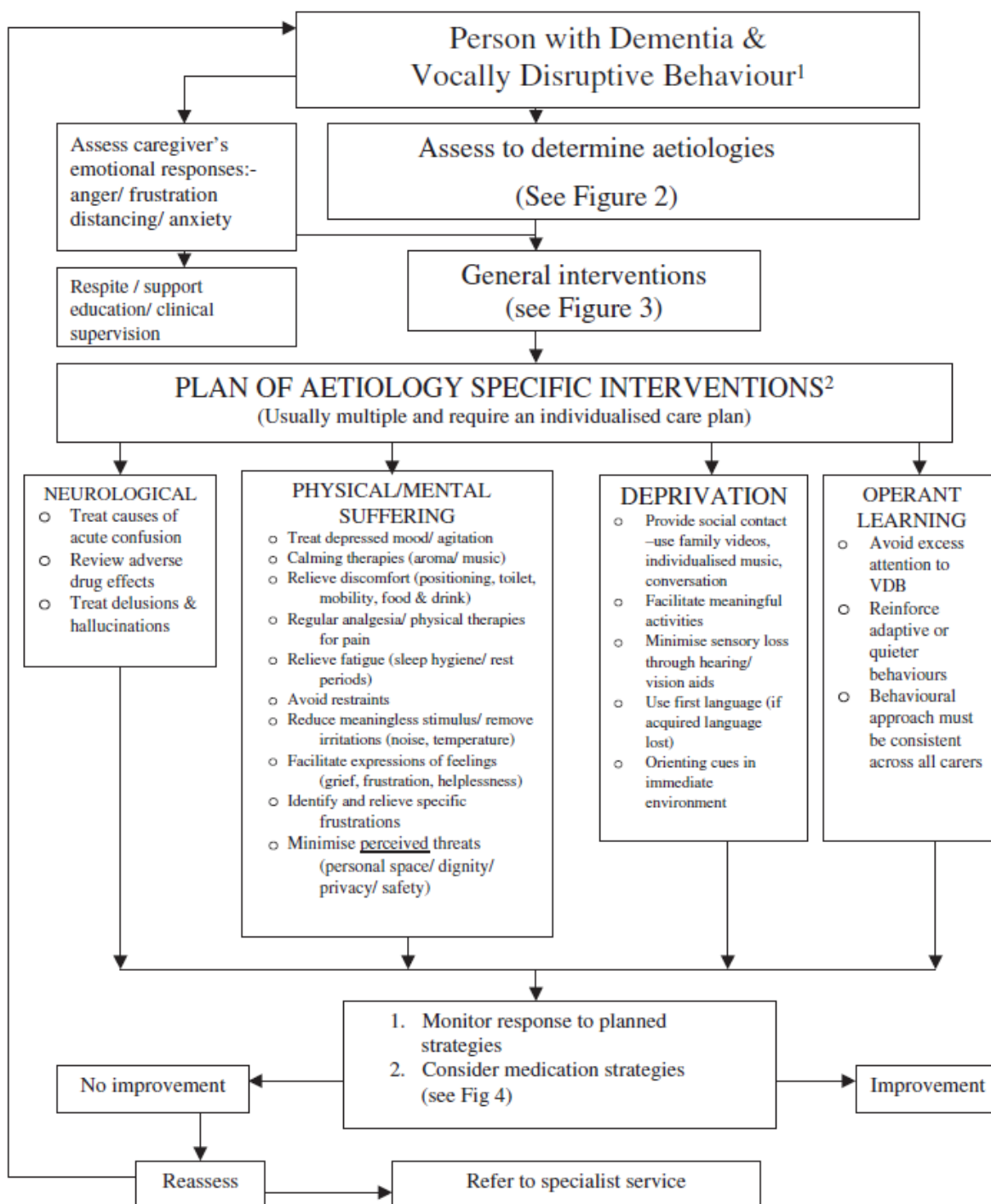
# MODULE 12: Wandering

## Key messages

- Wandering can be one of the most challenging and problematic co-morbid behaviours in dementia.
- Consensus on a unifying definition has not been reached, although an operational definition proposes that wandering occurs over time and space and includes four patterns of ambulation.
- Wandering behaviours have been classified as classic, moderate and subclinical, largely based on the duration and rate.
- Restlessness and a physical, non-aggressive form of agitation are used interchangeably to refer to wandering although these are overlapping, but not equivalent, phenomena.
- Prevalence rates for wandering in dementia reportedly range from 12.3% to 63%.
- Adverse effects of wandering are numerous. Absconding and becoming lost associated with wandering can have severe negative consequences including injury and death.
- By contrast, independent but safe wandering can potentially have positive effects.
- The crucial task for the clinician is to understand what the wandering means for the person although this can be difficult to determine.
- Some evidence for psychosocial interventions which are cost effective and simple to implement is provided by the environmental interventions, sensory interventions and touch therapies categories.
- The effectiveness of exercise and music studies lends initial support for their use.
- The use of chemical restraint by medication is not recommended; however, treating underlying depression or pain should be considered.

