

Assessment and Management of Behaviours and Psychological Symptoms associated with Dementia (BPSD)

**A Handbook for NSW Health Clinicians
providing services for people
experiencing BPSD**

NSW MINISTRY OF HEALTH

1 Reserve Road
St Leonards NSW 2065
Tel. (02) 9391 9000
Fax. (02) 9391 9101
TTY (02) 9391 9900
www.health.nsw.gov.au

Produced by:

Dementia Centre for Research Collaboration (DCRC) and
Centre for Healthy Brain Ageing (CHeBA), UNSW Sydney
Level 1, AGSM (G27),
Discipline of Psychiatry and Mental Health
Faculty of Medicine and Health
UNSW SYDNEY NSW 2052
Tel. +61 (2) 9385 7357
cheba@unsw.edu.au

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Note: Resources in this document linked to the DCRC website are
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Handbook overview

Persons living with dementia can experience a good quality of life for long periods but may also experience behaviours and psychological symptoms associated with dementia (BPSD).

When BPSD are present, people require care across multiple settings and NSW Health teams. BPSD may be the focus of care or at other times a co-morbid issue requiring management. In either situation, the person with BPSD and their carers should receive high-quality care with a consistent underlying approach to BPSD. This Handbook aims to provide both a reference point and practical resource to assist NSW Health staff to meet this expectation.

Language use and application matter. The term BPSD is used in this handbook to clearly and succinctly communicate concepts that will assist NSW Health clinical staff with the goal of providing optimal care for people living with dementia and their families.

Clinical terms such as BPSD exist to guide clinical care and should never be used to objectify, demean or otherwise disempower people.

Person-centred care puts the 'person', rather than the 'patient,' at the centre of the service.

Thus, in this Handbook the term 'patient' is used only sparingly to align with specific language in current legislation and NSW Health policy directives, such as in the context of emergency care and consent to medical treatment.

The term 'carer' refers to the person or persons who primarily fulfill the role of 'carer' for the person living with dementia. A carer provides ongoing, unpaid support to a family member, partner, neighbour or friend who needs help because of disability, terminal illness, chronic illness, mental illness and/or ageing. A person is not referred to as a 'carer' if they care for a person as a paid employee, a volunteer or as part of education or training.

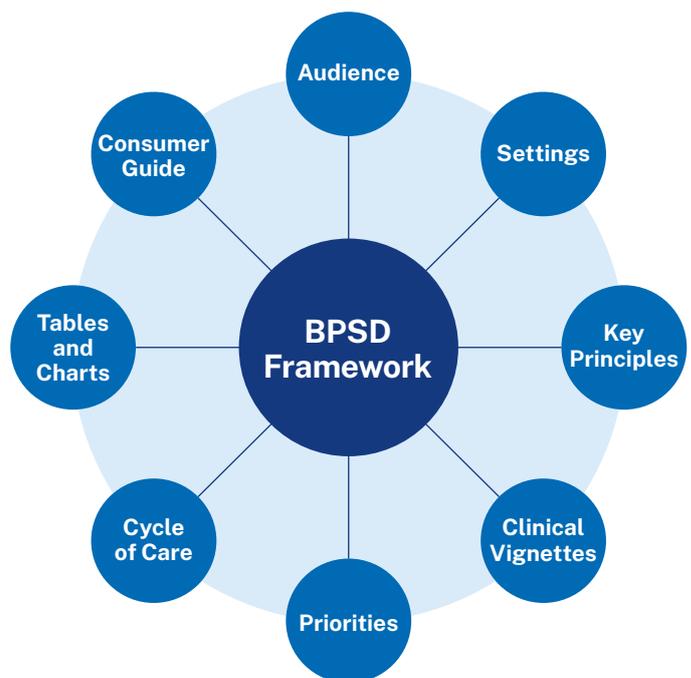
See the NSW Health website for information on [Consent to treatment](#) the [NSW Carers \(Recognition\) Act 2010](#), and for definitions of '[designated carers](#)' and '[principal care providers](#)' under the [Mental Health Act 2007](#).

BPSD Handbook framework

There are many useful resources for clinicians providing care for people experiencing BPSD. This Handbook has been designed using a framework to meet specific requirements with several distinguishing features, see Figure 1 below.

References and further available online resources are included at the end of each chapter. A bibliography and list of online resources can also be found at the end of the Handbook (pages 97-111).

Figure 1. Main features of BPSD Handbook



Audience: NSW Health clinical staff

The Handbook is intended to be a practical and ready reference for NSW Health staff working in settings where they will care for people with dementia who are experiencing BPSD. It does not intend to capture the full extent of specialist practice that may be applied by expert practitioners given the variety of disciplines and roles within NSW Health.

The Handbook may be used in many ways. Less experienced staff may use it as an overview of key

concepts and practical resources to apply and discuss with their supervisors. Experienced staff may use it as a refresher or teaching resource, and multidisciplinary teams as a common reference point to assist in coordinated care. **The Handbook should be applied within a framework of local policies and procedures.**

Settings: emergency departments, in-patient wards and community settings

People with dementia and BPSD are cared for in many settings and may be transferred between settings. This Handbook addresses emergency departments, in-patient units and community settings. Staff providing consultancy to residential aged care facilities and other community providers should see online resources provided by [Dementia Support Australia](#) which provides [Dementia Behaviour Management Advisory Services](#) (DBMAS) and [Severe Behaviour Response Teams](#) (SBRT). GPs should be aware of the [Royal Australian College of General Practitioners \(RACGP\) Dementia Guidelines](#) and the [Department of Health website](#).

Key principles

A person with dementia and behavioural disturbance is firstly a person who may be unwell and requires care. The key principles for providing care are:

1. *Person-centred care*: This emphasises understanding the person, not the behaviour or disease to be “managed” (Chapter 3). Person-centred care incorporates *trauma-informed care*. Trauma-informed care emphasises that trauma can affect mental and physical health and care should be provided in ways that do not re-traumatise people (Chapter 3).
2. *Multidisciplinary and multi-team care*: Caring for people with dementia and BPSD is a complex clinical challenge and requires expertise from different health professions. Providing optimal care for the person and their carer and family requires an attitude of acceptance and respect for the different roles health professionals play (Chapter 9).
3. *Legal and ethical responsibilities*: People with dementia and BPSD may have diminished capacity for consent. In addition, BPSD present health professionals with ethical and legal challenges.

NSW legislation sets out specific legal and ethical obligations for health professionals (Chapter 8).

Clinical vignettes

The Handbook uses vignettes based on clinical experience to illustrate the application of the BPSD framework. Clinical vignettes include:

Sebastian – an 86-year-old man with dementia who is displaying inappropriate sexual behaviour that is presenting challenges for the nursing staff who are caring for him. His story is told on 13.

Nancy – a 64-year-old Gundungurra woman. She is a respected Elder held in esteem by the community. Nancy was diagnosed with vascular dementia two years ago and has been receiving in-patient treatment following a recent stroke. Nancy lives with her daughter Susan and other family members. Their story is told on 19.

Thomas – a 60-year-old man who is admitted for a procedure under general anaesthetic. He is unable to provide personal information, becomes frustrated and anxious and begins calling out for his husband Joe. Their story is told on 21.

Maria – an 89-year-old woman who is convinced people are stealing her belongings. Maria also presents with verbally and physically aggressive behaviours and intrudes into others’ space. Her story is told on 28 and 37.

Yasmin – an 82-year-old woman from a culturally and linguistically diverse background and with a history of psychiatric illness presents with rapid onset of agitation and confusion. Yasmin is diagnosed with delirium and dementia. Her story is told on 33.

Bianca – a 79-year-old woman with a history of mild dementia. Bianca is admitted to hospital following a fall and is required to undergo surgery while an in-patient. Her story is told on 64 and 68.

Kenny – an 89-year-old man who is distressed and confused after being transferred from a hostel to an in-patient setting. Kenny’s story begins on 71.

Priorities

The Handbook presents five priorities when caring for a person with dementia and BPSD (Table 1).

Table 1. Priorities

Priority	Examples	References
1. Management of physical care needs	<p><i>Particular attention must be paid to the assessment of potential delirium, which is a medical emergency requiring immediate treatment.</i></p> <p>Is there drug interaction? Could the person be in pain, hypoglycaemic, need to go to the toilet or have other basic unmet needs such as thirst and hunger?</p> <p>Consult the carer for their expert advice on potential strategies to meet the person with dementia’s needs.</p>	Chapters 3 and 4
2. Behaviour management plan—behavioural and environmental management strategies	<p>Creation of a behaviour management plan in the prescribed format is required.</p> <p>Optimal communication, Antecedent Behaviour Consequence (ABC) approach to behaviour modification, noise reduction, distraction minimisation, preferred music, sleep hygiene and other psychosocial strategies should be provided, based on an understanding of the person, their needs and capacities.</p> <p>Residential Aged Care Facilities (RACF) are required to have a <i>Behavioural Support Plan (BSP)</i> in place for any resident who is receiving care and experiencing BPSD. People with younger onset dementia who receive NDIS funding may have a BSP.</p>	Chapters 3, 4 and 5
3. Psychological engagement	<p>Is the person distressed and anxious because of separation from loved ones, social isolation, bereavement or frustration?</p> <p><i>Psychological engagement enables the clinician to assess the presenting behaviour or symptom in the context of the person’s psychosocial and cultural background.</i></p> <p>In addition, it is important to distinguish BPSD from delirium and comorbid psychiatric disorders such as depressive disorder, mania and schizophrenia, and vice versa.</p>	Chapters 4 and 5
4. Cautious use of psychotropic medications	<p>Important but limited roles, used with caution and appropriate consent.</p> <p>Antipsychotics should be limited in use for up to 12 weeks.</p> <p>Prescription of psychotropic drugs should be considered only after psychosocial approaches have been unsuccessful, unless in an emergency. Psychotropics should be prescribed carefully with regard to potential benefits, which can be limited, and adverse effects, which can be substantial. The principles of prescribing are:</p> <ul style="list-style-type: none"> • start with low doses • increase doses slowly • clearly identify the target symptoms or behaviours • regularly review medication effects and side effects • avoid polypharmacy • limit the duration of medication use • notify the GP of need for review and discontinuation plan in discharge summary from hospital or community care • provide indications for use of psychotropic medication in discharge summary 	Chapters 6 and 7

Priority	Examples	References
5. Care with and for the carer	Engage with and be mindful of the needs of the carer and family. Carers are partners in care. They understand the person's background and triggers for behaviours and can assist in management. It is essential to provide the carer(s) and family with support, education about appropriate techniques for managing behaviours and information on community resources.	Chapters 3, 4, and 9

The Cycle of Care

Almost all health care settings will care for people with dementia and BPSD. In addition to managing the primary reason for admission (e.g. medical or surgical treatment), health care professionals need to incorporate the Cycle of Care for BPSD into the treatment plan. The Cycle of Care involves four stages, depicted in Figure 2: **ACCEPT**, **ASSESS**, **ACT** and **(RE)ASSESS**.

Figure 2. The Cycle of Care for BPSD

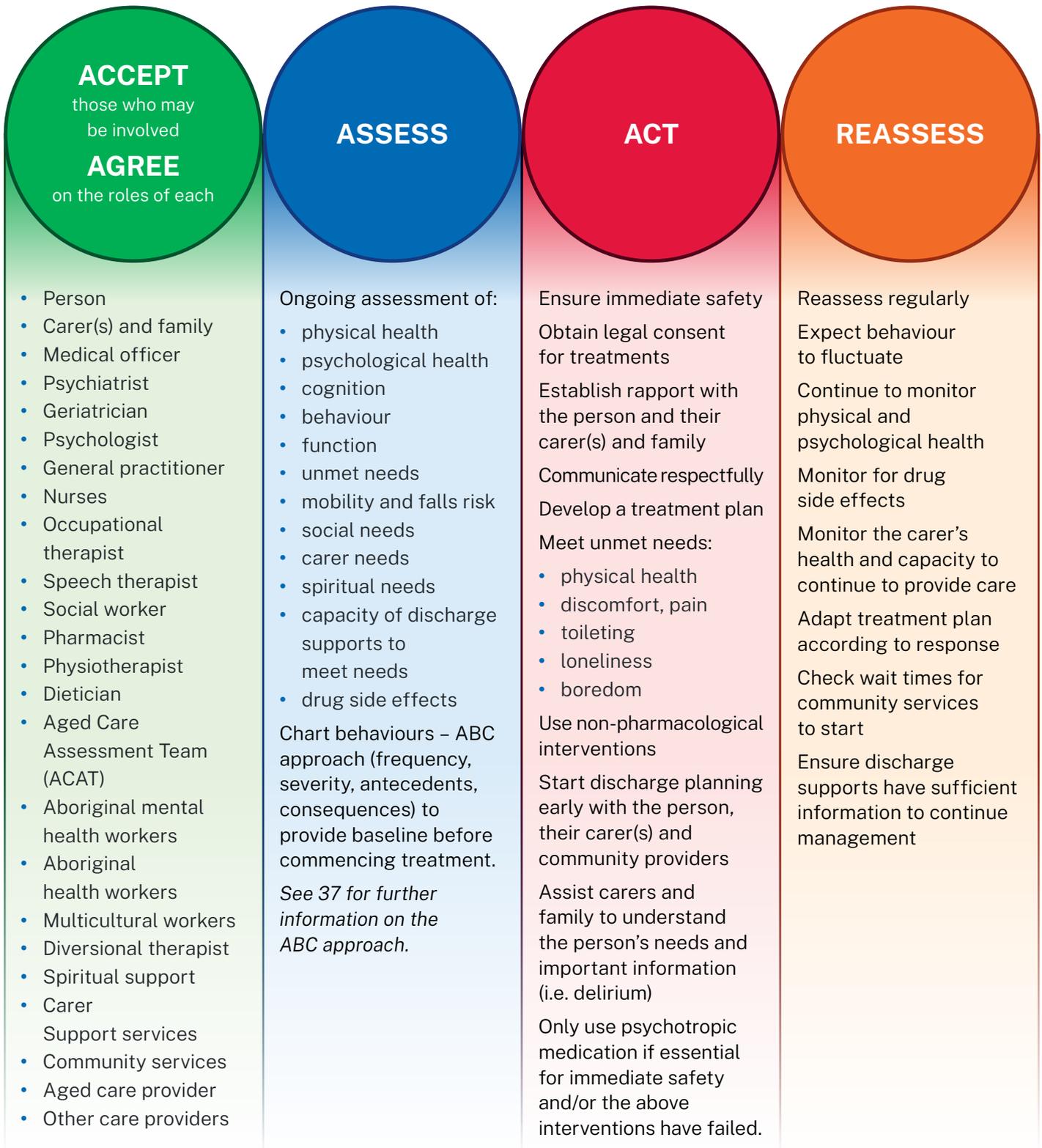


1. Key clinician roles

Key tasks for clinicians are shaped by the Cycle of Care. Table 2 presents key tasks for each stage of the cycle. The range of professionals involved can be diverse. In addition to the person and their carer, medical staff, psychologists, nurses, occupational therapists and social workers are just some of the

professionals involved in providing care. Each will assess the person's health drawing on their respective professional training. Each will act to ensure optimal care for the person. Planning for discharge or transfer should be commenced early in the treatment. The care plan should be re-assessed regularly to monitor changes in the person's behaviour.

Figure 3. Key clinician tasks



Key communication points

2. Tables and charts

The Handbook presents tables and charts to summarise information for ready reference. For

example in emergencies, clinicians will need to obtain information quickly (available at Table 7.1 Medication in in-patient behavioural emergencies). Table 3

below provides information on medication classes that may be considered where non-pharmacological management is not sufficient.

3. Carer and health care staff resources

The Handbook also includes an outline of a guide that may be appropriate for the carer, family and friends of the person (see 'Making the most of time with a person who is living with dementia and experiencing changed behaviour or emotions' at the end of this Handbook), and a similar guide for health care staff. It is recommended that if these resources are to be used locally, they be adapted to local needs with involvement of people with dementia and their carers.

4. Chapter structure

Each chapter begins with a text box, which is colour-coded to link to the relevant section of the Cycle of Care diagram. The box contains a key message for that chapter.

Each chapter then presents content in the form of vignettes, tables and figures to extrapolate the key learnings.

This table provides general guidance only. Every individual will have different needs that will require a tailored approach and review. For a more detailed review of the evidence for intervention and treatment effectiveness for specific BPSD see ['Behaviour Management – A Guide to Good Practice, Managing Behavioural and Psychological Symptoms of Dementia \(BPSD\)'](#).

Table 2. Drug classes used to treat BPSD

Type of medication	Name of drug class	Example agents (total daily dose)	BPSD indication	Selected adverse effects
Analgesic		Paracetamol, up to 3g	Pain-related agitation	Sedation, hepatic dysfunction
Antidepressant	SSRI	Citalopram 10–20mg Sertraline 25-100mg Escitalopram 5-10mg	Non-urgent treatment of agitation, aggression or psychosis Severe depression	QTc prolongation monitor ECG (citalopram), hyponatraemia, falls, sleep disturbance
Cognitive enhancing	Cholinesterase inhibitor (ChEI)	Rivastigmine (Exelon Patch) 4.6– 9.5mg Donepezil 5-10mg Galantamine 8-16mg	Agitation, psychosis in DLB	Exclude bradyarrhythmias – need ECG, gastrointestinal AEs, urinary symptoms
Antipsychotic	Atypical	Risperidone 0.25–2mg Aripiprazole 2.5mg – 15mg	Psychosis and aggression in Alzheimer's disease (PBS indication); psychosis, aggression, agitation in dementias other than DLB Second line for psychosis, aggression, agitation in dementias other than DLB	Falls, confusion, hypotension, extrapyramidal side effects, QTc prolongation, monitor ECG Aripiprazole: Nausea, vomiting, constipation, other GI symptoms, headache, dizziness
Sedative/hypnotic	Benzodiazepine	Lorazepam 0.5–1mg Oxazepam 15-30mg	Very short term only, Agitation, severe anxiety Nocturnal sedation	Falls, confusion, rebound insomnia
Anticonvulsant		Carbamazepine 100–300mg	Agitation Possibly 3rd or 4th line treatment, only with specialist consultation	Falls, disturbed gait, confusion, hepatic dysfunction, blood dyscrasias.

Summary of figures and tables

This Handbook contains several resources that encapsulate key information and which can be used as a ready reference. Hyperlinks and page numbers are included in the tables below.

Figures

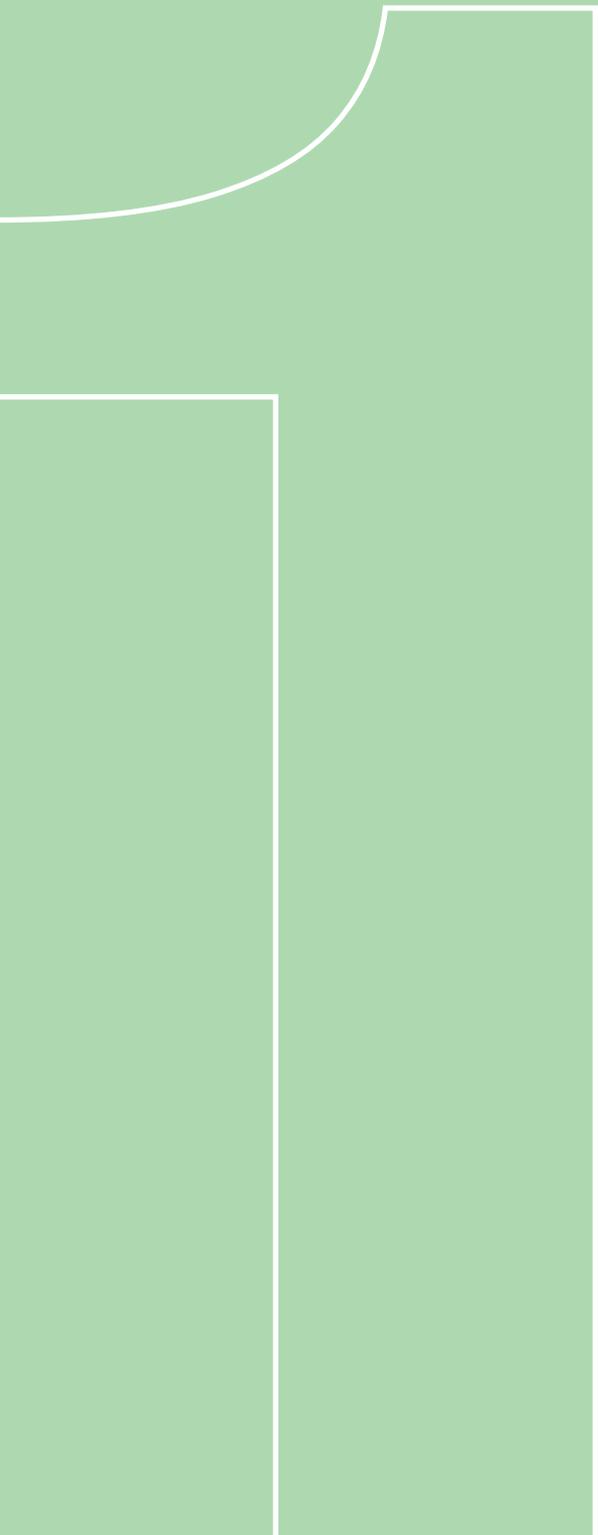
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2.1	Ranges of inappropriate sexual behaviour	Presents ranges of inappropriate sexual behaviour and examples	12
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CHAPTER 1

The basics: principles, priorities and Cycle of Care



This chapter sets out the framework, key principles and the Cycle of Care

- **Behaviours and psychological symptoms associated with dementia (BPSD) refers to the non-cognitive presentations of dementia, such as agitation, aggression, psychosis, anxiety, depression, apathy and nocturnal disruption**
- **A person with behavioural disturbance is a person who is trying to communicate and/or is unwell and requires help**
- **Key principles to remember:**
 1. Person-centred care incorporating trauma-informed care
 2. Multi-disciplinary and multi-team approach
 3. Legal and ethical responsibilities
- **Priorities in care:**
 4. Understand factors (often multiple) that may underpin the behaviours
 5. Management of physical care needs
 6. Behavioural and environmental management strategies including creation of a Behaviour Management Plan
 7. Psychological engagement
 8. Cautious use of psychotropic medication
 9. Engage with and care for the carer

Introduction

The person with dementia will experience a good quality of life for long periods but may also experience behaviours and psychological symptoms associated with dementia (BPSD). Persons with BPSD, and their carers, expect to receive high-quality care with a consistent underlying approach. This handbook aims to provide both a reference point and practical resource to assist NSW Health staff to meet this expectation. It should be applied within the context of local policies and procedures.