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**Before you move on, have the following been done?**

1. A *risk assessment* to identity any immediate risks to the person with dementia or others within the care environment

2. A *comprehensive assessment* that is person centred and considers the following key aspects:
   - Referrer's description of behaviour
   - The behaviour
   - The person
   - The carer
   - The care environment

3. Any reversible causes of the behaviour(s) excluded and/or treated

(See *Module 1* for further details)

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**Wandering Summary**

**What are wandering behaviours and what do they look like in dementia?**
The construct of wandering has been used to encapsulate a range of observable motor behaviours. An operational definition based on empirical study of behaviour in RACF residents with dementia proposes that wandering can manifest in the following patterns:
- Lapping - locomotion which is circular
- Pacing - locomotion back and forth between two points
- Random - locomotion without a direct path and with multiple directional changes
- Direct - locomotion from a point to a destination without diversion

A descriptive typology of wandering as opposed to a single definition has also been outlined:
- trailing
- pottering
- aimless walking
- increased motor activity
- inappropriate walking
- appropriate but excessive walking
- attempts to leave place of residence
- being brought back home
- night-time walking

**Causes of wandering**
Wandering has different meanings and causes for each individual. It may be:
- looking for a loved one
- a habitual pattern of activity
- a reaction to medication
- a symptom of depression
- escaping from a perceived threat
- intrinsic to dementia-related brain pathology
- a wish to return to a familiar environment such as the person's home
- a response to pain, infection or bodily discomfort (such as constipation)

**Differential diagnosis**
Wandering is often subsumed within the syndromes of agitation and restlessness. Restlessness and a physical, non-aggressive form of agitation are used interchangeably to refer to wandering although these are overlapping, but not equivalent, phenomena.

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

**Prevalence of wandering behaviours**
Prevalence rates for wandering reportedly range from 12.3% to 63%. Wandering, in the form of restlessness, has been linked to side-effects of psychotropic medications, particularly akathisia with antipsychotics. The rate and duration of wandering increase as cognition declines but then subsides in late-stage dementia.

**Effects of wandering behaviours**

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

**Management interventions**

The first step is to understand the person and what underpins the behaviour. Clearly, addressing the cause of the wandering is crucial, although finding the cause is not always possible. It is important to identify the significant aspects of the behaviour including the issues for the person with dementia versus the issues for carers and/or staff.

*Psychosocial and environmental interventions*

- The majority of studies fell within the environmental interventions category.
- Subjective barriers generally involve visual manipulation of the environment to reduce exiting. Moderate support is provided for the effectiveness of two dimensional grid patterns and the use of mirrors and modest support for camouflage and concealment. However, this has not been supported by further research in more recent years.
- Most studies reported positive results or a trend toward reduced wandering but the quality of the evidence varies and reports of sustainability are extremely limited.
- Reduction in wandering has been associated with increased lighting, variations in sound levels, proximity to others, addressing emotional needs and underlying distress as well as positive social interaction. Published research is lacking in these areas.
- Environmental ambiance in NHs and assisted-living facilities has been shown to be a more robust predictor of wandering behaviours than MMSE scores.

*Biological interventions*

- One RCT provided strong evidence for a reduction in wandering behaviours with antipsychotic medication however, expert consensus recommends against their use.
- Pharmacotherapy for underlying depression or pain may be helpful where this results in wandering in the form of motor restlessness.

**Limitations**

Wandering is multifaceted and most studies focussing on this behaviour have been descriptive and exploratory in nature because 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 the management of wandering.

**Conclusions**

The use of chemical restraint by medication is not recommended, however treating underlying depression or pain should be considered. Some evidence for psychosocial interventions which are cost effective and simple to implement is outlined. While benefits appear to be immediate, it is not possible to determine whether these are maintained. The effectiveness of exercise and music studies lends initial support for their use.