The term behaviours and psychological symptoms associated with dementia (BPSD) is controversial; many prefer 'changed behaviours'. BPSD refers to the non-cognitive **presentations of dementia**, such as agitation, aggression, psychosis, depression and apathy. While a convenient term, BPSD is not a diagnosis; each behaviour requires individual description and understanding.

A person with dementia who is experiencing BPSD may be communicating an unmet need and **may be unwell; the person requires care.**

This Handbook aims to provide information that will assist clinicians to provide coordinated care for the person, the carer and others around them.

A person with BPSD may receive care in many settings, including in-patient hospital wards, emergency departments, and community settings. BPSD may be the focus of care by specialist mental health or aged care services or as an issue to be addressed in the management of other conditions or problems. BPSD should be managed by all medical, nursing and allied health clinicians, with consultation of specialist mental health or aged care services if needed.

Often multiple factors underpin a behaviour or psychological symptom. These may be biological (e.g. brain changes, an infection), psychological (e.g. feeling lost, confused, abandoned, lonely), interpersonal (e.g. lack of loved ones, negative interactions with strangers), or environmental (e.g. unfamiliarity, disorientation). By constructing an aetiological map, a rational plan to address multiple factors can be designed and prioritised.

This Handbook discusses three essential principles and five priorities when providing care for the person with BPSD across different settings. Application of these will improve consistency of care, patient outcomes, and staff satisfaction in providing care. Detailed implementation in each setting will require utilisation of other resources which are referred to in this Handbook. Universal application of the principles to older people with dementia or cognitive impairment should assist in providing the best 'treatment' of BPSD and improve prevention of their emergence.

Key principles

Principle 1: Person-centred care

In person-centred care the person is provided with care to meet their needs, rather than the dementia managed.

The care team strive to understand the meaning or communication behind the behaviour. Care is provided with recognition of the possible effects of past and ongoing trauma on health and behaviour and avoids re-traumatising the person. The person, carer and clinicians work in partnership to develop a behaviour management plan with shared goals based on the person's values and experiences. Physical, psychological and social goals are considered and prioritised. Clinicians strive for empathy, respect and understanding and focus on development of rapport to enable this partnership.

Principle 2: Multidisciplinary and multi-team approach

The person with BPSD typically has a wide range of needs requiring the expertise of diverse health disciplines, including a range of nursing, medical and allied health professionals, as well as formal carers in community settings. Many clinical scenarios will require a rapid response, which should not be delayed by awaiting a particular professional.

As management is likely to occur across multiple settings, integrated care requires clinicians to work with the person's primary carer and other teams, to ensure the person's multiple needs are met and there is minimal disruption during transfers of care and at discharge. Each clinician should respect the expertise

of other disciplines and teams and carers as of equal value in the care of the person with BPSD.

Principle 3: Legal and ethical responsibilities

Consent is a cornerstone of care. Clinicians have a responsibility to obtain consent to treatment. That is, the person providing consent should be able to understand their condition and recommended treatment, balance the potential benefits and risks of treatment, consider alternatives, and arrive at a rational choice.

It should not be assumed that all people with dementia lack capacity. A person may be capable of making simple, but not more complex treatment decisions. Capacity may be regained, for instance, after a period of delirium. A person may have made an Advanced Care Directive or appointed a substitute consent provider such as an Enduring Guardian. When this has not occurred and the person lacks capacity, the 'Person Responsible' (as defined by the [Guardianship Act](#) or the [NSW Civil and Administrative Tribunal \(NCAT\)](#)) should be consulted to help guide decisions. In certain situations of clinical urgency, treatment may proceed without consent, for the period of the emergency only. This decision and reasons must be documented. Thereafter, the Person Responsible or [NCAT](#) should be consulted.

Priorities

The person with BPSD may have one simple or many complex issues requiring attention. The following five priorities will assist the person to receive optimal treatment and attain best outcomes.

1. Management of physical care needs

A thorough assessment of physical health is essential. **Particular attention must be paid to the assessment of potential delirium**, which is a medical emergency requiring immediate treatment, **pain, infection** (commonly urinary or chest), and other basic physical needs such as thirst, hunger, the need to urinate or defecate.

2. Behaviour management plan – behavioural and environmental management strategies

Creation of a behaviour management plan in the prescribed format is required. Strategies to enhance communication, environmental changes and behaviour modification as well as other psychosocial strategies should be provided based on an understanding of the person's needs and capacities. Residential aged care facilities (RACF) are required to have a behavioural support plan (BSP) in place for any resident who is receiving care and experiencing BPSD. Information on BSP and toolkits to assist aged care providers are available through [Dementia Support Australia](#). Similarly, people with younger onset dementia who receive NDIS funding may have a BSP. Information on NDIS and BSP is available through [Dementia Australia – NDIS Support – Younger Onset Dementia Hub](#).

3. Psychological engagement

The person may be distressed and anxious because of separation from loved ones, social isolation or bereavement; fear of a strange environment; fear of medical procedures; frustration with their disability; or sad about their future. Psychological engagement enables the clinician to assess the presenting behaviour or symptom in the context of the person's psychosocial and cultural background. In addition, it is important to distinguish BPSD from delirium and psychiatric disorders such as depressive disorder, mania and schizophrenia, and vice versa.

4. Cautious use of psychotropic medication

Prescription of psychotropic drugs should be considered only after psychosocial approaches have been unsuccessful, unless in emergency. Psychotropics should be prescribed carefully with regard to potential benefits, which can be limited, and adverse effects, which can be substantial. The principles of prescribing are:

- start with low doses
- increase doses slowly
- clearly identify the target symptoms or behaviours
- regularly review medication effects and side effects
- avoid polypharmacy

- limit the duration of medication use
- notify the GP of need for review and discontinuation plan in discharge summary from hospital or community care
- provide indications for use of psychotropic medication in discharge summary.

5. Care with and for the carer

Carers, whether the spouse, child, other family or friend, should be partners in care. They understand the person's background and precipitants for the development of behaviours and can assist in management. It is essential to engage with the person's carer and family as partners in care and to provide general support, education about appropriate techniques for managing behaviours and information on community resources and Carer Support services.

The Cycle of Care

The person experiencing BPSD requires care integrating **a cycle of acceptance, assessment, action and reassessment** (Figure 1.1). This needs to address the physical, psychosocial and environmental needs of the person, and of the ability of current and future providers to meet proposed care needs. Failure to ensure that successful strategies for improving BPSD are communicated to, and can be continued by, follow-up care providers upon discharge, transfer within a facility, or between shifts is harmful to the person and their carer; and frustrating for all involved. Continuity and consistency can bring about significant rewards.

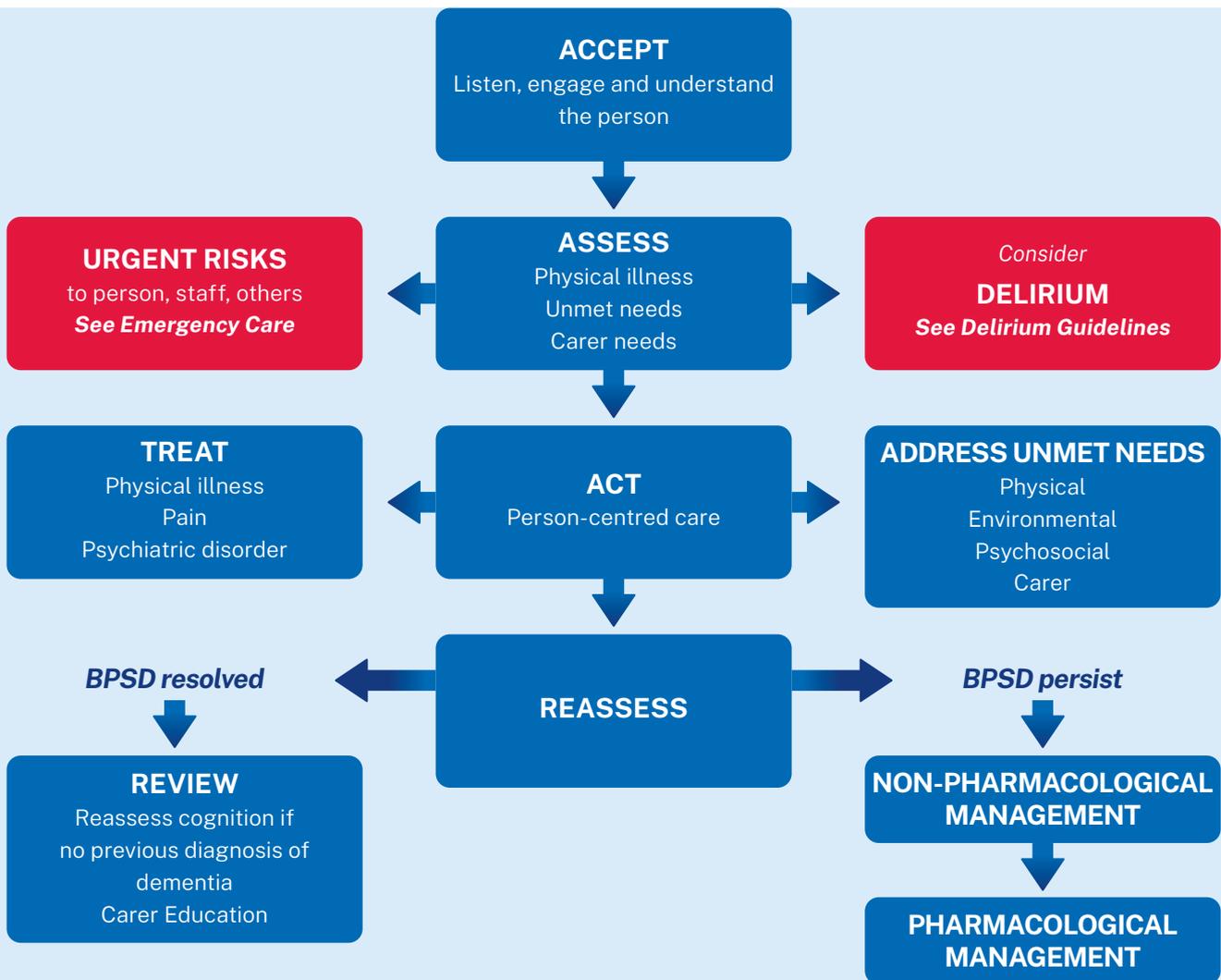
Central to the Cycle is the principle of person-centred care, which is a dynamic process involving the following elements:

1. **ACCEPT:** The person and their history, and the involvement, acknowledgement and expertise, of their family and different health professionals.
2. **ASSESS:** Assessment of the person's physical and psychosocial care needs.
3. **ACT:** Development and implementation of an initial behavioural support plan.
4. **REASSESS:** Ongoing assessment of the person and immediate outcomes, and refinement of the behavioural support plan.

Figure 1.1. The cycle of evaluation and care for the person experiencing BPSD and their carer



Figure 1.2. Prioritisation of actions with the person experiencing BPSD



Further resources

[A better way to care: Safe and high-quality care for patients with cognitive impairment or at risk of delirium in acute health services \(Second edition\)](#). Australian Commission on Safety and Quality in Health Care resource for clinicians with pathway to improve care for people with cognitive impairment.

[NSW Government Agency for Clinical Innovation: Care of Confused Hospitalised Older Persons \(CHOPS\)](#). Resources for health care professionals, older people and their carers/families to improve the experiences and outcomes of confused older people in hospital.

[Victorian Government Department of Health: Older people in hospital \(Third edition of the Best care for older people everywhere: the toolkit\)](#). Evidence-based information and strategies for clinicians, supported by principles of person-centred practice.

[Victorian Government Department of Health: Ageing & Aged care: Dementia-friendly environments](#). Simple guide of the practical implications of person-centred care for people with dementia.

[NSW Government Agency for Clinical Innovation: Living well in a Multipurpose Service \(MPS\) Toolkit](#). A toolkit to support health care professionals in rural communities in providing individualised person-centred care.

[NSW Government Health Education and Training \(HETI\) - My Health learning - Dementia modules](#). My Health Learning is the NSW Health eLearning system providing high quality, self-managed online learning for NSW Health staff. My Health Learning provides access to online and face-to-face education.

CHAPTER 2

Accept: Overview of dementia and BPSD



This chapter provides an overview of the types and stages of dementia and BPSD. It discusses aggressive behaviour, agitation, psychosis, depression, anxiety and apathy, and introduces Sebastian – an older man who has been exhibiting inappropriate sexual behaviour that is upsetting to staff and other people.

- **Acceptance of the person requires an understanding of the impact of dementia and BPSD on the person and their carer and family**
- **For people living with dementia:**
 - cognitive impairment is only one feature
 - behaviours such as agitation and aggression occur in 60-90%
 - psychological symptoms such as psychosis and depression occur in up to 25%
 - apathy occurs in 55-90%

Overview of dementia

Dementia is a syndrome defined as cognitive decline resulting in impairment in functioning. It is associated with personality and behaviour changes and is usually but not always progressive. The common types of dementia are listed in Table 2.1.

It has been estimated that 7.8% of people aged 65 years and over living in Australia experience dementia. In 2021, there were an estimated 472,000 people with dementia in Australia, including 157,000 in NSW.

Dementia incidence and prevalence rates are higher for Aboriginal and Torres Strait Islander people, in whom dementia often presents at a younger age.

There is expected to be an increasing prevalence of dementia in people from culturally and linguistically diverse (CALD) backgrounds due to the rapid ageing of many CALD communities.

Characteristics of dementia

Dementia is characterised by decline in one or more cognitive domains and in function, in particular:

- memory disturbance (amnesia)
- loss of receptive or expressive language skills (aphasia)
- impaired ability to carry out motor functions (apraxia)
- failure to recognise objects (agnosia) or a familiar face (prosopagnosia)
- disturbances in executive functions such as planning, organising and sequencing tasks, and abstract thinking
- decline in activities of daily living and in social functioning
- behavioural changes and psychological symptoms, emotional changes, impaired judgement, loss of empathy and inhibition

Most (but not all) dementias are progressive. While most dementias are not yet curable, there are many strategies to maintain good quality of life. Investigations for reversible causes should always be undertaken.

Types of dementia

Table 2.1. Common types of dementia

Type	Prevalence	Distinguishing characteristics
Alzheimer’s disease (AD)	50–70%	Early memory and language loss
Vascular (multi-infarct) dementia (VaD)	15–25%	Fronto-executive dysfunction (problems with judgement, planning and executing tasks), relative preservation of memory
Dementia with Lewy bodies (DLB)	10–20%	REM Sleep Behaviour Disorder, fluctuating cognition, visual hallucinations, idiopathic or drug-induced parkinsonism
Fronto-temporal dementia (FTD)	5–10%	Two main sub-types: (i) behavioural variant FTD, characterised by behavioural and personality changes (ii) semantic dementia or progressive non-fluent aphasia, characterised by language dysfunction

All types of dementia are associated with BPSD. Many dementias are ‘mixed’ in aetiology with overlapping pathology. For example, Alzheimer’s disease and vascular dementia commonly coexist and Parkinson’s dementia overlaps with dementia with Lewy bodies. Recently described dementias, LATE (Limbic-predominant, age-associated TDP-43 Encephalopathy) and Hippocampal Sclerosis, occur commonly in the very old and have Alzheimer-like symptoms. The older the person the less likely they are to have single pathology. Most people over 85 years of age have mixed pathologies. Also, note that alcohol-related dementia occurs in older people.

Stages of dementia

For convenience, using Alzheimer’s dementia as the prototype, three main stages of dementia may be considered broadly. It is important to realise that it is usually difficult to determine the onset of dementia and the exact time when the person moves from one stage to another.

In early dementia, the person may be more apathetic, lose interest in hobbies, find more complex tasks difficult, and experience difficulties with memory. Misplacing items may be blamed on others stealing from them. Insight into the loss of memory and function may result in depression.

In moderate dementia, cognitive symptoms are more obvious and self-care is increasingly problematic.

BPSD such as agitation, aggression and psychosis are most likely to present at this stage of dementia.

In severe dementia, the person needs around-the-clock care for basic functions such as bathing, dressing and toileting. Physical problems such as difficulty walking and talking, and incontinence occur. The person may be disturbed at night, agitated and aggressive. The person will be bedridden in the last few months of life.

Behaviours and psychological symptoms associated with dementia

Although cognitive decline is the hallmark of dementia, non-cognitive symptoms termed “neuropsychiatric” or “behaviours and psychological symptoms associated with dementia” (BPSD) are common.

It is important to note that BPSD is not a specific diagnosis, more a descriptive term that highlights an important clinical dimension of dementia. BPSD is a collection of observed behaviours and psychological symptoms that tend to occur in clusters.

BPSD typically presents in the middle to later stages of dementia, with up to 90% of people with dementia experiencing at least one BPSD during the course of the disease. While the prevalence of total BPSD increases with dementia severity, individual BPSD have different trajectories.

BPSD are associated with significant carer stress, increased duration of hospitalisation, greater likelihood of placement in a residential aged care facility, and possibly faster decline and death.

The course of BPSD varies. Hallucinations and mild depression may resolve over a few months, although delusions, agitation and severe depression may be more persistent. In end stage dementia, some behaviours become less prominent such as depression and delusions, although apathy continues to increase with dementia severity.

The following section offers brief descriptions of specific BPSD including aggression, agitation, anxiety, apathy, depression, nocturnal disruption, psychosis and inappropriate sexual behaviour.

Aggression and non-aggressive agitation

Agitation and aggression are inappropriate verbal or motor behaviours that occur in 60% of people who have dementia and may occur on a spectrum (Tables 2.2 and 2.3). Such behaviours may occur for many reasons such as pain, physical illness, depression, disorientation, separation from family or other unmet needs.

One example of an agitated behaviour is a “catastrophic reaction”. These are instances when a person suddenly becomes tearful, angry and abusive. These are usually brief episodes caused by frustration over reduced ability to do simple tasks such as getting dressed, misinterpreting what someone has said or misinterpreting environmental cues. A non-aggressive behavioural response to the same situation might be to stop talking and withdraw.

Table 2.2. Verbal agitation/vocally disruptive behaviour

Non-aggressive	Aggressive
Constant requests for attention or complaints	Swearing
Expressions of unrealistic fears	Temper outbursts
Repetitive questions or verbalisations	Verbal intimidation or threats
Expressions of anxiety	
Complaints about health	
Moaning	

Table 2.3. Physical agitation

Non-aggressive	Aggressive
Purposeless, repetitive physical movements	Hitting, kicking, pushing, grabbing
General restlessness	Scratching
Wandering or pacing	Spitting, biting
Rummaging	Throwing objects
Hiding things	Actively resisting care (e.g. pulling out drip)
Inappropriate dressing or undressing	Inappropriate sexual behaviour
Resisting care (e.g. refusing medication)	
Intrusiveness	
Inappropriate sexual behaviour (see Figure 2.1)	

Anxiety

Anxiety occurs in an estimated 16–35% of people with dementia. Anxiety can be overwhelming for people with dementia in hospital, distressing for the carer, and can present challenges for staff. People who feel very worried or anxious may be unable to explain why. The person may seek-out or try to stay near familiar people. When people are anxious or fearful they may feel that they need to protect themselves (fight), that they need to leave the situation (flight) or need to shut down entirely (freeze). It is important to identify when someone is feeling anxious as anxiety can be debilitating, intrusive and may also be mistaken for agitation and aggression.

Common anxieties are:

- fear of being left alone
- concerns, sometimes unrealistic, about finances, future or health
- worries about previously non-stressful events and activities.

Apathy

Apathy occurs in 55–90% of people with dementia. Symptoms of apathy are diminished initiative, motivation, and drive, goal-directed behaviour, cognitive activity, and emotional reactivity. For example, an apathetic person will eat or drink if fluids or food are supplied but may make little effort to prepare food spontaneously.

Apathy is distinguished from depressive disorder by the absence of sadness, suicidality, other features of psychological distress, and fewer vegetative symptoms (e.g. sleep disturbance, loss of appetite).

Depression

Depression occurs in about 20% of people who have dementia. Although depression may present at any stage of dementia, it is more prevalent in the early-moderate stages. As dementia progresses, diagnosing depressive disorder becomes more difficult due to increasing language and communication difficulties. In addition, certain symptoms such as apathy, reduced eating, weight loss, and sleep disturbance and agitation are not specific to

dementia or depression; i.e. they may occur in both. Depression is more common in vascular dementia and Parkinson's dementia.

Depression should be considered if the person demonstrates any of the following, particularly if they have a previous or family history of depression:

- tearfulness
- pessimistic thoughts
- expressing a wish to die
- sudden change in trajectory of cognition.

Nocturnal Disruption

Most people with dementia experience sleep difficulties that are associated with worsening of cognition, mood and behaviour. The sleep architecture is disrupted in dementia. In particular, there may be disruption of the sleep-wake cycle due to environmental changes or physical problems. Dementia with Lewy bodies is associated with REM sleep disorders with abnormal movements.

Psychosis

About 25% of people with dementia will experience psychosis. Psychosis involves delusions, hallucinations and misidentifications.

Delusions

Delusions are fixed, false beliefs that are implausible or untrue. Delusions in people with dementia tend to reflect underlying memory loss or perceptual changes, such as the conviction that other people are stealing money or personal items, that their spouse or carer is an imposter, or that their spouse is being unfaithful.

In contrast, delusions in schizophrenia are more bizarre, for instance thinking that fictional characters are trying to kidnap the person's family.

Hallucinations

Visual hallucinations may be vivid in dementia with Lewy bodies, such as seeing brightly coloured crocodiles in the house. Auditory hallucinations ("voices") are less common - their presence may indicate an underlying psychiatric disorder. More commonly, auditory illusions occur when the person misinterprets sounds. For

example, discussion amongst the care team may be misinterpreted as plotting to kill people. Hallucinations may also be a side effect of prescribed medications.

Misidentifications

Misidentifications occur when the person with dementia mistakes people or objects for something else. Examples include:

- believing someone else is in the house (phantom boarder)
- thinking that people are not who they claim to be, e.g. perceiving familiar people as imposters (Capgras syndrome)
- thinking that events on television are happening to them
- being unable to recognise their own reflection in the mirror.

Inappropriate sexual behaviour (ISB)

Inappropriate sexual behaviour (ISB) is verbal or physical action of a sexual nature displayed within an inappropriate social context, directed at the person

or others. As is the case with other behaviours, there is a spectrum of ISB (Figure 2.1). Many factors in the environment and the values of other people in it, affect both the expression of sexual behaviour and responses to it. Various physical and psychological factors may be associated with inappropriate sexual behaviour:

- absence of sexual partner(s)
- lack of privacy
- living in an unfamiliar environment or one that does not provide adequate stimulation
- misinterpretation of cues, such as touching by a person when assisting with personal hygiene or assisting with clothing
- the person's sexual behaviour prior to dementia onset
- dopamine-elevating drugs used to treat Parkinson's disease
- alcohol use
- mood disorder
- delusions, hallucinations.

Figure 2.1. Ranges of inappropriate sexual behaviour

IMPLIED	<ul style="list-style-type: none"> • reading pornography in public • requesting unnecessary genital care • unnecessary requests for assistance in bathing/changing
NON-AGGRESSIVE	<ul style="list-style-type: none"> • suggestive signs and gestures • removing clothes in public • masturbation in public • exposing breasts or genitals in public
INTRUSIVE	<ul style="list-style-type: none"> • suggestive/sexually explicit language out of keeping with the person's personality prior to the onset of dementia • describing past sexual exploits • unwanted sexual remarks • unwanted flirtatious behaviour
AGGRESSIVE	<ul style="list-style-type: none"> • unwanted kissing • touching inappropriately • unwanted fondling • unwanted sexual advances • grabbing • actual attempts of sexual intercourse without consent

Case vignette – Sebastian

Sebastian is an 86-year-old widower with dementia of moderate severity who lives at home with the assistance of a community aged care package. He is physically well, although he seems intoxicated on some days. He has repeatedly hugged a female community nurse who feels uncomfortable with the intensity of physical contact.

Occasionally he has not pulled up his trousers after going to the bathroom and has been seen masturbating in his room by the homecare cleaner. On one occasion, he used sexually explicit language with a female nurse.

Discussion of case vignette

Sebastian's inappropriate sexual behaviour and apparent use of alcohol are creating a threatening work environment for the care staff who visit his home. In this situation, a home care package would suspend Sebastian's care. It is important for everyone in Sebastian's community team to work together toward solutions that enable optimal care while ensuring the safety and well-being of Sebastian and care staff.

The community team may contact Sebastian's GP and discuss a home review. The team may also recommend a geriatrician follow-up and where available, enquire if a community visiting geriatrician can make a home visit.

Whilst Sebastian is exhibiting inappropriate sexual behaviour, each behaviour needs to be analysed separately. His hugging may be a demonstration of affection and gratitude, and it must be remembered that he is now widowed and does not receive regular physical contact. He may have simply forgotten to pull up his trousers after going to the toilet, or he may have been too hot and tried to remove his clothes. However, there is also an example of more aggressive behaviour. Contact Dementia Support Australia (DSA) on their 24-hour helpline 1800 699 799 to refer for an assessment or refer online.

It would be important for the community team to explain their concerns about his behaviour and why it is inappropriate. Repeated explanations will likely be required over time and all staff need to be aware. The use of male support workers, if available, may help. Sebastian may also have family in the community who are willing to assist when care is provided. The place of alcohol in the presentation of his behaviour should be considered and managed appropriately.

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Further resources

- [Dementia Australia](#)
A wealth of resources for clinicians, carers, and people with dementia. National Dementia Helpline 1800 100 500
- [Australian and New Zealand Society of Geriatric Medicine](#). More detailed information and resources for clinicians.
- [International Psychogeriatrics International](#)
Information and guides on BPSD for different clinical roles.
- [World Health Organisation: Health Topics: Dementia](#)
Fact sheets, guidelines and resources.
- [Alzheimer's Disease International](#)
Reports, advice and latest global research on dementia.

CHAPTER 3

Accept: Person-centred care, communication and working with the carer



- **Person-centred care:**
 - focuses on helping the person, rather than managing the behaviour
 - uses principles that apply to all people with dementia that may reduce the emergence of BPSD
 - utilises development of rapport and partnerships between the person, carer and clinicians
 - is supported by good communication
- **Clinicians' body language and tone of voice provide the most communication**
- **Verbal communication must be modified to meet the person's needs**

Person-centred care

Person-centred care is a time-efficient, evidence-based approach to improving the care of people with dementia. Applying the principles to all people with dementia offers the prospect of reducing the incidence of BPSD.

Key in person-centred care (PCC) is the recognition of 'personhood' (i.e. selfhood), defined as a status that is conferred on one human being by another in the context of relationship and social being. It implies recognition, respect and trust in forming such relationships. PCC stresses the importance of feeling valued and recognised as a unique individual.

Person-centred care puts the 'person', rather than the 'patient,' at the centre of the service, and adapts services to the person's unique context, history, needs and preferences. In doing so, the person's subjective experiences and the way the person perceives his or her reality, are acknowledged and valued. This approach to care requires the clinician to strive for empathy, respect and understanding in the process of forming a therapeutic relationship with the person and their carer(s) and family.

As a core principle of care, the person is always seen as an individual with a unique personal and cultural history. A specific behaviour may be a communication of an unmet need, and the response must include care beyond the physical needs of the person, or medication alone. It is essential to remember when providing care to people with dementia that behaviour is an attempt to communicate and/or to meet a need. It is the responsibility of clinicians to identify and respond to the message being conveyed by the person.

This requires the person with BPSD, their carer and clinicians to work in a partnership to identify what matters to the person in developing a care plan, including a behaviour management plan. The care plan, including the plan for behavioural support, requires shared goals to be based on the person's values, experiences and preferences. Holistic goals (physical, psychological and social) should be considered. The development of trust and rapport is essential to enable this partnership. Factors that should guide assessment and care planning include:

- the person's response to past and current health care environments
- their personal history, cultural and religious background
- personal values, likes and dislikes, usual routines and preferred care approaches
- interpretation of causes/triggers for behaviours arising from unmet needs and/or the psychosocial environment
- carer and family advice on how to reduce triggers for behaviour in the health care context.

Person-centred care with Aboriginal and Torres Strait Islander peoples

Person-centred care for an Aboriginal and/or Torres Strait Islander person with dementia needs to be 'family-centred' and 'community-centred'. Culturally safe, appropriate, objective and reliable assessment and identification of cognitive impairment and dementia in acute care is required. The needs of every Aboriginal and Torres Strait Islander community are unique, as are the connections between community members and the broader community. Recognition

of the unique cultural and historical background of Aboriginal and Torres Strait Islander communities is essential to understanding the many factors that contribute to BPSD.

When providing person-centred care for an Aboriginal or Torres Strait Islander person, there needs to be an understanding of their connectedness to family, community and country; their role within family and community, particularly the significant and special role an Aboriginal or Torres Strait Islander Elder person may have within one or many communities; and the significant sense of loss, grief and trauma from past and current events that many Aboriginal and/or Torres Strait Islander people experience.

Aboriginal and Torres Strait Islander communities traditionally view health holistically: social and emotional wellbeing and 'health' are interlinked. Management of dementia and BPSD requires an understanding of ill health from a cultural perspective, including approaches to wellness. An understanding of local communities including local culture and service access issues will assist in the support of Aboriginal and Torres Strait Islander peoples who present with BPSD.

Aboriginal and Torres Strait Islander health workers are primary contacts for health-related issues. Effective assessment and management of BPSD may require additional attention to communication strategies using appropriate language, preferred ways of addressing Elders, body language and other cultural cues. 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. More information may be found in the [Aboriginal Older People's Mental Health - Resources for Local Health District SMHSOP](#) and [Communicating Positively: A Guide to Appropriate Aboriginal Terminology \(GL2019_008\)](#). Health workers supporting people with dementia in Aboriginal communities in remote areas of Australia can access [culturally appropriate posters](#) developed in collaboration with the DBMAS Northern Territory (DBMAS NT) and other expert clinicians. Additional resources are available through [Dementia Australia](#).

Person-centred care with people from culturally and linguistically diverse (CALD) backgrounds

Providing person-centred care for people living with dementia and their carers from CALD backgrounds is complex and requires understanding of individual experiences and unique cultural differences. Some people from CALD backgrounds with dementia, and their carers, may have different perspectives of what dementia is and/or view dementia and symptoms such as depression and anxiety as stigmatising.

Language issues may arise for older people with dementia from CALD backgrounds in care. People living with dementia who have migrated recently or long ago may only speak a language other than English, non-native English speakers may lose their English language skills, and people who are bilingual or multi-lingual may use a mixture of words from different languages when they speak. People with dementia may not understand what others are saying (receptive aphasia) or why others cannot understand them.

It is important to apply respectful, culturally appropriate ways of approaching and communicating with people and their carers to support effective therapeutic relationships and enable the best possible outcomes. People from CALD backgrounds and their families should receive support from bilingual staff and/or professional interpreters throughout their care experience. Appropriate resources may not be available to address all circumstances. Use of remote/video interpretation services during diagnosis and assessment of dementia in older people from CALD backgrounds should be obtained where needed.

Resources for aged care service providers regarding culturally appropriate care for people from CALD communities are available at [Australian Government Department of Health and Aged Care](#). Information, multi-media and other resources produced in various languages for people living with dementia and carers may be found at the [National Ageing Research Institute \(NARI\): Moving Pictures - Dementia awareness for CALD communities](#), [Dementia Australia](#) and [Dementia Training Australia](#).

Further information for clinicians working with Aboriginal and Torres Strait Islander peoples and

people from CALD backgrounds who are living with dementia and BPSD may be found in [Behaviour Management: A Guide to Good Practice](#).

Trauma-informed care practice

Person-centred care is respectful and responsive. It involves culturally safe practices and recognises that people have many different experiences in their lives. How people experience and express BPSD when they present to acute care settings may be influenced by the effects of past or ongoing traumatic experiences. Thus, person-centred care for people with dementia and BPSD requires trauma-informed approaches to care.

Some people and some communities are at greater risk of experiencing historic, recent, repeated and ongoing trauma than others. These include people who have experienced community violence, Indigenous peoples, Holocaust survivors, refugees and asylum seekers, and people who identify as lesbian, gay, bisexual, transgender, intersex or queer/questioning (LGBTIQ). It is essential that all people receiving care and their carers receive access to support from appropriate, identified community representatives, family and peers, and that families are consulted and involved in care decisions.

Trauma-informed care practice helps clinicians to better interpret, understand and address needs and behaviours in ways that support the person to feel as safe as possible in care. Trauma-informed care helps to avoid re-traumatising the person. It may help to avoid onset of BPSD and better enables optimal care and recovery. Trauma-informed care practice in acute settings may also help to support reduction in use of seclusion and restraint for people with dementia experiencing BPSD.

Develop a positive social environment through day-to-day interactions with the person and their family, thereby promoting respect and trust. Interact in a calm, respectful and professional manner with and around the person and their carer(s) and family throughout care; this may help reduce distress and associated adverse outcomes. Reassuring orientation to place and context may be helpful but always first consider the person's feelings and well-being. Some people may have specific needs for privacy, worry about access to exits or relate better when only one or two

other adults are present. Do not destroy hope or cause undue distress; for example, do not repeatedly remind a person that a family member is no longer alive.

More information on trauma informed care may be found at [NSW Government Agency for Clinical Innovation -Trauma-informed care and practice in mental health services](#) and [Royal Australian and New Zealand College of Psychiatrists: Trauma-informed practice](#), and more about strategies to reduce use of seclusion and restraint may be found in the [NSW Health Guideline GL2012_005](#).

Communication

Communication is the key to caring for the person with BPSD. It is important to remember that all behaviour is an attempt to communicate, e.g. to express discomfort, fear or thirst, or to request something such as a drink or information. People with dementia will experience a gradual decline in their communication skills, including their capacity for self-expression and understanding of others. Interpreting non-verbal and verbal behaviour is vital in understanding the message the person seeks to convey

A person with dementia may have difficulty in finding a word and may use another word instead of a more familiar one they cannot remember. They may talk fluently but not make sense to others. Speech may be slurred or slow. They may lose the normal social conventions of conversation, such as interrupting or ignoring a speaker or may fail to respond when spoken to. The person may also have difficulty expressing emotions in socially acceptable ways. Writing and reading skills deteriorate.

As noted earlier in this chapter, people with dementia may lose second languages such as English. In such cases:

- health care interpreters should be used wherever possible
- be aware of cultural and communication protocols
- multilingual resources such as communication cards and signs may be important aids.

These and other useful resources can be obtained from the [Centre for Cultural Diversity in Ageing](#) website.

The two most important elements of communication are **body language** – the messages given out by facial expressions, posture and gestures – and the **tone of our voice**. The actual words used are less important, so that

active listening, a warm smile, laughter or touch, where appropriate, may be more effective than conversation.

Strategies for improving verbal communication are included in Table 3.1.

Table 3.1. Tips for improving verbal communication

Non-verbal actions	Verbal actions
Minimise background noise	Talk in a gentle tone
Stay calm and still while talking, in the person's line of sight	Use short sentences and simple words
Ensure hearing aids are functioning and turned on Use a portable hearing amplifier if no hearing aids available	Explain all procedures and activities slowly in simple terms
Check that prescription glasses are available and worn	Allow time for what you say to be understood
Break down tasks into smaller steps	Clarify what they have said - repeat or reword
Communicate at eye level	Use personal references where available, e.g. "your son Yichén", "your pink jumper", "this photograph of your granddaughter", etc.
Use simple, calm hand gestures and facial expressions	
Allow plenty of time for the person to reply	

Further information on managing communication changes can be found at [Dementia Australia - Managing Changes in Communication](#).

Clinicians need to collect information and to communicate this information to others in the care team. As the person with dementia may have difficulty with communication, there may be greater reliance on the carer to provide this information. The '[Sunflower Tool](#)' (Figure 3.2), the '[TOP 5" Toolkits](#)' (Figure 3.3) or similar tools are helpful resources to collect, display, and communicate information easily and consistently throughout the person's care experience.

As indicated above, person-centred care is individualised to the person. This requires **an understanding of each person as unique**; that is, recognising and valuing their personal strengths and vulnerabilities, life experiences, cultural background, coping resources, and social, family and community networks. **Personal engagement** is required. That is, effective verbal and non-verbal communication pays respect to the person as a feeling and sensitive human being.

Understanding the person's socio-cultural background is crucial. Person-centred care approaches are influenced by the person's cultural and social contexts.

Case vignette - Nancy

Nancy is a 64-year-old Gundungurra woman. She is a respected Elder held in esteem by the community for her wisdom and cultural knowledge. Nancy lives with her daughter Susan and other family members. Many in their community are distressed by the changes evident in Nancy since she was diagnosed with vascular dementia two years ago. Nancy has been receiving in-patient treatment following a recent stroke.

Staff are concerned by Nancy's obvious unhappiness and frequent periods of tearfulness. Nancy has also expressed negativity and a sense of hopelessness, taking little or no interest in her recovery or rehabilitation plan. Night staff report that Nancy is awake for long periods during their shift. Susan is distressed when her mother refused food she regularly prepared and brought to the hospital. She reported her memories of seeing her grandmother present this way many years ago. Members of the community are keen to support Nancy, but they indicate that they feel rejected and unsure how to help when she doesn't respond to their visits or phone calls.

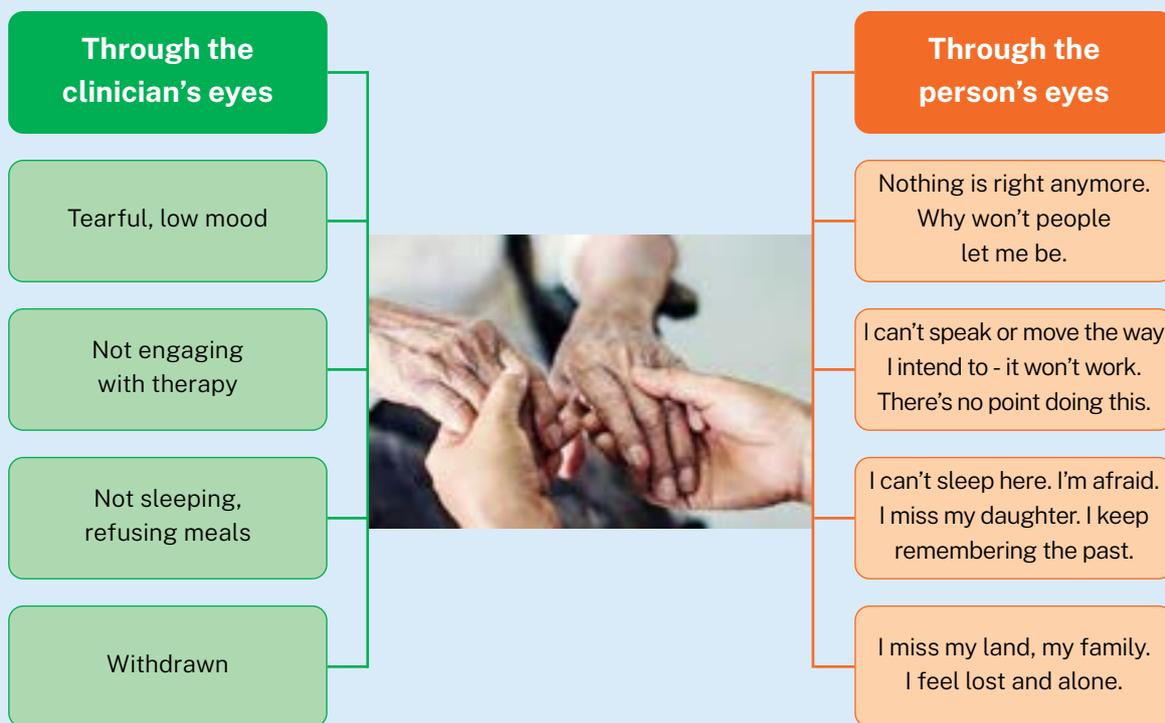
The medical team have investigated Nancy's low mood and a psychiatry consultation was requested to

differentiate her current symptoms from the underlying dementia or hypoactive ('quiet') delirium. A referral to the Aboriginal Mental Health Worker has also been made to ensure Nancy's assessment and ongoing care management and behavioural support plan are culturally sensitive and appropriate. The psychiatry registrar confirmed a diagnosis of depression and recommended a trial of psychosocial interventions initially and review. The

ward social worker contacted Susan to arrange a family/ community conference to uncover more about Nancy's social history, interests, the activities she enjoyed doing prior to the stroke and what is important to her.

This scenario illustrates the differences in perception between clinicians and the person with dementia. To assist the person the clinician must try to see the world as they do.

Figure 3.1. Relating to the person experiencing BPSD: through the clinician's eyes – through the person's eyes



Maximise residual strengths in the person

It is easy to become focused on the deficits of a person with BPSD. Successful interventions will usually, intentionally or unwittingly, be based upon building on a person's strengths. These may be intrinsic to the person, or in the supports around them. Strategies are best developed with a knowledge of the personal history and values of the person (see Chapter 3: Person-centred care). These may be aimed at maximising the person's overall function or their ability to maintain fulfilment of key life roles, thereby reducing the drivers for BPSD. Such strategies may also assist if resistance to care (such as bathing or eating) occurs.

After identifying strengths, strategies may include:

- task modification
- aligning daily routines to the person's preferences
- facilitating community integration
- equipment prescription and home modification
- risk reduction such as falls prevention.

Such approaches will often use the expertise of an Occupational Therapist. More information about the role of the Occupational Therapist in dementia can be found at [Dementia Training Australia: Guiding Occupational Therapy Practice for People Living with Dementia in the Community \(2018 Edition\)](#).

Case vignette – Thomas

Thomas is a 60-year-old man who has been admitted to the day surgery unit for arthroscopy under general anaesthetic. His husband Joe was not permitted to accompany him to the day surgery unit due to COVID restrictions, although he did attempt to explain at reception that Thomas would find it difficult to answer questions without his support.

Thomas has been medically well most of his life apart from a recent history of pain and mobility limitations due to a left knee injury. He was diagnosed with younger-onset dementia six months ago.

Thomas and Joe have been together for many years but their early years as a couple were impacted by the need for caution and secrecy around their relationship. Thomas' family ceased all contact with him when he eventually came out about his true relationship with Joe.

During the admission procedure Thomas was unable to provide details of his personal information or confirm when he last ate or drank anything. He quickly became distressed, frustrated and anxious and began calling out loudly for Joe.

Thomas' behaviour prompted a rapid response from multiple staff in the unit and he was quickly surrounded, further escalating his distress and anxiety. Another person receiving care nearby yelled at Thomas to "shut up".

Work with carers and families

The carer and close family are important members of the care team. Carers and other family members can provide a wealth of information that will help you better care for the person with dementia. Concurrently, it is important to understand and consider the level of health literacy of the person and their significant others. With appropriate education, the carer and family may be the best persons to advise you on how to respond to support the person with BPSD. The carer knows them intimately; particularly because they understand and can share the person's history and information on previous responses to the health care context. It is therefore essential to support the carer and family of a person with BPSD, and to utilise their expertise.