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

Wandering can be one of the most challenging and problematic co-morbid behaviours in dementia. Researchers and clinicians have failed to reach a consensus on a unifying definition (932, 933) although the construct has been used to encapsulate a range of observable motor behaviours (934). An operational definition has been proposed as a move toward aiding clinical recognition, research validity and the standardisation of language in relation to wandering (935). According to this definition, wandering occurs over time and space and can manifest in the following patterns of ambulation:

- Lapping - locomotion which is circular
- Pacing - locomotion back and forth between two points
- Random - locomotion without a direct path and with multiple directional changes
- Direct - locomotion from a point to a destination without diversion (also termed non-wandering because no deviation occurs between point A and point B).

Additionally, wandering behaviours have been classified into three types: classic, moderate and subclinical, largely based on variations in duration and rate over the course of daytime hours (936). Classic wanderers exhibited the most wandering behaviours according to rate and duration; moderate wanderers exhibited noticeably lower rates and duration than classic wanderers and subclinical wanderers exhibited sporadic, low levels of wandering (263).

A clinical definition of wandering has been proposed (937) to identify associated consequences of the behaviour. Wandering is defined as "repetitive locomotion that makes one susceptible to harm due to its incongruence with boundaries and obstacles which may culminate in exiting, elopement and/or becoming lost". Alternately, a descriptive typology of wandering as opposed to a single definition has been outlined (938):

- increased motor activity
- trailing
- pottering
- aimless walking
- inappropriate walking
- appropriate but excessive walking
- attempts to leave home or current place of residence
- being brought back home
- night-time walking

Various anecdotal explanations have been suggested for the different patterns of wandering, some of which are related to cognitive deterioration. Changes to the amygdala may be associated with disrupted wayfinding which results in pottering and becoming lost. Disruption of diurnal rhythm is related to increased walking at night (939), and searching for a loved one frequently prompts attempts to leave home or an RACF. The aetiology of wandering has not been well conceptualised, however biomedical, psychosocial and person-environment factors are proposed as contributing factors (933, 940). Wandering is a multifaceted behaviour which can vary between and within individuals in its expression (936, 941).

## Causes of wandering behaviours

Wandering has different meanings and causes for each individual. It may be:

- looking for a loved one or a person they recognise (942)
- a wish to return to a familiar environment such as the person's home (943)
- escaping from a perceived prison or persecution
- misperceiving incidents in the environment as frightening and needing to flee
- a habitual pattern of activity (944)
- an expression of stress or anxiety
- a reaction to medication (303)
- a symptom of depression (304)
- a response to pain, infection or bodily discomfort (such as constipation) (303, 304, 945)
- intrinsic to dementia-related brain pathology (939)
- setting out with the intention of going to a destination or completing an action but becoming distracted and forgetting what the purpose was

Attempting to understand the cause of the wandering will enhance the clinician's ability to reduce the behaviour.

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### PRESENTATION

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

*Family and community members have been supporting Mr E in the family home with the assistance of an Aboriginal-specific community service and this arrangement has been working well until recently. On three occasions in the past month Mr E has been found after dark some distance from home, underdressed for the weather and distressed. On the most recent occasion, a concerned passer-by alerted police after Mr E was unable to provide his address or contact details for his family. When the police approached Mr E he became uncooperative and verbally aggressive. Police ultimately located Mr E's daughter who collected him from the local police station to take him home.*

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### Differential diagnosis

Presentation of wandering is not always consistent in those with dementia, and the behaviour is often subsumed within the syndromes of agitation and restlessness (946). Restlessness and a physical, non-aggressive form of agitation have been used interchangeably to refer to disordered motor behaviours or wandering. Confusion exists regarding the features that differentiate these BPSD (947). It has also been suggested that anxiety (854) and low mood (948) may underpin some wandering behaviours.

### Measuring wandering behaviours

Although wandering in dementia is differentiated by severity rate, duration and frequency, no standardised measure currently exists. The Neuropsychiatric Inventory (NPI) (6) and the Cohen-Mansfield Agitation Inventory (CMAI) (258) include items pertaining to wandering and have been widely used and recommended for research and clinical practise (1) when looking at behaviours that may be viewed as expressions of agitation. The Revised

Algase Wandering Scale (RAWS) for long-term care (LTC) and the community version (CV) (949, 950) are the only assessment tools specifically designed to measure wandering and capture the multifaceted nature of the behaviour.

- The **RAWS-LTC** is a 19-item scale which was designed for formal carers to rate wandering behaviour according to three subscales: persistent walking, spatial disorientation and eloping. Scores range from never to always (951).

- The **RAWS-CV** includes five subscales with a total of 37 items: persistent walking, spatial disorientation, eloping behaviours, routinised walking and negative outcomes. Respondents rate observations of the behaviour from never to always as they occurred in the preceding week (951). The RAWS is a reliable and valid tool that has been widely used for research purposes to identify and quantify the level of wandering behaviour, however further evaluation is indicated to extend its clinical applicability (950).

- The aberrant motor subscale of the **NPI** includes a question on pacing (6) and is completed during an interview with the carer, in which they rate the frequency and severity of the person with dementia's motor behaviour as well as their own subsequent distress. The reliability and validity of the NPI overall is well established (178). The NPI-Clinician (**NPI-C**) (7) version has added an additional question relevant to wandering in the revised aberrant motor disturbance subscale.

- The **CMAI** is a 29-question, three-factor carer questionnaire that assesses the frequency of a given behaviour as observed in the preceding fortnight (258). The physically non-aggressive subscale of the CMAI includes an item relevant to pacing and aimless wandering. Findings from Algase and colleagues, however, indicate that physically non-aggressive behaviours and wandering are overlapping, but not equivalent, phenomena (947).

**Prevalence of wandering behaviours**

The prevalence of wandering in dementia is difficult to assess due to its imprecise definition and the variety of measurement tools used for assessment. Accordingly, the literature reports wide disparity in prevalence rates for wandering in those with dementia in residential settings ranging from 12.3% to 63% (940, 952). Similar rates have been reported in community based samples (953).

Wandering is reportedly more prevalent in men and in younger persons with dementia (944). Those with AD are more likely to wander than those with VaD (954). Persons with FTD reportedly have a greater tendency to pacing and lapping behaviours whereas those with AD are more inclined to engage in a higher proportion of random locomotion (934). Wandering in the form of restlessness, with a compelling need for movement or pacing, has been linked to side-effects of psychotropic medications, particularly akathisia with antipsychotics (766, 955).

The occurrence of wandering is associated with greater cognitive impairment (956) and it has been demonstrated that the rate and duration of wandering increases as cognition declines, but the behaviours then subside in late-stage dementia (936, 957). Frequency of wandering has been linked to greater independence in mobility and dependence in those ADLs associated with hygiene (952, 953). These findings are consistent with the Need-

driven Dementia-compromised Behaviour (NDB) model which postulates that cognitive impairment and mobility directly impact on the expression of wandering (945, 957).

**Effects of wandering behaviours**
Wandering is a challenging and dangerous behavioural problem that has been identified as a salient factor for earlier entry into residential care, due to increased carer burden and anxiety around the associated risks (958, 959). Distress in the person with dementia can likewise be increased when they are barred by locked doors and/or agitated by alarms or surveillance devices (960). Adverse effects of wandering include falls and subsequent injury and/or fractures, (961, 962) weight loss, resident to resident violence, the use of physical restraint and social isolation (263, 945).

Absconding (or elopement) and becoming lost pose some of the most significant safety risks, at times resulting in death (963, 964). Absconding is more likely to occur around the time of meals and/or staff changeover (943) whereas exit-seeking behaviour can be precipitated by the person with dementia experiencing physical and/or emotional discomfort (942). The person who is attempting to wander will likely incite interest from others with dementia, through their enthusiasm and determination to leave. This may prompt additional restlessness and attempts to abscond, in other residents. Wandering behaviours in persons with dementia can occur as a consequence of many potential antecedents (see *Table 1.2, Module 1* for a list of contributory factors).

Conversely, wandering can have positive effects through exercise (936, 965) by improving circulation and oxygenation. Further, independent but safe wandering can potentially be therapeutic in that it reportedly improves sense of wellbeing and agency, stimulates appetite, relieves boredom, improves mood as well as encouraging feelings of empowerment and control (960).

While safe walking within the least restrictive environment has been the goal

| ***ASSESSMENT*** |
| --- |
| *In order to reduce the presenting behaviour, potentially contributing factors must be identified:* <ul><li>*Investigate possible pain/discomfort and/or illness/infection/constipation*</li><li>*Medication review: interactions, dosage, recent changes, adverse effects*</li><li>*Assess the immediate environment for potential triggers*</li><li>*Exclude underlying depression*</li><li>*Lack of stimulation/boredom*</li><li>*Changes to the physical environment*</li><li>*Searching for family members or childhood home environment*</li></ul> *Assessing the situation* <ul><li>*Encourage Mr E to express his needs and concerns as far as he is able*</li><li>*Arrange medical and pharmacological review to exclude potentially reversible contributing factors*</li><li>*Directly observe and document Mr E's behaviour preceding wandering incidents and on the occasions when he made no attempts to leave home*</li><li>*Ask community workers who have become familiar with Mr E if they have identified situations which provoke his wandering behaviours*</li><li>*Consult Mr E's life history for further information*</li><li>*Consult family members to identify possible strategies that may discourage Mr E's wandering attempts*</li></ul> |