Utilising the family and carers' expertise

The presence of a carer or an appropriate family member may be an effective intervention in settling behaviour and distress. In particular, a carer may provide information on how to avoid triggering BPSD or strategies to deal with BPSD should they occur.

The person or people who know the person best should write down:

- strategies that keep the person reassured and settled
- situations/approaches that may cause distress
- signs that indicate need/requests
- set routines, rituals and objects that help the person settle

See Figure 3.3 Creating and using TOP 5 strategies at the end of the chapter for an example of how to collect, display and communicate such information with others.

Other strategies that are likely to improve outcomes for both the person with BPSD and their carer include:

- developing care plans with goals that are meaningful for the carer and person with BPSD
- ensuring discharge planning (including from ambulatory care) is discussed with the carer from the point of admission
- ensuring behaviour management plans can be continued with appropriate supports after discharge.

Supporting the carer

Carers may experience chronic fatigue, anger, depression, anxiety, frustration, isolation, changes in physical health, and financial strain and more. Interventions that may assist the carer, and thereby the person with BPSD include collaboratively determining the **social, economic and health care assistance required** to maintain optimal independence of the person.

Particular attention should be given to the following:

- issues and support needs in the person's social environment
- assessing the need for further assessment of dementia and providing a referral for further geriatric or psychiatric assessment in a timely way

- finances
- home or residential care environment
- domestic assistance, maintenance, in-home respite and personal care
- social networks
- transitional care to support the move from hospital to community
- respite care
- support for guardianship applications
- direct support for the carer's stress or mental health
- education about dementia and BPSD
- training in how to utilise strategies to support with settling the person presenting with BPSD.

It is also important to consider the following when supporting carers:

- level of health literacy
- potential implications of living in rural or remote areas
- the presence of other disabilities in the person or their carer
- being a member of an Aboriginal and/or Torres Strait Islander community or having a CALD background
- Identifying as a person who is L.G.B.T.I. or Q.

Table 3.2 at this end of this chapter provides a list of evidence-based tips for applying person-centred care with people with dementia and BPSD and their family/ carers in acute care settings.

Anyone with concerns about the quality of care provision can contact the [Australian Commission on Safety and Quality in Health Care](#) and/or the [Older Persons Advocacy Network \(OPAN\)](#).

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Wilson, A., Hutchinson, M., & Hurley, J. (2017). Literature review of trauma-informed care: Implications for mental health nurses working in acute inpatient settings in Australia. *International Journal of Mental Health Nursing*, 26(4), 326-343. <https://doi.org/10.1111/inm.12344>

Further resources

[Australian Commission on Safety and Quality in Health Care: A Better way to care - Safe and high-quality care for patients with cognitive impairment or at risk of delirium in acute health services - Second edition.](#)

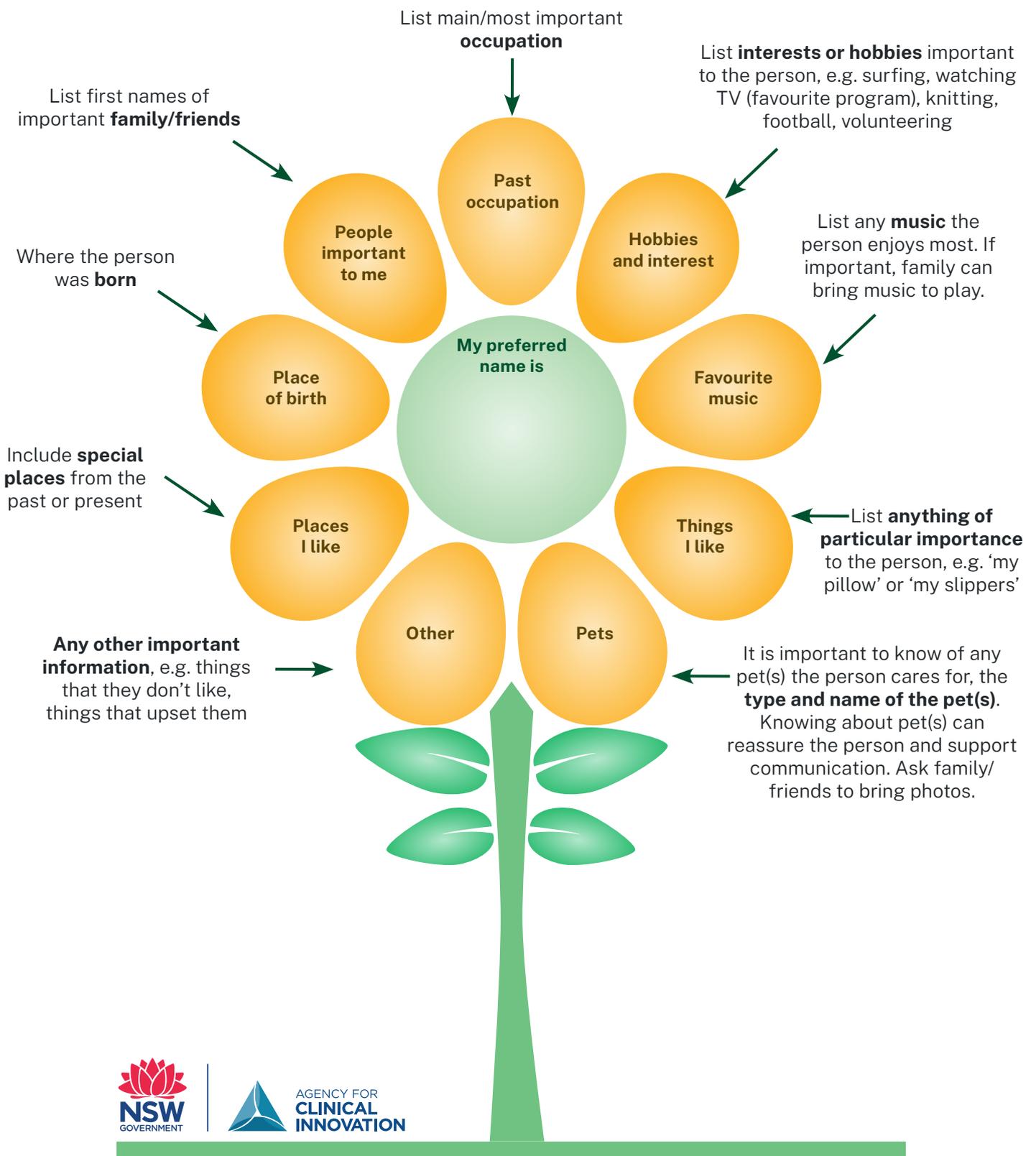
[NSW Government Agency for Clinical Innovation: Get to know your patients: "Get to know you" systems.](#) Includes links to **Sunflower Tool**.

[NSW Government Clinical Excellence Commission: Dementia Care - TOP 5 model.](#) **TOP 5** downloadable implementation resources and background information.

[Dementia Training Australia: Guiding Occupational Therapy Practice for People Living with Dementia in the Community \(2018 Edition\).](#) An updated and revised version of the original Dementia: Osborne Park Hospital Guide for Occupational Therapists in Clinical Practice.

[Dementia Australia: Support for families and carers.](#) For information on education and support groups call National Dementia Helpline 1800 100 500 or enquire online.

Figure 3.2. Creating and using a 'Sunflower Tool' with a person living with dementia and carers



Acknowledgement of source: This figure has been adapted from the 'Sunflower Tool' resources created and designed by the Agency for Clinical Innovation (ACI) and sourced through the Care of Confused Hospitalised Older Persons (CHOPS) website 2021: <https://aci.health.nsw.gov.au/chops/chops-key-principles/effective-communication-to-enhance-care/get-to-know-your-patients>

Figure 3.3. Creating and using TOP 5 strategies with a person with cognitive impairment

<div style="background-color: #c00000; color: white; padding: 5px; text-align: center; font-weight: bold; font-size: 24px; margin-bottom: 5px;">T</div> <div style="background-color: #fff9c4; padding: 5px; margin-bottom: 5px;">Talk to the Carer</div> <div style="background-color: #c00000; color: white; padding: 5px; text-align: center; font-weight: bold; font-size: 24px; margin-bottom: 5px;">O</div> <div style="background-color: #fff9c4; padding: 5px; margin-bottom: 5px;">Obtain the information</div> <div style="background-color: #c00000; color: white; padding: 5px; text-align: center; font-weight: bold; font-size: 24px; margin-bottom: 5px;">P</div> <div style="background-color: #fff9c4; padding: 5px; margin-bottom: 5px;">Personalise the care</div> <div style="background-color: #c00000; color: white; padding: 5px; text-align: center; font-weight: bold; font-size: 24px; margin-bottom: 5px;">5</div> <div style="background-color: #fff9c4; padding: 5px;">5 strategies developed</div>	<h3 style="color: #c00000;">Identifying TOP 5 strategies</h3> <p>Work with the carer to create the TOP 5 most effective strategies to support care and communication with the person in the current setting.</p> <p>When creating a TOP 5 on a person with dementia, explain that you have questions about their family member/ person that they care for and that answers will assist with personalising their care.</p>
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Are there things/situations that you know of that may cause them distress?	e.g. colours, topics, gender of staff, visitors
If unsettled, are there words or actions that will help them to settle and calm?	e.g. listening to music, relocation, reading, lighting, cup of tea, read the paper
Do they have set routines that have been developed to help keep them reassured?	e.g. at bedtime, with meals, personal care, when taking medication
Do they ask repeated questions or have recurring issues that may need specific answers?	What is the preferred answer?
Is there somebody that they might call out for?	e.g. could be a person or a pet
Are you aware of any signs or triggers that indicate that they have an unmet need or a want?	e.g. fidgeting to indicate a need to go to the toilet

NEXT STEPS

Place document with completed questions into the clinical notes.

Place a 'TOP 5' tag or note on top of bedside notes so everyone in the team will be aware that strategies to support care and communication with that person are in the notes.

Place sticker/note in person's progress notes that says: "TOP 5 strategies identified and negotiated with the carer (who is the, e.g. partner, child, etc.)."

Acknowledgement of source: This figure has been adapted from material in the [TOP 5 Toolkit for Hospitals](#) that were designed by the Clinical Excellence Commission (CEC) and based on the TOP 5 initiative developed in the Central Coast Local Health District (CCLHD, NSW). Materials were sourced in 2021 from <https://www.cec.health.nsw.gov.au/improve-quality/teamwork-culture-pcc/person-centred-care/dementia-care>

Table 3.2. Person-centred care with people living with dementia and BPSD in health care settings

Communicate with the person	Use a gentle manner and clear and calm communication; reintroduce yourself, actively listen, remind/reorient the person who/where/why but don't argue with them, reassure the person.
Communicate with other staff	Use simple, clear, reliable systems across staff/wards/shifts for identifying when someone has dementia with or without BPSD.
Work with and support the carer(s) and family	Communicate regularly with the carer(s) and family, listen to and document their knowledge, apply the knowledge they share with you, support the carer(s) and assist them throughout their care experience—it will help the person, it will help the family, it will help you.
Ask about, assess and identify needs	Ask, assess and identify, don't assume: each person with dementia will have different needs and abilities in activities of daily living; some people will need more assistance, others will be more independent.
Investigate, do not overwhelm	Where there are communication difficulties, proactively assess for needs including thirst, hunger, pain, toilet use and soiled clothes/bedding, and explain what you are doing; asking questions is good practice but repeatedly asking people what they need may not be an effective strategy.
Consistency is key	Aim for familiarity, keep staffing and rooms consistent; avoid moving people where possible, avoid moving staff where possible, avoid surrounding the person with too many staff.
Calm environment	Try to reduce overstimulation in their environment, e.g. noise and glare.
Document, document, document...	Document psychological well-being and/or distress, and wherever possible document antecedents/triggers.
Get to know the person	Invest time getting to know the person in the near term to save time in the long term; the person's needs and responses will be related in part to their personal history, beliefs, culture, and social relationships.
Ensure that everyone gets to know the person	Use a simple, clear reliable system (e.g. 'Sunflower Tool') to document and remind staff of the person's preferred name, family, likes, dislikes, etc.
Tailor and target activities to the person	Tailor activities to the person and provide access to activity resources (e.g. easily replaceable, age-appropriate items such as playing cards, magazines, newspapers).
Personalise the environment	Encourage the carer and family to personalise the person's environment where appropriate and possible (e.g. photos, favourite blanket).
Involve the carer/family in care	Consider extending visiting hours for carers and family of people with dementia, invite interested family to assist with daily care practices such as meals, drinks, grooming.
Mealtimes are important - give people time and space to eat	Create protected mealtimes so that the person and their carer can focus on nutrition and hydration without interruption.
Help people to eat when and what they want	Provide 24-hour access to a range of beverages and foods including cutlery-free meals, finger foods, and snacks that meet the person's individual needs.
Help people who need help	Help people to eat in a timely manner; use a simple, clear, reliable system to identify who needs help and who will provide the help. Providing contrasting colours of crockery and food can help people to better see/identify their food.

CHAPTER 4

Assessment of the person with BPSD



Chapter 4 discusses the assessment and possible causes of BPSD in a person with dementia. Special attention is given to the assessment of delirium, the person's physical health and presence of pain (which can be easily overlooked), psychological factors and assessment for psychiatric disorders. The chapter introduces Maria, an 89-year-old woman who has been admitted to a general medical ward in a rural hospital.

- **The following factors require assessment:**

1. The person (for delirium, pain, unmet needs or other physical problems)
2. Safety
3. Communication
4. Environment
5. Psychological symptoms
6. Behaviours

- **The person may have:**

- communication problems and so they express unmet needs through behaviour, rather than through specific complaints
- personality and cultural factors and past experiences that influence why/when/what/how BPSD present

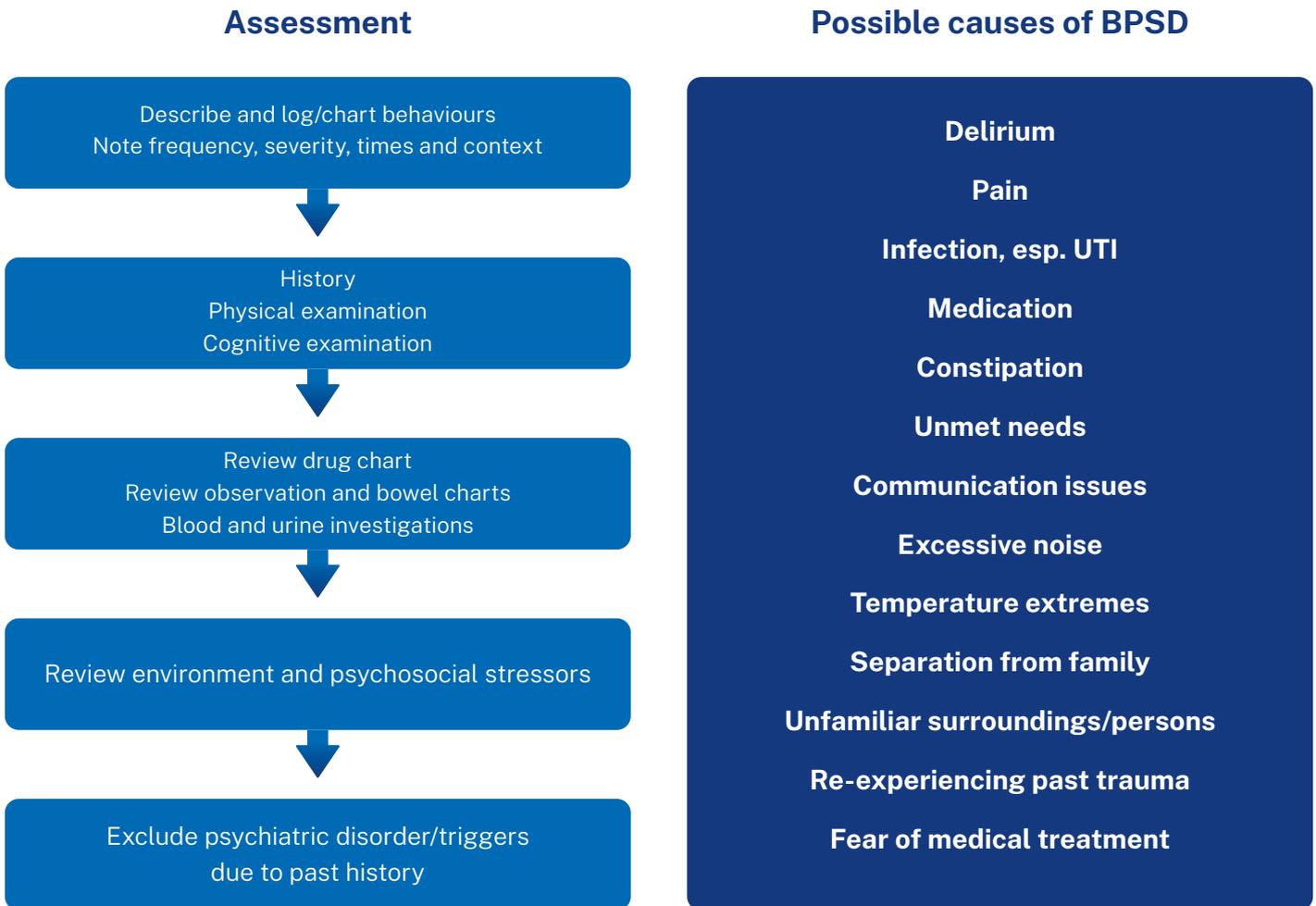
- **If dementia has not been diagnosed previously, determine if a diagnosis of BPSD is appropriate after acute physical and psychiatric problems have resolved**

Introduction to BPSD assessment

This chapter focuses on identifying the BPSD that the person may be experiencing, but it is equally important to identify the person's residual strengths and how these may be utilised. Carers are particularly important in identifying strengths. The person's existing cognitive and functional capacities and current support networks should be considered.

Assessment of the person with BPSD must cover multiple domains, as shown in Figure 4.1. As indicated in previous chapters, assessments should be conducted in a way that maintains the dignity and privacy of the person while ensuring their safety and minimising distress.

Figure 4.1. Assessment of BPSD



Maria's case vignette

Maria, an 89-year-old woman from a local nursing home, was admitted directly to the general medical ward of a rural hospital because of confusion. In hospital, she has walked into other persons' rooms. On one occasion when a nurse tried to take her back to her bed, Maria became very angry and tried to hit the nurse. She later said that all her money had been stolen and she wanted to find out who had taken it.

Maria's son said that she had been moved to the nursing home three years earlier because she had become "senile" and could not care for herself at home. Nursing staff at the facility reported that she did tend to wander aimlessly, including to other residents' rooms, but she was always polite and pleasant, and had never been paranoid. Her memory and wandering had been even worse than usual recently.

Maria's presentation is typical of someone with dementia and agitation, both of which had been noted in the community for some time. The delusion of theft is new. Although dementia may account for the worsening in her agitation and onset of psychosis, other causes must be considered in the assessment of BPSD.

Applying therapeutic relationship components may help to minimise the person's distress, reduce the risk of escalating responses and symptoms, and facilitate better assessment outcomes. As noted previously, these are:

- provide person-centred care
- use non-judgmental and non-confrontational approaches
- show sincerity and empathy
- use plain language and avoid jargon
- consult and involve carers and family.

Assess the person

Chapter 3 discusses person-centred care and aspects of the person that require assessment to enable acceptance and engagement in such care. This section identifies other priorities for assessment of

the person, particularly their physical health. Figure 4.2 outlines key factors to consider in assessment and treatment of physical illness.

Figure 4.2. Assessment of physical health

Assess and treat physical illness

First Priority Screen for and treat Delirium	Toxicity	Pain	Sensory impairment
Potential causes: Physical illness <ul style="list-style-type: none"> • Infection • Metabolic • Haematological • Cerebral • Cardiac • Endocrine 	From: <ul style="list-style-type: none"> • Medications • Polypharmacy • Alcohol/other drugs • Anaesthesia 	From: <ul style="list-style-type: none"> • Constipation • Wounds, fractures • Surgery • Comorbidities, e.g. arthritis, stroke 	Including: <ul style="list-style-type: none"> • Hearing • Vision

Delirium

Dementia is a chronic state of cognitive impairment. Delirium is an acute confusional state. The two conditions often co-occur. Dementia itself is a risk factor for delirium. The presence of delirium should be considered in any older person with new or worsening confusion and/or behavioural change. **Delirium is a very serious acute syndrome in older people. It can lead to changed behaviours. Detection and treatment are a priority.** Potential causes and investigations for delirium are listed in Table 4.1.

Characteristics of delirium

Indications that a person has delirium are:

- **sudden, acute onset** over hours or days
- **altered consciousness or awareness** disorientation
- **fluctuating presentation:** at times may appear to be functioning normally, at other times appears very confused and disorganised; similarly agitation may alternate with withdrawal
- **inattention:** unable to focus on conversations, with wandering and disorganised thoughts.

The Confusion Assessment Method (CAM) takes 5 minutes to administer and can assist clinicians in identifying and rating these issues. The CAM is available in the [Dementia Outcomes Measurements \(DOMS\) Suite](#). The 4 'A's' test (4AT) takes less than 2 minutes and can be used for people with sensory impairment. Information on these and other delirium assessment tools may be found in the [NSW Health - Agency for Clinical Innovation: Screening and assessment tools for older people resource](#).

Table 4.1. Causes and assessment of delirium

Causes of delirium	Investigations, as appropriate
Metabolic (renal impairment, dehydration)	Electrolytes and renal function Liver function
Infection	Full Blood Count, COVID-19 swab Mid-stream urine, chest X-ray
Physical trauma	X-ray suspected site of fracture
Neurological (stroke, haemorrhage)	Cerebral CT scan
Acute myocardial infarction	Electrocardiogram (ECG) cardiac enzymes
Endocrine	Thyroid function tests Calcium Glucose
Substances - intoxication, withdrawal	Check history of alcohol, benzodiazepine use or recent cessation of these or other medications
Drug toxicity, especially agents with strong anti-cholinergic activity (tricyclic antidepressants, oxybutynin, benztropine, olanzapine, chlorpromazine, antihistamines, incontinence medications) Opiate medications Anaesthetic agents	Review all medications – check digoxin, lithium, anticonvulsant levels
Sensory decline	Check aids for hearing and vision
Sleep deprivation	Check for pain

Other resources include the Royal Australian College of General Practitioners (RACGP) [The RACGP Aged Care Clinical Guide \(Silver Book\)](#).