of management strategies for many years, recent times have seen a shift to promote greater independent mobilisation in the presence of impaired wayfinding (365). It has been

suggested that interventions to reduce wandering should only be implemented when the wandering disrupts the person with dementia's fluid and/or food intake, causes physical exhaustion and/or exacerbates their discomfort (966), or when safety is an issue.

**Technologically mediated devices**

In response to the risks associated with wandering, devices to disguise exits and a range of technological devices are available to alert carers when persons with dementia attempt to exit. Such devices have been developed for use in the community and RACFs. The implementation of GPS technology and monitoring systems has helped to reduce exit-seeking and/or relocate the person with dementia where wandering has occurred (959, 967). The aim of signal-transmitting devices is to help navigate the person to a safe location, notify the carer of that location and alert emergency services as required (968). Likewise, video and sensor monitors in RACFs have been used to alert staff when residents approach exit points (969, 970). The use of technology should only be implemented after careful consideration of the autonomy of the individual with dementia and the risks involved in the behaviour (963).

**Results**

A systematic literature review to set criteria (see *Appendix 7*) yielded 22 psychosocial and environmental and one biological intervention study with outcomes relevant to wandering in dementia. Psychosocial and environmental interventions were grouped into seven broad categories: environmental interventions, sensory interventions, touch therapies, models of care, behavioural/cognitive-behavioural interventions, exercise and music. Only four of the psychosocial studies assessed sustainability of the interventions. Follow-up results were largely based on a period of a few days but multisensory stimulation provided data for one month post-intervention. None of these studies indicated that benefits, if any, were maintained at follow-up.

**Management of wandering behaviours**

The first step is to understand the person and what underpins the behaviour. Clearly, addressing the cause of the wandering is crucial, although this can be very difficult to determine when the person with dementia is unable to express their needs. Clinical judgement in this situation frequently relies on historical factors such as previous personality, nonverbal cues and/or informant knowledge. *Appendix 1* provides suggested questions to facilitate comprehensive behavioural assessment. It is important to identify the significant aspects of the behaviour such as intensity, duration, peak period, boundary crossing and the issues for the person with dementia versus the issues for carers and/or staff.

***Psychosocial and environmental interventions***

Psychosocial and environmental intervention studies were predominantly conducted in residential settings. The environmental interventions group incorporated the greatest number of interventions. Behavioural/cognitive-behavioural interventions, exercise, music, sensory interventions and touch therapies yielded few studies.

The majority of the environmental interventions are in the form of subjective barriers. Subjective barriers generally involved two-dimensional visual manipulation of the environment, including grid patterns placed on floors and doors, mirrors and the use of concealment and camouflage techniques to reduce exiting behaviours (932). Intervention

trials with small sample sizes were conducted in locked RACFs and/or hospital units. Modest support is provided for using camouflage and concealment methods (971, 972) and moderate support for the effectiveness of two dimensional grid patterns (972-975) and mirrors (976) to divert exit attempts. A single case study also showed a reduction in intrusions into others' rooms in a RACF by placing a mirror in the female resident's own room (977). These findings have not been supported by further research which may be indicative of potential ethical issues inherent to these interventions (932).

The sensory interventions category comprised multisensory stimulation and aromatherapy with and without massage. A strong quality study of multisensory stimulation showed no reduction in wandering (439). Strong evidence was provided for *Melissa officinalis* (lemon balm) oil as a lotion to the face and arms, as motor activity was reduced with the additional benefit of improving overall well-being (978). Similarly, moderate evidence supports the use of massage with lavender oil in reducing motor behaviours (979). Another study of modest quality , however, showed an increase in wandering after receiving Melissa and lavender oil, but qualitative data suggest this involved recreational rather than aimless wandering, reflecting improved mobility in the persons with dementia (980).

Touch therapies included slow-stroke massage and therapeutic touch. Strong evidence for therapeutic touch involving massage to the neck and shoulders showed a trend toward reduced escaping, searching and pacing behaviours in RACFs (352) as well as a trend toward reduced walking/pacing behaviour in a community sample (981). Slow-stroke back massage also showed a trend to reduced pacing, walking, searching and wandering

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**STRATEGIES/OUTCOMES**

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

in a trial of moderate quality (982). The only study in the models of care group provides moderate support for special care units; reduced wandering was reported by care staff (983).