Pain and other physical problems

Pain is a non-specific indicator of distress, which requires investigation to identify the underlying cause. People with dementia have a high prevalence of pain, but are more likely to have their pain unrecognised, under-assessed and inadequately managed. Poorly controlled pain can lead to sleep disturbance, depression, agitation and slower recovery after surgery.

Dementia impacts both the experience and reporting of pain. While there may be an alteration in the

experience of pain for the person, dementia inhibits the person's ability to communicate their pain accurately. Non-specific, non-verbal expressions of distress due to pain include grimacing and clutching at a part of their body. The use of a pain rating scale is recommended to improve the detection of pain in a person who has dementia (Appendix 1). Table 4.2 outlines some possible causes of pain.

Evidence-based guidelines for pain control should be followed.

Table 4.2. Possible causes of pain

Nociceptive pain	Neuropathic pain
<ul style="list-style-type: none"> • Musculoskeletal e.g. arthritis • Urinary retention; constipation • Cancer • Bowel disease • Fractures • Vascular disease • Dental • Pain in genital/anal area due to thrush, haemorrhoids • Bony protrusions due to weight loss • Wounds, including pressure injuries and skin ulcers • Gastro-oesophageal reflux 	<p>(Damage to peripheral or central nervous system)</p> <ul style="list-style-type: none"> • Neuropathy • Sciatica • Phantom limb pain • Trigeminal neuralgia

Physical problems associated with BPSD that should be assessed include:

- impaired vision (check that prescription glasses are available and worn)
- impaired hearing (check that hearing aids are available, batteries are charged and aids are worn)
- thirst or hunger
- dehydration, malnourishment, electrolyte imbalance
- nutrition (formal review by dietitian/clinical nutritionist)
- constipation and faecal impaction
- urinary retention
- urinary infection
- other infections such as cellulitis, COVID-19 which may present atypically
- medication non-compliance, toxicity, high anticholinergic load or polypharmacy.

Safety

Assessment of safety in a person with BPSD must be considered in the context of developing a behaviour management plan that balances identified risks with the risks of interventions, informed by the current and past values of the person and their carer. It must consider much more than the risk of aggression to others. Key risks to consider are outlined in Table 4.3 below.

Clinicians should:

- consider these risks within local policies and protocols for the assessment and management of risk and patient safety
- seek advice from more senior clinicians if unsure of appropriate action
- discuss their assessment and plan, in appropriate language and detail, with the person and the carer
- request pharmacy review if concerned about medications or interactions
- check policies on restrictive practices, e.g.:
 - [Safe Assessment Rooms](#)
 - [Aggression, Seclusion & Restraint in Mental Health Facilities – Guideline Focused Upon Older People](#)
 - [Seclusion and Restraint in NSW Health Settings](#)
 - [Management of patients with Acute Severe Behavioural Disturbance in Emergency Departments](#)
 - [Managing Acute Severe Behavioural Disturbance \(ASBD\) during COVID-19](#)

Communication

Chapter 3 provided information regarding how to communicate with persons with dementia and BPSD. As communication involves interactions between people, it is essential to also assess issues that may impede such communication. Some people with dementia may apparently retain adequate verbal skills although this may mask issues related to reliability of content or disturbance of expressive or receptive language function. Receptive aphasia, where the person can hear you but not process what is being said, is often missed. Assessment by a

speech therapist or other specialist may be needed at times for assessment of communication, and the development of strategies to overcome these. A portable amplifier with headphones is inexpensive and should be used whenever someone has difficulties with hearing that are not improved by wearing hearing aids. Note that impaired attention can also present as an apparent hearing impairment; attention ability can fluctuate significantly. Common reasons for communication difficulties with a person with BPSD are outlined in Table 4.3.

Table 4.3. Common reasons for communication difficulties with a person who is experiencing BPSD

Individual	Environmental
Hearing impairment (including reversible) Visual impairment Disturbed language (written and/or verbal) function: <ul style="list-style-type: none"> Expressive dysphasia and/or Receptive dysphasia Dysarthria Thought disorder 	Excessive background noise Excessive visual activity/stimuli Use of different language to person's Written material too small, or too far away Inadequate time for communication

A knowledge of cultural differences in communication may be required as well as the use of interpreters or 'cultural brokers' such as family or a bilingual mental health worker. Staff should consider opportunities to

develop their own cultural competency skills. In some cultures it is important that communication be with a professional of the same sex as the person.

The environment

Environmental factors which may contribute to the behaviour are included in Table 4.4 below.

Table 4.4. Common environmental factors impacting on a person who is experiencing BPSD

Noise (e.g. loud TV/music, unanswered call bells, medical equipment, doors banging, other people)	Extremes of temperature
Clutter (such as furniture)	Other people who are intrusive
Extremes of lighting	Reminders of past institutionalisation
Mirrors	Unfamiliar environment
Misinterpretation of contrasting surfaces (e.g. change in floor covering/colour)	Disturbance around other persons' care needs

Psychosocial factors and psychiatric disorder

Agitation, aggression and mood changes are all non-specific presentations, common to dementia, stress, and psychiatric disorders. Dementia and a psychiatric disorder may coexist or a person with dementia may have a pre-existing psychiatric disorder. Psychosocial stressors may contribute to agitation or mood changes. Common stressors are:

- change in usual routine, such as community services closing for holidays
- new or unfamiliar support workers or care staff
- family or friends absent, or changes in availability.

Persons with dementia may react to changes in the behaviours of others around them. e.g. in response to a stressor, such as the death of a family member, without being able to articulate why they are becoming upset or agitated.

Psychiatric disorders, whether new presentations or a recurrence of a long-standing disorder, may lead to behavioural changes. As in all psychiatric and medical assessments a careful history usually provides the most information to guide assessment, complemented by careful direct assessment of the person and consideration of investigation results.

Agitation associated with severe depression may be mistaken for dementia. This should be particularly considered in the presence of:

- a past, or family, history of depression or other mood disorder
- rapid onset of symptoms
- suicidal ideation or a desire to die
- prominent anxiety
- delusions of poverty, guilt or nihilism (e.g. their bodies are empty or rotting)
- frequent 'don't know' answers and/or the person highlighting their memory problems.

Mood 'lability' in which expression of emotion changes rapidly (e.g. crying to calm, then smiling) – often within minutes – is more frequently present in delirium or dementia than in depression; this may be a difficult differential diagnosis.

If there are concerns about depressive symptoms, the possibility of suicidal ideation should always be sensitively explored.

Case vignette - Yasmin

Yasmin was an 82-year-old woman who was born in Iran and had a history of bipolar disorder. She was admitted from home to a geriatric unit with a three-week history of agitation and confusion. Her family reported that whereas she communicated well in English and was self-caring before, she now only spoke in Farsi and was not cooking or eating properly. A UTI and dehydration were treated, and she was noted to have stable chronic renal failure.

Her behaviour in hospital did not change over the next two months. She was noted to be responding to voices, giggling at times, believing the secret police were going to kill her, and restless at night. She was discharged to a residential aged care facility; her discharge diagnoses were dementia and BPSD. Her discharge medications included risperidone 1mg BD.

Whilst some cases of delirium may be prolonged, multiple and/or severe acute physical problems are usually present in prolonged episodes, which is not the case here. In such cases, psychiatric disorder needs to be considered. In addition, Yasmin was living independently prior to hospitalisation, which should raise concerns about the diagnosis of dementia.

If psychiatric symptoms or behavioural problems persist once physical illnesses have been treated adequately, the clinician needs to consider whether a psychiatric disorder is present. Given the similarities between BPSD and the common psychiatric disorders (depressive disorder, psychotic disorders and mania), referral to a psychiatrist or specialist mental health service for older people is essential.

The GP asked an old age psychiatrist to see Yasmin at the facility. The psychiatrist assessed her with her daughter-in-law and an interpreter present. Knowledge of the history of Iran during her lifetime and her personal exposure to trauma were important in understanding her distress, as was the use of an interpreter. The psychiatrist reviewed her hospital mental health files, which showed multiple admissions for acute mania over the previous 20 years, with clinical features similar to her current presentation and response to lithium. The family said that another GP had ceased her lithium because of renal failure one week

before she became unwell. A provisional diagnosis of acute mania was made and she was admitted to hospital, where sodium valproate was commenced. She responded well within four weeks, with complete resolution of her agitation,

insomnia and psychosis, and she started speaking in English again. The family said she had returned to her usual self. After cognitive testing as an outpatient, she was diagnosed with mild vascular dementia.

Figure 4.3. Assessment of comorbid psychiatric illness

Assess and treat psychiatric comorbidities

NB. Assess and treat once physical issues adequately addressed, and/or if pre-existing psychiatric illness

Schizophrenia/ delusional disorder

- More extreme delusions
- Auditory hallucinations
- Past history
- Family history

Mania

- Persistent physical overactivity
- Rapid speech
- Difficult to interrupt
- Grandiose ideas
- Irritability/disinhibition

Depressive disorder

- Persistent depressed mood
- Morbid/suicidal thoughts
- Feeling of hopelessness/
worthlessness/guilt

Refer to specialist psychiatry services if there are persistent distressing symptoms or concerns regarding safety.

Further resources

Delirium

Australian Government Department of Health & Aged care [Delirium Care Pathways](#)

Other resources include the Royal Australian College of General Practitioners (RACGP) [The RACGP Aged Care Clinical Guide \(Silver Book\)](#).

Pain

[Faculty of Pain Medicine \(FPM\), Australian and New Zealand College of Anaesthetists \(ANZCA\) - Acute Pain Management: Scientific Evidence 5th Edition](#)

[Dementia Australia](#)

Assessing mental health needs

[NSW Health Agency for Clinical Innovation: Screening and assessment tools for older people](#). A joint initiative between the ACI and Ministry of Health. This site provides a centralised list of screening and assessment tools for clinicians caring for older people and can be used to help identify cognitive and mental health needs in older people. Contains 55 screening

and assessment tools relating to behaviour, cognition, delirium, dementia, depression, disability, multicultural tools and tools that may be appropriate for people from Aboriginal communities.

[Dementia Outcomes Measurements \(DOMS\) Suite](#). The DOMS project was originally commissioned under the Australian Government's National Dementia Initiative and was designed to develop a suite of instruments that would be used in Australia to standardise assessment and dementia outcome measures. Accompanying each tool is detailed information on the quality metrics for that tool, based on an extensive overview of the scientific literature. The DOMS Suite, hosted previously by the Dementia Centre for Research Collaboration (DCRC), is hosted by the Centre for Healthy Brain Ageing (CHeBA), UNSW Sydney.

See [NSW Health](#) website for emerging policy documents and resources for supporting suicide assessment and prevention

[\[Clinical Care of People Who May Be Suicidal PD2022_043](#) – currently under revision]

[Safe Assessment Rooms GL2020_001](#)

CHAPTER 5

Act 1: Non-pharmacological and psychosocial management



This chapter discusses modifying the environment and activities to provide tips on how to adapt care to address the person's particular needs. The chapter also presents a before and after scenario to demonstrate the positive outcomes that are possible when non-pharmacological interventions are used.

- **The care of a person with dementia and BPSD should be managed within a model of person-centred care**
- **Display key personal information**
- **Identify residual strengths for use in management**
- **Actions include:**
 1. Maintain safety
 2. Modify communication (see Chapter 3)
 3. Modify environment
 4. Meaningful activities
- **Distinguish between a palliative approach to care and end-of-life care**
- **Consider the following specific non-pharmacological therapies:**
 - behaviour management
 - aromatherapy
 - music
 - validation and reminiscence therapy
 - sleep hygiene
- **In general, the person should be cared for in an environment free of restraints**
- **Work with the carer**

The care of a person with dementia and BPSD should be provided within a model of person-centred care. This chapter outlines specific and non-specific non-pharmacological strategies that may be used. Restraint is not a therapeutic intervention. Generally, people should be cared for in an environment free of restraints.

Maintain safety

In considering non-pharmacological management it is essential to ensure overall safety issues are addressed. Key aspects in achieving this include:

1. Meet ongoing needs.
 - a. treat causes of delirium
 - b. manage pain and other physical conditions
 - c. meet unmet needs
 - d. treat psychiatric illness
- e. continue review and treatment of other physical conditions such as polypharmacy, nutrition, falls and pressure areas.
6. Escalate response if there is an immediate risk.
 - a. good, calm communication combined with a 'safe space' and time can assist an agitated person with BPSD to become calm
 - b. this may require modifying the person's environment, staff routines, or the location of other people who are receiving care
 - c. in hospital, know your local procedures for managing behavioural emergencies
 - d. in the community, discuss the appropriate use of emergency services with carers.
3. Ensure the 'Cycle of Care' continues:

ACCEPT- ASSESS - ACT- REASSESS.

Behavioural assessment and management

Behavioural management requires a thorough assessment (see Chapter 4) and structured and systematically applied interventions, such as using an individualised ABC approach. This can be applied by a variety of health professionals; advice should be sought from an appropriately trained clinician in more severe cases.

The ABC approach is a way of characterising precipitating events and resultant behaviours, as follows:

A: the **antecedent** event or events that lead to the behaviour of concern. The various physical, environmental and psychiatric antecedents have been outlined in chapter 4.

B: the specific **behaviour** observed.

C: the **consequences** of the behaviour on the person, staff, other people and the environment.

It is important to:

- document all incidents, keep a chart of frequency, severity and other details
- understand the context and contributing factors
- **discuss** with all staff, family and other carers
- determine the risks
- determine whether the behaviours relate to the person’s background
- consider the multiple factors contributing to the behaviours and prioritised solutions when devising a behaviour care plan.

Vignette

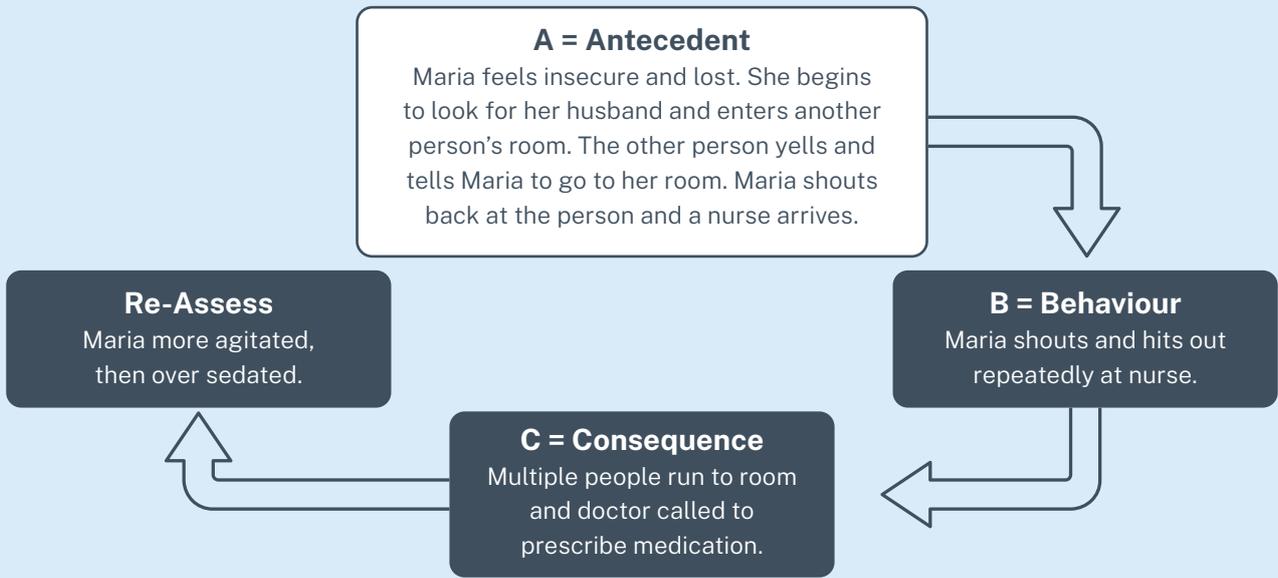
Maria is 89 and experiences behaviours and psychological symptoms associated with dementia. Her searching for her husband is perceived by others as aimless and intrusive wandering. When staff attempt to direct Maria back to her room she can become verbally and physically aggressive. Refer to page 28 for full scenario.

Table 5.1 and Figure 5.1 illustrate the application of the ABC approach to the assessment of searching and intrusive behaviour exhibited by Maria.

Table 5.1. ABC chart entry

Date / time	Antecedent (before behaviour)	Behaviour (provide details)	Consequence (what happened next)	Re-assess/comment
25/12 16:00	Maria looking for her husband, entered Room 12. Person in bed 4 yelled at her; Maria yelled back. Person in bed 2 then shouted at Maria and called for a nurse.	Repeated shouting. Nurse entered Room 12 and approached Maria who hit nurse 4x with fist.	Two more nurses entered Room 12 and attempted to remove Maria from the room. Doctor called. Maria continued to hit out. Meds given 16:25.	26/12 04:00 Maria slept 12 hrs. Poor balance on walking.

Figure 5.1. ABC assessment: behavioural assessment and intervention using a person-centred care approach



Maria is 89 and experiences behaviours and psychological symptoms associated with dementia. She enters other people's rooms while searching for her husband. She becomes upset when confronted and defends herself by hitting if others try to guide her back to her room.

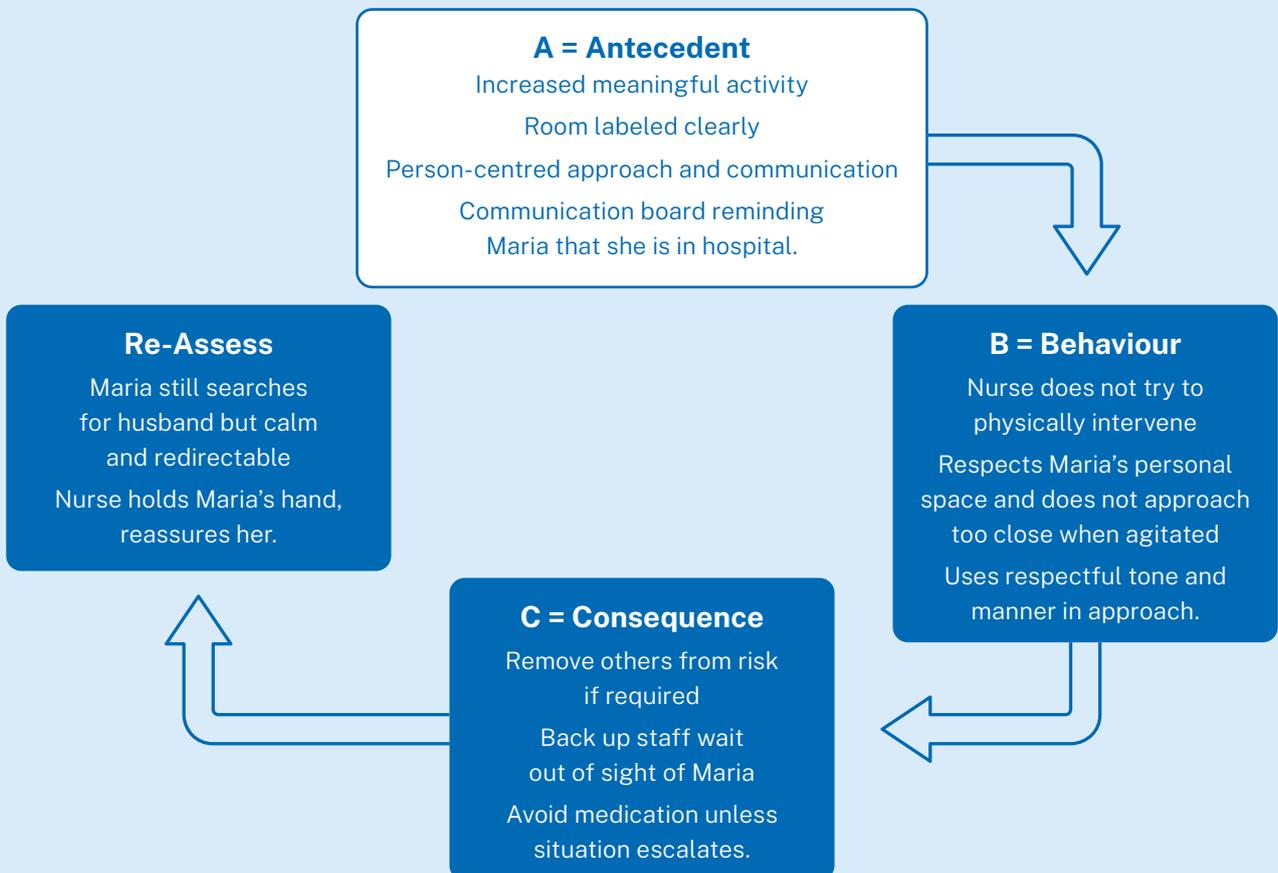


Table 5.2. Common diversional or recreational activities

Category	Activity
Creative	Knitting, drawing, painting, woodwork, music and art performance and appreciation, hobbies
Cognitive	Card games, board games, reading, book club, console games, bingo etc.
Cultural	Activities and excursions associated with community and religious festivals such as Christmas, Chanukah, Ramadan, Diwali, Vesak, local food festivals etc., participation in and appreciation of sport, dance, singing, drama art and music
Physical	Walking, exercise, aerobics, aqua aerobics, supervised swimming, gardening, yoga
Sensory	Cooking, aromatherapy, smelling the flowers, hand and other massage

Modify the environment

A person-centred assessment guides appropriate modification of a person's environment (see Chapter 3, Table 3.2). Evidence suggests that changing the environment to make it more dementia-friendly may help to keep healthy walking behaviour from becoming wandering/exiting.