*older family and community members.*
- *The additional support from multiple community members meant that Mr E was afforded greater supervision.*

Two studies involving solution-focused therapy and a behavioural communication intervention were included in the behavioural/cognitive-behavioural interventions group. Moderate evidence for reduced frequency and severity of wandering is presented for solution-focused therapy which focused on the positive aspects of the person's life situation, identifying their strengths and finding solutions (984). A series of three case studies demonstrated that communication and behavioural reinforcement successfully reduced wandering from the table during meals and improved food intake (985).

Two exercise intervention studies of modest quality provided mixed results. Involvement in a walking group had minimal impact on reducing wandering frequency (986), but aerobic, strength, balance and flexibility exercises reduced wandering (965). Outcomes were also mixed for the two studies included in the music interventions group. Strong support was provided for exposure to repetitive, slow tempo music which reduced pacing for up to an hour post-intervention (987), while a study of moderate quality saw no reduction in wandering with music therapy (988).

Additionally, reduction in wandering has been associated with increased room lighting, greater variations in sound levels and proximity to others (989). Likewise, addressing emotional needs and underlying distress as well as positive social interaction have also been suggested as potential management strategies (966), although published research is currently lacking in these areas. Interestingly, a study of environmental ambiance in RACFs and assisted-living facilities found ambience was a more robust predictor of wandering behaviours than were MMSE scores (933).

*See Appendix 3 for interventions reported above.*

### Biological interventions

Only one antipsychotic RCT identified from the literature which provided strong evidence that risperidone was more effective than haloperidol in reducing wandering (369). The dearth of pharmacological intervention studies is not unexpected as it is widely accepted that the use of pharmacological and physical restraints to manage wandering and excessive motor activity is unethical. Furthermore, wandering has been identified as a BPSD that does not justify the use of antipsychotic medications in its management (264).

Agitation with motor restlessness can be secondary to depression, and pharmacotherapy for the underlying condition may be helpful (see *Module 8* for further information). Analgesics, even as simple as paracetamol 1 gram nocte three times per day, may reduce agitation with motor restlessness if pain underlies the behaviour. On the other hand, sedation to control wandering (sometimes called chemical straitjackets), such as with benzodiazepines, antihistamines or antipsychotics, can worsen confusion, increase the risk of falls and, in the case of antipsychotics, may exacerbate motor restlessness through akathisia. Wherever possible, the use of symptomatic, pharmacological agents, when deemed necessary for

treatment of wandering, should be time limited, closely monitored, reviewed, reduced and/or discontinued when indicated, and prescribed in combination with appropriate psychosocial interventions. As always, the potential benefits to the person with dementia must be weighed against the side effects of pharmacological treatments (see *Table 2.3, Module 2* for side effects associated with neuroleptics).

*See Appendix 4 for interventions reported above.*

## Limitations

There is a paucity of sound intervention research to guide clinicians and carers on the management of wandering in persons with dementia. Wandering is multifaceted and most studies focussing on this behaviour have been descriptive and exploratory in nature because it has been understudied. This has limited the development of effective strategies to date (966). Additionally, studies employ a range of measurement tools and these are typically not specifically designed to quantify wandering. Wandering behaviour is often quantified by scores on the CMAI and NPI, both of which include single wandering items only. A diagnosis of wandering in dementia may not be straightforward, due to the overlap of symptoms with non-physical agitation, although higher level wanderers tend to be reliably identified by nursing staff (936). Wandering is rarely studied in isolation, which can hinder the development of effective strategies for management (966).

## Conclusions

In summary, wandering in dementia has significant consequences. Recognised expert guidelines are limited in the area of managing wandering in those with dementia. The use of chemical restraint by medication is not recommended. Reports on the outcomes of psychosocial interventions are limited in number, quality and evidence of sustainability. Environmental interventions in the form of subjective barriers provide the best evidence; however, this has not been supported by any further research more recently. Therapeutic touch and aromatherapy oils provide some evidence for psychosocial management of wandering in dementia. These interventions are cost effective, relatively simple to implement and the benefits appear to be immediate, although it is not possible to determine whether benefits are maintained. The need for a multidisciplinary, individualised and multifaceted approach is stressed. The effectiveness of exercise and music studies lends initial support for their use, however further quality research is needed to draw any meaningful conclusions.