Priorities, and the ability, to do this may be different in different settings.

In hospital consider:

- personalising the person's room or bedside area, e.g. displaying personal items such as photos that help in the understanding of the person and provide prompts for social connection
- if safe to do so (e.g. no infection risk or if items are replaceable), ask the carer(s) to bring specific individualised items relating to hobbies (e.g. knitting, personalised music/player)
- displaying signs to assist orientation to key areas (e.g. bed, toilet, staff) in the person's primary language
- displaying information about the person's life and preferences, in particular their interests and hobbies, that is readily accessible to treating staff
- changing the person's room to one closer to main clinician activities, or away from 'triggers' (including other people receiving care)
- increasing exposure to natural light
- replacing poor lighting
- night lighting matching past preferences
- reduce glare/reflections/shadows

- adding communal areas with amenities
- changing wards to an area designed for people with dementia.

At home consider:

- ensuring the person's room or bedside area has objects they still recognise, e.g. personal items such as photos may need to change to older ones
- displaying signs to assist orientation, if required
- developing an area for the person to walk safely
- changing night lighting
- removing or covering mirrors.

Further information on the environment and dementia can be found at the [Dementia Australia website](#).

Modify activities

A key factor in managing BPSD is applying knowledge about what the person with dementia liked doing before they developed dementia and what they currently like doing. An understanding of the person's preferred music, movies, pastimes, hobbies, reading and their preference for physical activities and excursions can be used to divert the person and thereby avoid escalation of BPSD while at the same time meeting needs for meaningful activity, stimulation and social contact. This may help to reduce loneliness, boredom and frustration, as well as enhance cognition and quality of life.

Staff working in hospital in-patient units may ask the carer(s) to bring in familiar materials or may develop a set of local resources in conjunction with allied health and nursing staff. Sometimes this can be done collaboratively by nursing staff and carers in a

general ward without special equipment. Other times a diversional therapist, an individualised program or specific equipment may be required. Staff in health care settings that often accommodate people who present with BPSD may wish to develop a set of appropriate equipment and/or develop mechanisms to assist carers to obtain these in a timely manner.

Examples of diversional activities are presented in Table 5.2 by category. Different activities will be suitable for different settings. [The Sunflower Tool](#) (Figure 3.2), the [TOP5 toolkits](#) (Figure 3.3) or similar tools may be used by clinicians to highlight the individual's likes and dislikes to facilitate person-centred care.

Considerations for people with COVID-19

This Handbook has been updated in the midst of the COVID pandemic which has highlighted specific challenges in the care of people experiencing BPSD. Guidance has been developed to support clinicians in this context which may also be relevant in the case of future pandemics. For additional resources see [Australian Commission on Safety and Quality in Health Care – Cognitive impairment and COVID-19](#).

If a person with dementia contracts COVID-19, there needs to be balance between social isolation, which can worsen anxiety, depression and agitation, and the need to provide a safe environment that allows adequate room for the person to walk around. In applying the appropriate infection control measures, it is important to remember that many people with dementia lack insight into the need to socially distance, wear masks and maintain hand hygiene. Separation from people who do not have COVID-19 is recommended. One-to-one care may be required; staff and carers will often need to redirect the person and provide distracting activities.

Further advice is available in the [NSW Health Acute Severe Behavioural Disturbance \(ASBD\) management during COVID-19: COVID-19 Acute Severe Behavioural Disturbance Risk Formulation Framework](#).

Specific Non-pharmacological treatments

Many psychological and alternative therapies have

been researched in dementia, each with the advantage of being associated with no or few adverse effects and requiring little additional training or resources. Table 5.3 provides a list of possible influencing factors and interventions that may be useful for general BPSD and for specific behaviours and symptoms. Table 5.3 and associated references are located at the end of this chapter. Staff working in wards caring for people with dementia should consider which therapies are to be resourced and used.

In general, non-pharmacological treatments should be tried first. In emergency or acute situations associated with risk to the person or others, medication may be required as an immediate response in addition to non-pharmacological treatments.

Aromatherapy and hand massage

Lavender oil may have limited temporary benefits for calming agitation. The main benefit may be to create a more pleasant environment for people in care, visitors and staff. The advantages of aromatherapy include that it is well tolerated and easy to administer by applying a few drops behind the person's ears or on their pillow. Always check that the person finds the aroma pleasant prior to use. Hand massage/therapeutic touching may also be a positive non-verbal communication. Note individual allergic reactions and preferences should be monitored.

Music therapy

When personalised to the person's preference, music can be very effective. There is some evidence that individualised music listening may help to lessen depressive symptoms, anxiety, and verbal and physical agitation in the short term.

Psychological interventions

All interventions should be applied within a person-centred framework and trauma-informed awareness that the person's individual experiences may lead to them reacting adversely.

Validation therapy involves acknowledging the person's feelings in the here and now as 'real' to the person, irrespective of facts. For example, an agitated person may say she cannot find her (deceased) husband. Rather than reply that he has passed away,

a more appropriate response is to acknowledge how she must miss her husband and to then discuss their relationship.

Reminiscence therapy aims to stimulate memory in the context of a person's life history. This may be about past personal events in their family or work. It may be about music of their era, or local and international events.

Orientation therapy aims to re-orientate the person by providing information about time, place and important others. The use of clocks, personal mementos, and regular visits from close family or friends can be helpful. Light should be bright during daylight hours. A night light may help reduce confusion and restlessness. Orientation therapy and human presence may be helpful approaches for psychotic symptoms including delusions and hallucinations.

Sleep hygiene

Most people with dementia experience sleep difficulties that are associated with worsening of cognition, mood and behaviour. The sleep architecture is disrupted in dementia. In particular, there may be disruption of the sleep-wake cycle due to environmental changes or physical problems. Delirium often causes reversal of the sleep-wake cycle.

Physical reasons for poor sleep that should be investigated and treated include:

- pain
- urinary symptoms
- lack of physical activity
- Restless Legs Syndrome (RLS)
- sleep disorders, such as REM Sleep Behaviour Disorder (which is common in Lewy body dementia) or Obstructive Sleep Apnoea.

Psychiatric reasons include

- depression and anxiety
- delusions or hallucinations
- mania or hypomania.

Simple environmental strategies that can be used to promote a regular sleep/wake cycle include:

- going to sleep and waking at regular times

- engaging in physical activity
- modifying ADLs
- if person is sleepy during the day, it may be helpful to encourage a nap after lunch and limit this to 45 minutes
- avoiding sleep in the early evening
- ensuring the sleeping environment is cool and well ventilated, free of distractions (noise and excess light) and the bed is comfortable
- avoiding heavy meals or caffeine in the evening.

How to advise carers:

- suggest that they consider sleeping in another room or having an occasional night of respite (e.g. asking someone else to sleep over)
- provide education about the increased fragmentation of sleep with age and in dementia
- provide practical training in improving sleep hygiene
- refer to Carer Support services or Carer Gateway.

Other considerations

Apathy

Apathy is associated with increased disability and reduced quality of life for both the person with BPSD and their carer. Research into effective interventions is sufficient to recommend the use of non-pharmacological strategies, but insufficient to support the efficacy of specific therapies. Types of therapies that have been used to address apathy have included exercise, music, multisensory approaches, presence of animals, special care programming, and therapeutic activities. Arranging a schedule of activities for the person may be helpful. Usually therapy needs to be sustained for effects to continue.

Revising approach to activities

The person's personal history and cultural background must be considered when planning and undertaking care or recreational activities. The timing of activities, especially personal care is important. If the person is not cooperative with personal care, consider allowing tasks such as showering to take place at a later stage or by whom they would prefer as their helper. Where possible consult the carer for essential information on how to provide appropriate individualised support.

One-to-one staffing

Although this is not an evidence-based treatment, one-to-one staffing, usually a 'nurse special,' refers to the employment of one trained clinician to maintain exclusive visual and/or proximity to one or more people.

The aims are to further assess the person, minimise the risk of harm to the person, staff or others, observe and document behaviours, provide early notification of possible adverse events, engage, build rapport and provide non-pharmacological management. One-to-one care also provides an opportunity to help alleviate boredom, isolation and loneliness via individualised social support which can reduce the incidence of BPSD.

A nurse, or patient, special may be appropriate in the following situations associated with increased risk, when routine interventions are inadequate:

- the potential for exiting the ward/building
- significant risk of harm to self or others
- observation of adverse effects due to medication
- the need for intensive and complex nursing care, beyond available resources
- high falls risk despite the use of environmental and mechanical interventions.

In some situations, the carer(s) may be able to provide a similar role, within the scope of locally agreed practice.

Palliative approach vs end-of-life care

The distinction between a palliative approach, focusing on quality of life, and palliative care, focusing on terminal care, is often poorly recognised. A palliative approach early in the continuum of care may help to improve the quality of life for a person living with dementia and their carer(s). End-of-life care is intended to assist the person to experience a better quality of death when they are at the end-stage of their illness. Although it can include end-of-life care, palliative care is much broader and can last for longer.

Palliative care and end-of-life care both involve early identification, and appropriate assessment and treatment, of pain and other distressing symptoms. A

person-centred approach that respects the individual's personal and cultural beliefs, attends appropriately to consent and advance care directives, involves the carer(s) and close family members, and clearly identifies the goals of treatment as well as potential side effects should help inform this distinction.

[The Royal Commission into Aged Care Quality and Safety](#) has called for improved access and higher quality of palliative care and end-of-life care for older Australians. Dementia refers to a group of neurodegenerative disorders with overlapping but variable, symptoms and patterns of progression. It is difficult to predict the time course of progression for a particular person. This should not prevent recognition, and sensitive discussion, of the irreversible nature of dementia.

While there are no treatments that 'cure' dementia, interventions that aim to address co-morbid conditions, whether physical or psychological may be implemented. In this sense, a palliative approach, focused on quality of life rather than curing dementia as an illness, may be appropriate from the time of diagnosis. This may inform decisions regarding interventions for other conditions but should not lead to an assumption that a palliative approach must be taken for co-morbid conditions. Indeed all efforts should be made to maximise the duration of time an individual experiences optimum quality of life.

This is very different from a decision to focus on palliative care during the terminal phase of dementia. A decision to move to palliative care must be made in partnership with a person responsible, considering the previously expressed views of the person with dementia and when it is clear that reversible factors such as delirium and depression are not making the person's dementia or BPSD appear falsely advanced. The latter point is vital – resolution of the impact of physical illness and psychological disorder on cognition and function may take weeks to months after treatment.

The implementation of palliative care should involve a senior medical clinician. Clinicians should be familiar with [NSW Health advance care planning policy directives](#) and encourage the discussion of related issues whilst the person can express their views.

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Further resources

[Royal Commission into Aged Care Quality and Safety: Final Report](#)

[Dementia Support Australia \(DSA\) Behaviour Support Plan \(BSP\) Resources](#)

[Behaviour Management a Guide to Good Practice Managing Behavioural and Psychological Symptoms of Dementia \(BPSD\)](#)

[Australian and New Zealand Society for Geriatric Medicine, Position Statement 20: Sleep and the Older Person](#)

[Advance Care Planning Australia: Health professionals: roles and responsibilities](#). A service funded by the Australian Government and administered by Austin Health. Advance care planning support service 1 300 208 582.

[Australian Commission on Safety and Quality in Health Care: Delivering and supporting comprehensive end-of-life care user guide](#)

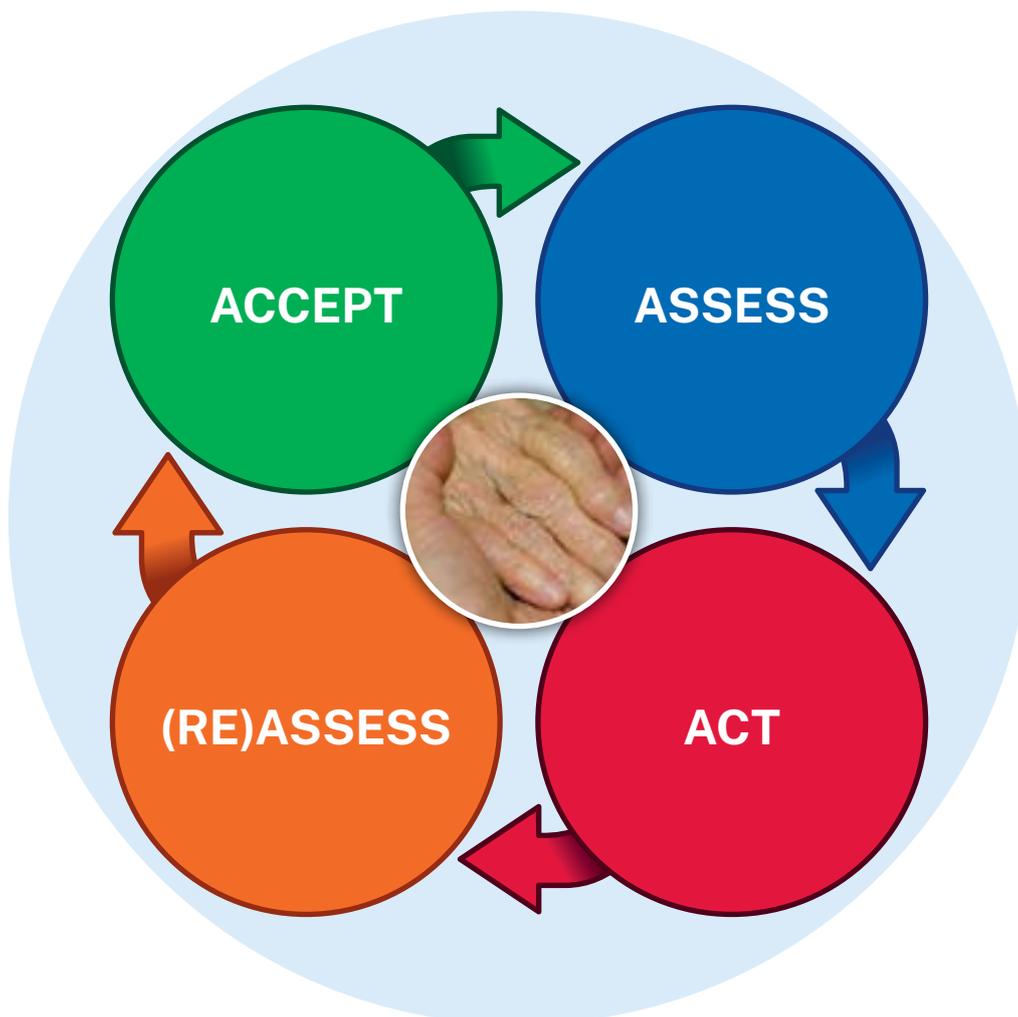
[International Neuropalliative Care Society \(INPCS\): Resources for Healthcare Professionals](#)

Table 5.3. Non-pharmacological interventions for general BPSD and for specific behaviours and symptoms

Behaviour or symptom	Possible influencing factors	Interventions that may be helpful based on currently available evidence
General BPSD	One or more of the factors listed below for individual BPSD	<ul style="list-style-type: none"> • Exercise tailored to the person’s needs and characteristics • Psychoeducational interventions for carers used in Australia to develop problem-focused coping strategies • Functional analysis-based interventions, e.g. Antecedent-Behaviour-Consequence-Description (ABCD) approach and analysis of cause/purpose behind behaviour that informs individualised targeted strategies • Music therapy • Reminiscence therapy • Analgesic pain management using a stepped protocol, low quality evidence
Aggression	Delirium, pain, use of physical restraints, loss of functional abilities, more direct care	Outdoor activities/gardening, massage and touch therapy Note: these interventions were assessed in long-term care and community settings and have not been assessed in hospital settings
Agitation	COVID-19, hospitalisation, seclusion/isolation, delirium, pain, benzodiazepines, younger age, younger onset dementia, poor communication techniques by health care staff, diagnosed Alzheimer’s dementia (AD)	Responding to unmet needs (e.g. pain, boredom, toileting), balanced sensory stimulation, appropriate music, and improving formal carer communication can improve some agitation; exercise combined with modification of any activity of daily living
Anxiety	Hospitalisation, pain, discomfort, loneliness	Some evidence that individualised music therapy may improve symptoms over time
Apathy	Behaviour variant Front-temporal Dementia (bvFTD) and young-onset AD, presence of other BPSD	Cognitive stimulation, therapeutic conversation, individually tailored activities

Behaviour or symptom	Possible influencing factors	Interventions that may be helpful based on currently available evidence
Depression	Vascular dementia, Alzheimer's dementia, people from CALD background, younger onset AD, some cardiovascular comorbidities, medication withdrawal, functional impairment, disengagement from exercise and activities	<p>Mixed evidence that individualised music therapy (passive and active) may improve mood and improve depressive symptoms over time, but also evidence of symptom worsening during intervention.</p> <p>A systematic review and meta-analysis comparing the efficacy of interventions for people with dementia who experience depression as a neuropsychiatric symptom, without diagnosis of major depression, indicated that drug approaches alone did not offer greater efficacy than usual care.</p> <p>Combined interventions: non-drug interventions including massage and touch therapy, cognitive stimulation combined with exercise and social interaction, and cognitive stimulation combined with a cholinesterase inhibitor were more efficacious than some drug interventions.</p> <p>Electroconvulsive therapy (ECT) may improve severe, otherwise intractable symptoms, but evidence from controlled larger trials are lacking.</p> <p>Multidisciplinary and non-drug approaches were found to be effective interventions with high probability of clinically meaningful benefit.</p> <p>Interventions found to be more efficacious than usual care in community, but not hospital, settings were:</p> <ul style="list-style-type: none"> • Animal therapy (e.g. activity, time spent with animals) • Cognitive stimulation (e.g. structured mental stimulation such as orientation, reminiscence, art therapy, games) • Exercise (e.g. active aerobic, resistance, or balance training) • Massage and touch therapy (e.g. massage, acupressure, therapeutic touch) • Reminiscence therapy (e.g. activity cueing memories from their life) • Multidisciplinary care • Occupational therapy • Cognitive stimulation and a cholinesterase inhibitor • Exercise combined with social interaction and cognitive stimulation • Psychotherapy (e.g. cognitive behavioural therapy, counselling, validation therapy, problem adaptation therapy, supportive therapy, or psychodynamic interpersonal therapy) combined with reminiscence therapy and environmental
Disinhibited behaviours	Young-onset, bvFTD, presence of other BPSD	No non-pharmacological method recommended in recent literature
Nocturnal disruption	Pain, discomfort, anxiety, depression, medication side-effect	No treatment shows definitive effectiveness

Behaviour or symptom	Possible influencing factors	Interventions that may be helpful based on currently available evidence
Delusions and hallucinations (psychotic symptoms)	Delirium, pain, AD, bvFTD, greater impairment	Reorientation, human presence
Vocally disruptive behaviours	Delirium, pain, discomfort, emotional distress, loneliness	Some evidence that individualised (favourite) music listening may improve verbal agitation in the short term; no accepted pharmacological intervention is efficacious
Wandering/exiting	Pain, boredom, seeking a toilet, fear, social isolation, loneliness, wanting to leave/go home, searching for a loved person or pet	Systematic review of the literature found no evidence to justify recommendation of interventions for preventing people with dementia wandering/exiting Review of dementia-friendly environmental design of health care and residential settings recommend modifying the environment: i.e. replace poor lighting, reduce glare/reflections/shadows, increase exposure to natural light, create clearer signage and visual cues, personalise décor, and add communal waiting/living areas and amenities



CHAPTER 6

Act 2: Pharmacological management



Essentials of prescribing psychotropic medication to the person experiencing BPSD

- Check for and treat reversible causes (see Chapter 4)
- Ensure there is baseline assessment of frequency and severity of behaviour
- Ensure that appropriate non-pharmacological strategies have been trialled first, applying a person-centred and trauma-informed approach
- Ensure consent is present (see Chapter 8)
- Continue cognitive enhancing drugs unless there is clear evidence that their introduction may have caused the BPSD
- Consider whether any psychotropics previously prescribed for BPSD can be discontinued
- Continue psychotropics prescribed for another clinical indication (e.g. schizophrenia) unless the BPSD is considered to be an adverse effect of the psychotropic
- Use the 3t approach to prescription, namely:
 1. Target behaviours or symptoms that potentially respond to psychotropics
 2. Titrate carefully; start at a low dose and increase slowly
 3. Time limit the use of psychotropics
- Stop if there has been no response within 4 weeks or significant adverse effects
- Avoid using multiple psychotropics as far as possible
- Review the ongoing use and dose of each psychotropic at least every 12 weeks
- Planned review of antipsychotics with view to withdrawal should occur within 12 weeks
- Depot antipsychotics should not be used (unless prescribed for a co-occurring chronic psychotic disorder)

Many types of drugs have been trialled in the management of BPSD, but most have limited evidence of effectiveness. Importantly, drugs must be targeted toward specific behaviours or symptoms. The chapter provides information on the use of analgesics, psychotropic medications (antipsychotics, antidepressants, benzodiazepines and other sedatives), cholinesterase inhibitors, memantine, anticonvulsants, neuromodulation in BPSD, recommendations for sequential drug treatment, information about PBS indications and deprescription of psychotropics.

Medication hierarchy

If medications are indicated, the following hierarchy is recommended:

1. **Analgesics** – for agitation, most commonly paracetamol 500gm ii tds for agitation; (may use buprenorphine transdermal patch if already on paracetamol)
2. **Antidepressants** – for depression, sometimes for psychosis; short acting SSRI; best evidence is for citalopram (and by inference escitalopram): if potential for QT prolongation is risky may choose sertraline,
3. **Antipsychotics** for aggression, agitation, psychosis – only risperidone is PBS approved
4. **Cholinesterase inhibitors** – limited evidence for benefit except for Lewy body dementia
5. **Memantine** – limited evidence for benefit
6. **Benzodiazepines** – short term benefit for anxiety and agitation
7. **Anticonvulsants** – for agitation, poor evidence, use in consultation with appropriate specialist

Analgesic medication

As has been noted in an earlier chapter, agitation and verbal aggression in dementia can be caused by acute or chronic pain. There are some behaviours, such as wandering and vocal disruptions, for which there is poor evidence of benefits from pharmacological treatments unless they target co-morbid conditions. For instance, a person who screams repeatedly may require treatment for pain. Apart from determining the pain aetiology, a pain management regimen is indicated if scores on the pain rating scale are suggestive of pain being a factor. An adequate pain management regimen may also prevent BPSD.

Psychotropic medication

Psychotropic medications are drugs that have specific effects on the central nervous system and the potential to change mood, perception or behaviour.

Psychotropics have an important but limited role in the management of BPSD. After following essential steps listed in the box at the start of this chapter and prerequisites below, if medications are indicated, potential benefits and adverse effects should be weighed up.

The prerequisites for prescribing psychotropics to manage BPSD are:

- a thorough physical assessment
- an understanding of the behaviour or psychological symptoms
- that previous adequate trials of non-pharmacological therapies have not been of sufficient benefit
- that the targeted behaviour and/or symptoms are appropriate for treatment with a psychotropic and the benefits outweigh any risks
- consent has been obtained correctly, specifically noting the new requirements related to chemical restraints which includes any drug used to control behaviour and restrictive practices for residents of aged care facilities and for prescription of antipsychotics in aged care (see Chapter 8).

It is recognised that in emergency or acute clinical scenarios associated with risks to the safety of the person and others, immediate use of medication may be essential (see Chapter 7).

It is also recognised that in a hospital setting delirium complicating dementia is commonly associated with psychosis and agitation. Antipsychotics may worsen outcomes in delirium and are best avoided. However severe behaviour change not responding to non-pharmacological interventions may persist in people with dementia long after the acute medical disorder resolves. In that situation, this pharmacological management guide can be used.

Deprescription of psychotropics

There is considerable evidence that psychotropic drugs are prescribed without obvious benefit but significant harm in people with dementia, particularly in courses of antipsychotic treatment that extend beyond 12 weeks. Before considering prescription of a new psychotropic agent, deprescribe other psychotropics that have not been beneficial. This can be best achieved through education and support of care staff, the person's carer and families and the use of a gradual deprescription regimen. See [NPS MedicineWise Reviewing and tapering antipsychotic medicines for BPSD](#).

It is important to communicate with the person's carer(s) regarding (de)prescription and effects of psychotropic medication.

Classes of Medication

1. Analgesics

A systematic stepwise pain management protocol was effective in reducing agitated behaviour (and pain) in home care residents with moderate to severe dementia and agitation, even though pain was not an eligibility criterion. In this protocol, 70% received paracetamol (maximum 3g daily) and 20% received buprenorphine patch (maximum dose 10 microgram/hr). It should be noted that only a very small proportion of participants in this trial (2%) were administered morphine, which should not be used routinely or without review by a consultant physician. Pregabalin was added for neuropathic pain non-responsive to other agents.

2. Antidepressants

The evidence for the use of antidepressants, particularly selective serotonin reuptake inhibitors (SSRIs) in the treatment of depression in dementia and

the non-affective symptoms of agitation, aggression and psychosis is less robust.

Antidepressants do not have an indication for depression or other behaviours in dementia but if the criteria for major depression are met, particularly in people with a pre-existing history of major depression, their use is covered by the PBS, otherwise they are 'off-label'.

SSRI antidepressants have been trialled in the treatment of depression in dementia and for non-affective symptoms of agitation, aggression and psychosis. Most of the RCTs have involved citalopram or sertraline.

For depression in dementia, two large RCTs did not demonstrate benefit of SSRI antidepressants or mirtazapine over placebo combined with non-pharmacological care. Hence the first line treatment for mild to moderate depression in dementia is non-pharmacological. SSRI antidepressants have a role in severe depression and moderate depression where non-pharmacological treatments have failed, and in people with a pre-existing history of major depression.

In the treatment of agitation, aggression and psychosis with SSRIs, the strongest evidence is for citalopram having benefit, with weaker evidence for sertraline. Benefits may take up to 9 weeks to emerge. Due to the delay of onset, SSRIs may not be of practical benefit if there is any urgency. They are recommended as first line treatment before antipsychotics in non-urgent cases and as second line treatments after antipsychotics where there is urgency for onset of effect.

Although citalopram has the strongest evidence of benefit, concerns have emerged about cardiac side effects and prolongation of the QTc interval. If used, the dose range in older people is 10-20mg daily with regular monitoring of the QTc interval. Sertraline has weaker evidence of benefit but does not prolong the QTc interval. The dose range commences at 25mg daily increasing to 50mg after a week to a maximum dose of 100mg daily. Other SSRIs such as escitalopram, paroxetine, fluvoxamine and fluoxetine have not been adequately studied in people with dementia.

Adverse effects of SSRIs can also include falls, sedation, increased agitation in the first week, sleep disturbance, GIT bleeding and inappropriate secretion of antidiuretic hormone resulting in low sodium levels. The latter requires monitoring of serum sodium particularly in the first 2-4 weeks.

Of the other antidepressants mirtazapine was ineffective in a major trial in treating depression or agitation in dementia and venlafaxine has had limited research, while tricyclic antidepressants such as amitriptyline, dothiepin and doxepin, should not be used because of the risk of increased confusion.

3. Antipsychotic medication

Atypical (second generation) antipsychotics

The best evidence involves the use of atypical antipsychotics in the treatment of severe psychosis, agitation and/or aggression. The results of randomised controlled trials (RCTs) suggest modest benefits and the potential for clinically significant adverse effects. In most responders, antipsychotics can be withdrawn after three months with stable or improved behaviours.

Four atypical antipsychotics - risperidone, aripiprazole, quetiapine and olanzapine – have RCT evidence in BPSD. Choice is based on a trade-off between benefits for specific behaviours, symptoms and PBS indications with risk of specific adverse effects.

Risperidone is the recommended first line antipsychotic in most treatment guidelines for the treatment of aggression and psychosis in Alzheimer's disease commencing at 0.5mg daily (in frail persons 0.25mg) to a maximum of 2 mg daily. It is less effective for agitation and is more likely to have extra-pyramidal side effects than other atypical antipsychotics; avoid in dementia with Lewy bodies.

The only psychotropic medication that has a specific PBS indication for the treatment of BPSD is risperidone. Its indication is limited to behavioural disturbances characterized by psychotic symptoms and aggression in Alzheimer's dementia. In persons receiving care in the community, a telephone authority is required for initial treatment of up to 12 weeks. This is limited to one authority in a 12-month period.

For people who have a significant response to risperidone and have not responded to non-pharmacological treatment, a management plan should include formal documented review and plan for cessation of treatment. The authority required listing provides detailed instructions or discussion with a psychiatrist, geriatrician or other medical practitioner, monitoring of adverse effects, cessation if harms outweigh benefits, and trials of reduction or cessation of therapy with maintenance non-pharmacological

treatment all to be documented in the medical record.

While telephone authorities are not required in hospitalised persons, if the persons are discharged on risperidone, authority scripts are likely to be required in the community.

Use of risperidone for BPSD in other types of dementia or other antipsychotic drugs in any type of dementia is 'off label'. However, the maximum period of 12 weeks initial treatment and the processes of review for continuation, tapering and discontinuation still apply. An exception is in people with pre-existing mental disorders such as schizophrenia or bipolar disorder where the PBS authority for those indications remains valid. Other antipsychotics (commonly olanzapine, quetiapine or aripiprazole) have less evidence and are off-label.

Aripiprazole is the second line antipsychotic with recent reviews finding it to have an optimal combination of safety and efficacy for BPSD, particularly on psychosis and agitation. Commence at 2.5mg daily aiming for 5mg after 2 weeks to a maximum of 15mg daily.

Quetiapine has a much weaker evidence base for effectiveness. It has a greater risk of sedation and cognitive side effects. Commence at 25mg daily and with gradual titration the maximum dose is 200mg daily (100mg in the frail). It is better tolerated in dementia with Lewy bodies but with little effect on psychosis.

Olanzapine has modest evidence of efficacy in reducing BPSD but the adverse effects including anticholinergic effects on cognition, metabolic syndrome and risk of cardiovascular disease outweigh the benefits apart from acute use in the very short term. The dose range is 2.5mg to 7.5mg daily.

Other atypical antipsychotics either have insufficient evidence in BPSD (e.g. ziprasidone) and/or an unacceptable adverse effect profile (e.g. clozapine, amisulpride).

Typical (first generation) antipsychotics

These include haloperidol, which is associated with greater neurological adverse effects, falls and depression, and chlorpromazine with strong anticholinergic adverse effects. While there is modest evidence of effectiveness of haloperidol, neither drug is recommended for use as the risk of adverse effects outweigh the benefits.

Depot antipsychotics, typical or atypical, should NOT be used to treat BPSD due to the persistence of

adverse effects for weeks to months.

There are several risks associated with the use of antipsychotics including increased mortality.

- i. Increased risk of stroke and other cerebrovascular events
- ii. Confusion and decline in cognition
 - olanzapine and quetiapine are more sedating than risperidone.
- iii. Neurological adverse effects:
 - a. akathisia: subjective motor restlessness, manifesting as an inability to sit down, pacing
 - b. parkinsonism including tremor, stooped gait, limb rigidity – less with olanzapine, quetiapine, more with risperidone
 - c. neuroleptic malignant syndrome (NMS) – severe parkinsonism (rigidity), autonomic instability, confusion, elevated white cell count and CK enzymes.
- iv. Metabolic adverse effects particularly with olanzapine
 - a. weight gain
 - b. hyperglycaemia
 - c. hypercholesterolaemia.
- v. Falls
- vi. Anticholinergic side effects – dry mouth, constipation, urinary outflow impaired, narrow angle glaucoma exacerbated – less with risperidone, more with others

Several antipsychotics have been associated with ventricular tachycardia torsade de pointes and sudden cardiac death. Clinicians should assess for the presence of presyncope, syncope or arrhythmias prior to prescription, and monitor QTc interval if indicated.

Please see Chapter 8 for the specific consent requirements for the administration of psychotropic drugs in circumstances that the patient lacks capacity to consent.

4. Cholinesterase inhibitors (ChEIs)

Cholinesterase inhibitors are PBS indicated for the cognitive and other symptoms of mild to moderate Alzheimer's disease (Mini Mental State Examination (MMSE) score 10+), and memantine for the treatment of cognitive and other symptoms of severe Alzheimer's

disease (MMSE score 10–14), rather than BPSD per se.

There are three ChEIs – donepezil, galantamine and rivastigmine – that are similar in efficacy. Their main effects are in preventing emergent BPSD in Alzheimer’s disease rather than treating existing BPSD. They are most effective in preventing depression and dysphoria, anxiety, apathy and indifference. It should be noted that most studies did not target persons experiencing BPSD. The ChEIs do not appear to be effective for treating acute agitation and aggression in people with Alzheimer’s disease, vascular dementia or frontotemporal dementia. Withdrawal of ChEIs may lead to worsening of behavioural problems within six weeks thus unless the BPSD commenced shortly after the introduction of ChEIs, they should NOT be discontinued.

In contrast, rivastigmine and donepezil are of significant benefit in BPSD associated with dementia with Lewy bodies and Parkinson’s dementia, in particular for visual hallucinations, delusions and agitation. The ChEIs in this situation should be used as the first line treatment before antipsychotics.

5. Memantine

Memantine is similar to the ChEIs with BPSD in that its main effect is in the prevention of emergent behaviours. There is little role in the treatment of acute BPSD having at best a small benefit possibly for the cluster of aggression, hallucinations and delusions. It is not recommended to be prescribed solely for BPSD.

6. Benzodiazepines and other sedatives

Benzodiazepines and other sedative drugs have benefit for acute sedation in the very short term but have little evidence of efficacy beyond that.

There are no adequate studies of benzodiazepines or other sedatives such as the z-drugs in BPSD, but they may be used as a very short-term treatment for agitation, severe anxiety and insomnia. If benzodiazepines are used those with shorter half-lives are preferred given the risk of accumulation.

Lorazepam (0.5–1mg daily) or oxazepam (15–30mg daily) may be considered in the very short-term (days) management of agitation or severe anxiety.

Sleep hygiene is the preferred treatment for insomnia. If sleep hygiene is not effective, an agent such as

Temazepam 5–10mg nocte may be considered in the very short term (7–10 days) only. Similarly, there is little research on the use of z-drugs such as zopiclone and zolpidem in treating insomnia in dementia. Melatonin has consistently been found to be ineffective in the treatment of insomnia in dementia.

Psychotropics and COVID medications

The main psychotropic drugs recommended here – risperidone, aripiprazole, citalopram and sertraline – have a low risk of interaction with remdesivir but require monitoring, and a very low risk of interaction with tocilizumab. Clinicians should be aware that some non-approved drugs prescribed for COVID such as lopinavir/ritonavir, hydroxychloroquine, chloroquine, and azithromycin have moderate to high risks of interactions with many psychotropic drugs. Chloroquine can cause psychosis.

Other drugs for BPSD

Anticonvulsants

Of the anticonvulsant drugs, carbamazepine (100–300mg daily) has the best evidence of benefit in treating agitation and aggression in dementia but the evidence quality is low, it should not be used as a first line drug and specialist consultation is required.

There is insufficient evidence for the use of other anticonvulsants. Sodium valproate appears to be ineffective based on moderate quality evidence, while there has been insufficient research to recommend either gabapentin or lamotrigine.

Other drugs under investigation

There are other drugs being investigated in clinical trials that cannot currently be recommended for use in BPSD outside of these trials but have potential. These include cannabinoids, the new atypical antipsychotic pimavanserin and prazosin as well as the previously mentioned gabapentin. Methylphenidate was reported to be beneficial in the treatment of apathy.

Other drugs not recommended

These include antihistamines (e.g. diphenhydramine) and beta blockers (e.g. propranolol). The anti-androgen

cyproterone acetate has some evidence for use in hypersexual behaviour but is not recommended without a second consultant opinion and clear appropriate consent that includes consideration of the limited evidence base, adverse effect profile, and classification as a 'Special Treatment' under the Guardianship Act.

Neuromodulation for BPSD

Electroconvulsive therapy (ECT)

Some people with dementia, particularly those with a pre-existing history of major depression, develop severe psychotic depression non-responsive to antidepressants. In this situation ECT may be indicated with consent under the Mental Health Act. Case series studies have shown benefit albeit with a high risk of post-ECT confusion. There is some limited low quality evidence that ECT may be beneficial for aggression or agitation not responsive to other treatments, although the benefits may be transient. ECT should only be considered in exceptional circumstances with a second consultant opinion and clear appropriate consent that includes consideration of the limited evidence base for BPSD.

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Table 6.1. Drug classes used to treat BPSD

Type of medication	Name of drug class	Example agents (total daily dose)	BPSD indication	Selected adverse effects
Analgesic		Paracetamol, up to 3g	Pain-related agitation	Sedation, hepatic dysfunction
Antidepressant	SSRI	Citalopram 10–20mg Sertraline 25-100mg Escitalopram 5-10mg	Non-urgent treatment of agitation, aggression or psychosis Severe depression	QTc prolongation monitor ECG (citalopram) Hyponatraemia, falls, sleep disturbance
Cognitive enhancing	Cholinesterase inhibitor (ChEI)	Rivastigmine (Exelon Patch) 4.6– 9.5mg Donepezil 5-10mg Galantamine 8-16mg	Agitation, psychosis in DLB	Exclude bradyarrhythmias – need ECG, gastrointestinal AEs, urinary symptoms
Antipsychotic	Atypical	Risperidone 0.25– 2mg Aripiprazole 2.5mg – 15mg	Psychosis and aggression in Alzheimer’s disease (PBS indication); psychosis, aggression, agitation in dementias other than DLB Second line for psychosis, aggression, agitation in dementias other than DLB	Falls, confusion, hypotension, extrapyramidal side effects, QTc prolongation, monitor ECG Aripiprazole: Nausea, vomiting, constipation, other GI symptoms, headache, dizziness
Sedative/hypnotic	Benzodiazepine	Lorazepam 0.5–1mg Oxazepam 15-30mg	Very short term only, Agitation, severe anxiety Nocturnal sedation	Falls, confusion, rebound insomnia
Anticonvulsant		Carbamazepine 100–300mg	Agitation Possibly 3rd or 4th line treatment only with specialist consultation	Falls, disturbed gait, confusion, hepatic dysfunction, blood dyscrasias.

This table provides general guidance only. Every individual will have different needs that will require a tailored approach and review.

Further resources

[*Behaviour Management a Guide to Good Practice: Managing Behavioural and Psychological Symptoms of Dementia \(BPSD\)*](#)

Royal Australian and New Zealand College of Psychiatrists Practice [*Guideline 10: Antipsychotic medications as a treatment of behavioural and psychological symptoms in dementia.*](#)

CHAPTER 7

Emergency care



This chapter discusses safety issues and emergency management. Non-pharmacological and pharmacological strategies, and related consent issues, are described.

- **Any situation in which the physical safety of the person, carers and other patients is potentially seriously compromised is considered an emergency**
- **It is still essential to consider the cause of the behaviour – such as delirium or unmet needs**
- **Apply a person-centred, trauma-informed approach and use non-pharmacological actions to prevent the behaviour escalating**
- **Ensure that all staff are aware of local policies and procedures for responding to behavioural emergencies**
- **Acute sedation may be considered only if essential to immediately reduce risks to the person, other patients and/or staff in the immediate environment**

Whilst immediate action must be taken, it is still essential to consider the cause of the behaviour as it will influence management. Few cases have a single cause.

- Has the person any unmet needs (pain, discomfort, toileting, boredom)?
- Is this part of a long-term recurrent pattern of behaviour?
- Is this a new emergent behaviour over recent days, could it be delirium or an acute psychosis?
- Is the person suicidal?
- Has the person been a 'victim' reacting to the behaviour of someone else?

Early intervention and de-escalation

As far as possible, recognise warning signs before escalation. Attend to such persons as a priority – do not delay. Protect the person and others from coming to harm by engaging the person, using a calm, friendly, engaging approach and:

- do not chastise for 'bad behaviour', actively listen to their perceived cause of distress
- do not argue or raise your voice
- be aware of body language – adopt a non-threatening stance with arms by your sides and open palms
- manoeuvre the person away from open windows, balconies and doors

- remove objects that can harm others (such as cutlery) or the person (such as electric cords)
- remove from the immediate environment others who may be at risk
- summon the assistance of other staff, consider using staff who have previously developed rapport with the person
- give the person space and time to settle, do not rush them
- move the person to a quiet room so that continuous direct observation is possible, or to a safe assessment room where available
- involve the carer and family to find out what usually calms the person
- try distraction such as with food and beverage, music or TV.

These actions may suffice to quell the emergency

Consent

According to the Guardianship Act, there is no need to get substitute consent for urgent treatment that is considered necessary to save the patient's life, to prevent serious damage to the patient's health or to alleviate significant pain or distress. However, ongoing use of medication will require substitute consent. Chapter 8 will consider capacity and consent in more detail.

Table 7.1. Medication for use in in-patient behavioural emergencies

Route	Medications	Initial Dose	Maximum Dose in 24 Hours	Caution	
ORAL	BENZODIAZEPINE (preferred)	Lorazepam	0.5 - 1mg	Max dose 5 mg	Respiratory depression, confusion, ataxia
	And/or ANTIPSYCHOTIC	Olanzapine wafer or	5mg-10mg	Max dose 10 mg	Confusion, hypotension, bradycardia, ataxia
		Risperidone	0.5 - 1 mg	Max dose 2 mg	Hypotension, sedation, ataxia
IM	ANTIPSYCHOTIC	Olanzapine ¹	2.5 mg	2.5 mg increments 2-4 hours apart to max dose of 7.5mg DO NOT use if delirious; seek specialist advice	Confusion, hypotension, bradycardia, ataxia

Precautions:

¹ Do not use Olanzapine IM within two hours of parenteral benzodiazepines due to the risk of respiratory depression.

Monitoring

Emergency pharmacotherapy has a high risk of adverse effects due to:

- higher than usual dosing to gain control
- use in psychotropic naïve persons or persons already taking significant amounts of psychotropics
- possibility of medical comorbidity.

Main concerns are:

- oversedation
- increased confusion
- hypotension
- extrapyramidal effects
- unsteady gait and falls.

Vital signs (blood pressure, pulse, temperature, respiratory rate) should be monitored at a frequency determined by the clinical team.

Overall management beyond the emergency

A behaviour management plan based upon the causal factors identified in the emergency and during previous assessments should be developed. Attention should be given to:

- strategies to address unmet needs (as described in earlier chapters)
- identified warning signs of behavioural escalation
- non-pharmacological strategies such as verbal de-escalation, distraction, stress management, use of a quiet room
- if possibly dangerous, seek help from other staff
- consider one-to-one staffing in the short term (hours to days)
- medication as per the agreed medication plan below.

Pharmacotherapy beyond the emergency

It is essential to develop a medication plan with the carer(s) and staff and appropriate consent after the emergency has settled. This should include:

- what medication (if any) should be used if further episodes occur?
- is a short (days) to medium term (weeks) course of medication required to prevent further episodes?
- if so, which medication? (may differ from the medication used to gain control)
- determine a proposed end date for the course which will depend on the cause of the behaviour, for e.g. delirium might be some days, exacerbation of recurrent aggression might be up to 12 weeks.

Seclusion and restraint

NSW Health is committed to minimising and, where safe and possible, eliminating the use of seclusion and restraint.

Seclusion is the confinement of a person, at any time of the day or night, alone in a room or area from which free exit is prevented. Restraint is the intentional restriction of a person's voluntary movement or behaviour. Physical restraint is the use of 'hands-on' immobilisation or restriction of the person. Mechanical restraint involves using devices including lap belts, tabletops, mittens, wrist restraints, sheets, bedrails, deep chairs or other furniture to restrict movement. Chemical restraint involves the use of medication or chemical substance for the primary purpose of restricting the person's movement.

Physical restraints are associated with cognitive and functional decline, increased mortality, and may increase agitation in people with dementia. Seclusion can cause people with dementia to become socially isolated and this can increase depression and agitation as has become apparent in the COVID-19 pandemic. Thus, apart from the ethical and legal considerations, seclusion and restraints are not recommended for people with dementia as they may cause agitation and increase risk of falls

There may be rare instances in which seclusion or restraint is required in NSW Health settings. NSW Health staff must only use seclusion and restraint:

- where there is a lawful basis to do so
- as a last resort to prevent serious harm, usually associated with acute severe behavioural disturbance
- to allow administration of lawful medical treatment
- after less restrictive alternatives, including prevention strategies, have been trialed or considered, where safe to do so
- proportionate to the risk of harm
- for the minimum duration necessary
- the risks associated with the person being in open areas or unrestrained must outweigh the risks associated with restraint or seclusion
- the least restrictive form of seclusion or restraint should be used.

Staff should avoid:

- using prone restraints;
- restraining in ways that interfere with the person's airways, breathing, or circulation; and
- bending the person's head or trunk towards the knees if seated.

Physical restraint of a person with suspected, probable or confirmed COVID-19 is a high-risk intervention. See '[Managing Acute Severe Behaviour Disturbance \(ASBD\) in COVID-19](#)' for further details.

The restraint of a patient in a clinical care area is the responsibility of the clinical team. Clinicians MUST review and adhere to local policy and procedures if they need to use seclusion and restraints. [Seclusion and Restraint in NSW Health Settings \[PD2020_004\]](#) sets out the requirements for ratification and subsequent clinical reviews, summarised below:

All use of seclusion and restraint must be ratified by a senior clinician who was not involved in the decision to initiate seclusion or restraint, as soon as possible but not more than an hour after initiation. A medical examination is required. The outcome of the review will be to cease the practice or ratify its continuation. The outcome of the review must be documented in the Health Care Record.

Subsequent reviews should occur as frequently as possible but not less than every 4 hours and at each shift handover. If seclusion or restraint persists beyond 24 hours, a multidisciplinary review is required.

Throughout episodes of seclusion and restraint, staff must make every effort to ensure that the person's needs are met and dignity protected, such as with the provision of food and drink, and arrangements for hygiene and toileting. For the safety of the person, clinical staff must continuously observe, and where possible, engage with a person in seclusion or restraint in the manner mandated in NSW Health policy. See [Seclusion and Restraint in NSW Health Settings \[PD2020_004\]](#).

Clinical monitoring must include vital signs (respiratory rate, blood pressure, temperature, pulse rate) at a frequency determined by the clinical team. Observations must be in person and not on

CCTV. Mobility should also be regularly reassessed in older persons; if restraints are prolonged in use, physiotherapy or geriatric medical/rehabilitation review might be required to optimise mobility.

Where legally permitted and after considering privacy requirements, NSW Health staff must make every effort to notify the following persons (as applicable to the person and legal status) about the use of seclusion or restraint and the reasons for use – carer, guardian, and others as appropriate and determined by local protocols.

Prohibited practices

NSW Health staff must not:

- use seclusion and restraint as a form of discipline, punishment or threat
- use seclusion and restraint as a means to reduce behaviours not associated with immediate risk of harm
- use vest restraints for older people
- use seclusion for people who are actively self-harming or suicidal or who are mechanically restrained
- use metal handcuffs or hard manacles as a form of mechanical restraint.

See [Seclusion and Restraint in NSW Health Settings \[PD2020_004\]](#).

There are additional requirements for specific settings that are outlined below.

Mental health units

Some additional issues need to be considered in mental health units. Restrictive practices on older people in mental health units should be kept to a minimum by adopting strategies to prevent or minimise disturbed behaviour including the appropriate assessment of behaviour change as described in previous chapters.

Any use of a restrictive practice in a declared Mental Health Unit, as defined by the Mental Health Act 2007 (MHA), including chemical restraint, physical restraint, mechanical restraint, environmental restraint or seclusion should only be applied to a person detained under the MHA. If applied to a voluntary patient, they

must be assessed by a Medical Officer (MO) as soon as possible to determine their status under the MHA.

Seclusion and restraint in a mental health unit require consideration at a senior clinical level. All episodes of physical restraint must be coordinated by a senior clinician and reviewed afterwards. Full details of the procedures to be followed can be found in Section 3 and Section 4.1 of [PD2020_004](#).

Non-declared mental health facilities should have appropriate policies and procedures to ensure that if restraint is required within non-declared mental health units, such as Transitional Behavioural Assessment and Intervention Service (T-BASIS) units, then any necessary consent is obtained consistent with the NSW Guardianship Act (1987). In exceptional circumstances where emergency restraint may be needed, immediate consent would not be required; however, the Guardianship Division of NCAT must be notified to consider a guardianship order at the earliest opportunity thereafter. See Chapter 8 for further information.

All forms of high-level direct restriction require recording in a register, and compliance with record keeping, practice and reporting responsibilities as outlined in [PD2020_004](#).

These include:

- parenteral psychotropic medication
- physical restraint as defined in [PD2020_004] Section 1.2 Key definitions
- mechanical restraint as defined in [PD2020_004] Section 1.2 Key definitions
- mittens that cannot be removed by the consumer
- seclusion.

High risk indirect restriction includes:

- removing mobility aids
- use of bed rails
- tray table restraint
- oral medication with a significant likelihood of causing sedation.

These should only be initiated after an initial assessment of the need by a senior clinician and alternative options to restraint have been identified, actively implemented whenever possible, and the

assessment and decision appropriately documented. The assessment should include the person's mobility prior to initiation of restraint.

The removal of mobility aids should only be considered after completion of an appropriate falls assessment by the senior nurse on duty; discussion with the relevant psychiatrist or senior clinician as outlined above; and inclusion of appropriate falls prevention strategies in the person's care plan. The decision to remove mobility aids must be documented by the senior nurse on duty and reviewed daily.

Ensure care planning includes actions to maintain or improve the consumer's mobility including regular reassessment, physiotherapy and/or specialist medical review (e.g. geriatric or rehabilitation physicians).

The need for medication with a significant likelihood of causing sedation should be initially approved by a psychiatrist or duty medical officer. The impact of the use of sedating medication should be considered in all clinical reviews, and the need for ongoing PRN sedating medication reviewed at intervals of no longer than 1 week.

Bed rails, other than for patient transport, should only be used where there is a specific indication, and the potential benefits of using bed rails are considered to outweigh the potential risks of entrapment, falls from an increased height, or deliberate self-harm. Note that cognitive impairment increases the risks of accidental harm in this setting. The decision to use bed rails must be documented by the senior nurse on duty and reviewed each shift.

If mechanical restraints are used in a mental health unit, the equipment must be reviewed and approved for use in frail older persons by the relevant local governance committee(s) and specific policies and procedures must guide their use. Staff need to be trained in the use of physical restraints, mechanical restraints and seclusion.

Collaborative assessments including the medical superintendent, consumer and their primary carer must occur at intervals as determined in policy guidelines. There may be infrequent and specific situations that require prolonged or repeated episodes of restraint. If this occurs services must comply with current NSW Health guidelines and directives.

For more information see [Aggression, Seclusion & Restraint in Mental Health Facilities – Guideline Focused Upon Older People GL2012_005](#).

Restrictive Practices in the Community

NSW Health staff should not authorise nor condone any restrictive practices described here for patients being managed in the community, whether these are applied by formal aged care services or by family and other carers. Restrictive practices used by family and other carers might be a form of elder abuse.

For definitions, information and resources on preventing and responding to elder abuse see [NSW Ministry of Health Policy Directive PD2020_001 – Identifying and Responding to Abuse of Older People](#) and [NSW Government – Communities and Justice – Aging well in NSW: Seniors strategy 2021-2031 – How we are responding to elder abuse](#).

Restrictive Practices in Residential Aged Care

NSW Health clinicians need to be aware that there are [Commonwealth](#) and [State of New South Wales](#) regulations regarding restrictive practices in residential aged care facilities (which include multipurpose services and State Government residential aged care facilities).

Restrictive practices must only be used as a last resort and in the least restrictive form. In these settings, restrictive practices include chemical restraint (excluding treatments for a diagnosed mental disorder, physical illness or condition, and for palliative care), environmental restraint, mechanical restraint, physical restraint, and seclusion.

Except for an emergency, restrictive practices cannot be used unless there is a Behaviour Support Plan in place and included in the care and services plan for the care recipient. Explanation of the details required in a Behaviour Support Plan is available online from [Dementia Support Australia](#).

Whenever restrictive practices are used, the residential aged care provider is responsible for regular monitoring to determine if there are any signs of distress or harm, side effects, adverse events, changes in wellbeing and function as well as

responsible for providing feedback to the medical or nurse practitioner about the effectiveness and use of the chemical restraint.

NSW Health staff must not use or recommend the following restrictive practices in residential aged care and/or T-BASIS Units:

- Seclusion
- Posey crisscross vest
- Leg or ankle restraint
- Manacles/shackles (hard)
- Soft wrist/hand restraints.

Clinicians should be aware of state and local policy regarding restraint, including:

[Commonwealth of Australia Department of Health: Restrictive practices in aged care – a last resort.](#)

Explains recent changes to laws, practical measures that residential aged care providers must comply with.

Decision-Making Tool: Supporting a Restraint Free Environment in Residential Aged Care. [Australian Government Department of Health and Ageing 2012](#)

[Aggression, Seclusion & Restraint in Mental Health Facilities – Guideline Focused Upon Older People GL2012_005](#)

[Seclusion and Restraint in NSW Health Settings PD2020_004](#)

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Further resources

[Aggression, Seclusion & Restraint in Mental Health Facilities – Guideline Focused Upon Older People.](#)

Useful information about de-escalation and prevention of disturbed behaviour; as well as procedures for appropriate use of restraint where it cannot be avoided.

[Emergency Department Patients Awaiting Care PD2018_010](#)

[Regulation of restrictive practices and the role of the Senior Practitioner, Restrictive Practices RB 2021-13.](#)

Australian Government Aged Care Quality and Safety Commission Bulletin.

CHAPTER 8

Legal and ethical considerations



- **Consent must be obtained appropriately for treatment**
- **The clinician must assess the person's ability to consent**
- **It should not be assumed that all people with dementia lack capacity**
- **A person with dementia may be capable of making simple decisions but not more complex decisions**
- **A person with delirium may recover their ability to make decisions once the delirium has resolved**
- **In situations in which consent cannot be obtained**
 - No consent is required in a clinical emergency
 - Otherwise, written substitute consent must be obtained from the 'Person Responsible' or the NSW Civil and Administrative Tribunal (NCAT) for 'Major Treatment'
 - 'Minor treatment' can proceed without consent if the patient is not objecting and there is no Person Responsible or the Person Responsible is not available, and if the clinician documents this appropriately in the patient's Health Record
 - NCAT consent is required for all 'Special treatment'
- **Document consent and treatment decisions in the patient's Health Record**

Determining capacity to consent

Consent is a key element of all health care. The person must be informed of the benefits and risks of a proposed treatment, as well as the risks of not accepting care, so that an informed decision about accepting the treatment can be made.

NSW Health staff must determine whether a person is capable of giving consent to treatment. A person has the capacity to consent if they retain the ability to:

1. comprehend and retain information about their illness and treatment
2. balance the potential benefits and risks of treatment
3. communicate/indicate a choice.

Principles of capacity assessment

Every adult is presumed to have capacity until contrary evidence is provided. The more serious the decision, the greater the certainty must be regarding capacity.

There are some key principles of capacity assessment:

- always presume a person has capacity until otherwise shown
- capacity is specific to each decision
- don't assume a person lacks capacity based on appearances

- assess the person's decision-making ability, not the decision they make
- respect the person's privacy
- substitute decision-making allows for consent when capacity is lacking.

Case vignette – Bianca

Bianca, aged 79, was brought to hospital by ambulance. A neighbour had found her in her garden unable to get up after a fall. Bianca was a widow and lived alone in a two-storey house. Physical examination revealed bruising on her legs and hip; she did not have fractures and denied being in pain. The neighbour told the ambulance officers that she had known Bianca for many years and had been keeping an eye on her, as she had been 'getting a bit vague'. She said that Bianca seemed independent and active. Examination revealed disorientation for time and place, dehydration and low blood pressure. A urinalysis showed the presence of white cells +++; blood pathology showed microcytic anaemia and acute renal failure.

The hospital contacted Bianca's GP who advised that Bianca had a diagnosis of mild dementia but had been managing well with community supports. She has had no previous hospital admissions.

When admitted to the ward, the nurse settled Bianca into bed around 10pm. At 3am the nurse on duty discovered Bianca walking into other people's rooms, distressed and

confused. She then started to leave the ward despite being told that she was dehydrated and needed her urine infection to be treated. This only increased her agitation and distress.

Bianca was diagnosed as having delirium due to dehydration, a urinary tract infection and anaemia against a background of dementia. Her capacity needed to be assessed. Bianca was unable to believe the nurse's statement that she was unwell or follow directions to maintain her safety. This provided initial evidence of lack of capacity.

The on-call intern was paged and attended Bianca, who had become more agitated and insisted on leaving. The intern assessed that Bianca was incapable of giving consent for treatment in hospital because she could not describe where she was, that she was unwell, the nature of the treatment or that she was in danger if she left the hospital without treatment. Two nurses and the intern walked with Bianca and she was assisted back to her bed; the intern prescribed oxazepam 15 mg stat, commenced IV fluids and an antibiotic for a presumed UTI on the advice of the consultant physician.

Bianca's agitation settled considerably after ongoing treatment of her dehydration and urinary tract infection. Bianca's medical team proposed commencement and continuation of regular risperidone 0.25mg BD.

The medical team determined that the Person Responsible for Bianca was her only relative, her niece, in the absence of a guardian, spouse, unpaid carer or close friend. The nature, purposes, risks and alternatives of the risperidone were discussed with Bianca's niece. As Bianca was not objecting, her niece gave written consent to the use of risperidone.

Note: The use of psychotropic drugs like risperidone is a 'major treatment'.

Bianca's haemoglobin continued to decline, and rectal bleeding was noted. She was told that a colonoscopy and gastroscopy were necessary. Bianca said she didn't trust the doctors and wanted her niece to help her decide. When contacted, her niece was informed in writing about the nature, purposes, risks and alternatives of the procedure. After discussion with the medical registrar, the niece agreed that the treatments were necessary and gave her consent in writing, which was documented in Bianca's Health Record.

Note: As they are considered necessary to promote or maintain Bianca's health, gastroscopy and colonoscopy

are considered by the Guardianship Act to be 'minor treatments'.

When capacity is not present

Capacity is more likely to be impaired in dementia and during episodes of delirium, although it should not be assumed that all people with dementia lack capacity. Older, frail or ill people may be slow to comprehend and may need time to come to terms with new information. A person is entitled to be uncertain about a decision.

NSW Health staff may ask family, carers or friends with regular contact with the person for information to assist with the assessment of a person's decision-making capacity. If the person is incapacitated, they should ask these family/carers what the person's views or expectations about the proposed care might have been and about their own expectations of the strategy. Further information is available in the [Capacity Toolkit](#).

The Guardianship Act 1987 states that a person is incapable of consenting to their own medical treatment if:

- they are incapable of understanding the general nature and effect of the treatment, or
- they are incapable of indicating whether or not they consent to the treatment being carried out.

The person must understand the nature and effect of treatment, not in general, but with specific reference to their own situation.

Substitute consent

If the person lacks capacity, treatment should be given in accordance with the Guardianship Act. To give major medical treatment without the consent of the substitute decision maker, the treatment needs to be necessary to:

- save the patient's life;
- prevent serious damage to the patient's health; or
- prevent significant pain or distress.

In Bianca's case, oxazepam was considered necessary to allow the administration of IV fluids and antibiotics to prevent serious damage to her health, and to prevent significant ongoing distress.

Consent for the risperidone still needed to be sought either from Bianca if she had recovered sufficient capacity, or from a Person Responsible if Bianca lacked capacity. If there was no person responsible available, or if Bianca objected to risperidone and there was no appointed guardian to override her objection, then an application to the NSW Civil and Administrative Tribunal (NCAT) Guardianship Division would have been necessary.

Person Responsible

A Person Responsible is not necessarily the next of kin. The Guardianship Act 1987 defines the Person Responsible for consent according to the following hierarchy:

1. an appointed guardian/enduring guardian who has the function of consenting to medical treatments. If there is no guardian:
2. the most recent spouse or de facto spouse, including a same sex partner, with whom the person has a close, continuing relationship. If there is no spouse or de facto spouse:
3. a person who has regular care of the person otherwise for remuneration. If there is no carer:
4. a close relative or friend with whom the person has an ongoing relationship provided they are not being paid for any services provided.

In the absence of a Person Responsible, an application can be made to the Guardianship Division of NCAT for the Tribunal's consent to the treatment, or for the Tribunal to appoint a guardian who can consent to the treatment, before the treatment may be carried out lawfully.

A Person Responsible can consent to major and minor treatment but cannot consent to special medical treatment. If special medical treatment is proposed, consent must be sought from the NCAT Guardianship Division. Special medical treatment is defined in the Act and below.

For further information about the substituted consent process refer to the Guardianship Act 1987, and current NSW Health policy documents including the [NSW Health Consent to Medical and Healthcare Treatment Manual](#).

Major treatment

In the Guardianship Act, major treatment refers to:

- any treatment that involves administration of a restricted substance for the purpose of affecting the central nervous system (with the exception of those listed under minor treatment)
- any treatment that involves the administration of a drug of addiction
- any treatment that involves a substantial risk to the patient
- any treatment that involves the administration of a general anaesthetic or other sedation, but not involving:
 - sedation for fractured or dislocated limbs or
 - sedation for inserting an endoscope into a patient's body for diagnostic purposes
- other major treatments that are identified at the NSW Health's policy [NSW Health Consent to Medical and Healthcare Treatment Manual](#).

If the treatment is major treatment and there is no Person Responsible who is willing to provide consent and it is not an emergency, an application to NCAT for consent is required.

Minor treatment

Minor treatment refers to any treatment that is not major treatment, special treatment or treatment in the course of a clinical trial. Minor treatment includes:

- treatment involving general anaesthetic or other sedation, only for:
 - management of fractured or dislocated limbs
 - endoscopes inserted through an orifice, not penetrating the skin.
- prescription-only drugs that affect the central nervous system when:
 - used for analgesic, antipyretic, antiparkinsonian, antihistaminic, antiemetic, antinauseant or anticonvulsant purposes, or
 - it is to be given only once, or
 - it is a PRN treatment that may be given not more than 3 times a month, or
 - given for sedation in minor medical procedures.

Before minor treatment is given without substitute

consent, NSW Health staff carrying out/supervising the minor treatment must certify in the patient's Health Record that:

- the treatment is necessary
- the treatment is the form of treatment that will most successfully promote the patient's health and wellbeing, and
- the patient does not object to the carrying out of the treatment.

Special treatment

Special medical treatment includes:

- any new treatment that is not widely accepted by medical specialists in the area of practice concerned;
- any treatment that is intended or reasonably likely to have the effect of rendering a person permanently infertile; or
- any treatment declared by the regulations to be special treatment for the purposes of the Guardianship Act

The following treatments are declared by the regulations to be special treatments:

- any treatment that involves the use of an aversive stimulus, whether mechanical, chemical, physical or otherwise.
- Any treatment carried out for the purpose of terminating a pregnancy or in the nature of a vasectomy or tubal ligation.
- See NSW Health's policy [Medical and Healthcare Treatment Manual 2020](#) for further information about Special treatment.

Consent to the initial administration of Special Treatment may only be granted by the Guardianship Division of NCAT. NCAT can only consent to the Special Treatment if the treatment is necessary:

- a. to save the patient's life, or
- b. to prevent serious damage to the patient's health.

The Guardianship Act identifies two categories of special treatment for which different criteria apply for obtaining consent from the Guardianship Division:

1. any treatment that involves the administration of one or more restricted substances for the purpose

of affecting the person's central nervous system, but only if the dosage levels, combinations or numbers of restricted substances used, or the duration of the treatment, are outside the accepted mode of treatment for such a patient

2. any treatment that involves the use of androgen-reducing medication for the purpose of behavioural control.

In these cases, NCAT must be satisfied that:

- a. the treatment is the only or most appropriate way of treating the person and is in their best interests, and
- b. any National Health and Medical Research Council guidelines will be complied with.

Where there is no existing guardianship order in place for a patient, NSW Health staff should consider making both an application for guardianship and an application for consent to special treatment. The Guardianship Division can give consent to special treatment for a duration (for example 12 months) so guardianship may not be necessary in some cases, depending on the circumstances of the patient.

If the Guardianship Division gives consent to special treatment, it can then authorise the guardian to give consent to continuing the treatment or to further treatment of a similar nature.

For further guidance see:

- [NCAT Guardianship Division Factsheet Person Responsible](#)
- [NCAT Guardianship Division Special medical treatment guidelines](#)

If the patient objects to treatment

A Person Responsible cannot override a patient's objections to treatment. An objection includes where:

- the person has previously indicated in similar circumstances that he or she did not want the treatment and has not subsequently changed their views, or
- the Person Responsible is aware, or ought reasonably to be aware, that the patient objects to the treatment.

It is an offence under the Guardianship Act for treatment to be carried out if the patient is objecting, unless:

- the Guardianship Division of NCAT has consented to the treatment, or
- the Guardianship Division of NCAT has appointed a guardian with express authority to override the patient’s objections and the guardian has provided consent, or
- the patient has minimal or no understanding of what the treatment entails, and the treatment will cause the patient either no distress or distress that is likely to be minimal, tolerable and transitory.

An application may also be made to the Supreme Court under its *parens patriae* jurisdiction to consent to necessary treatment where the patient is objecting.

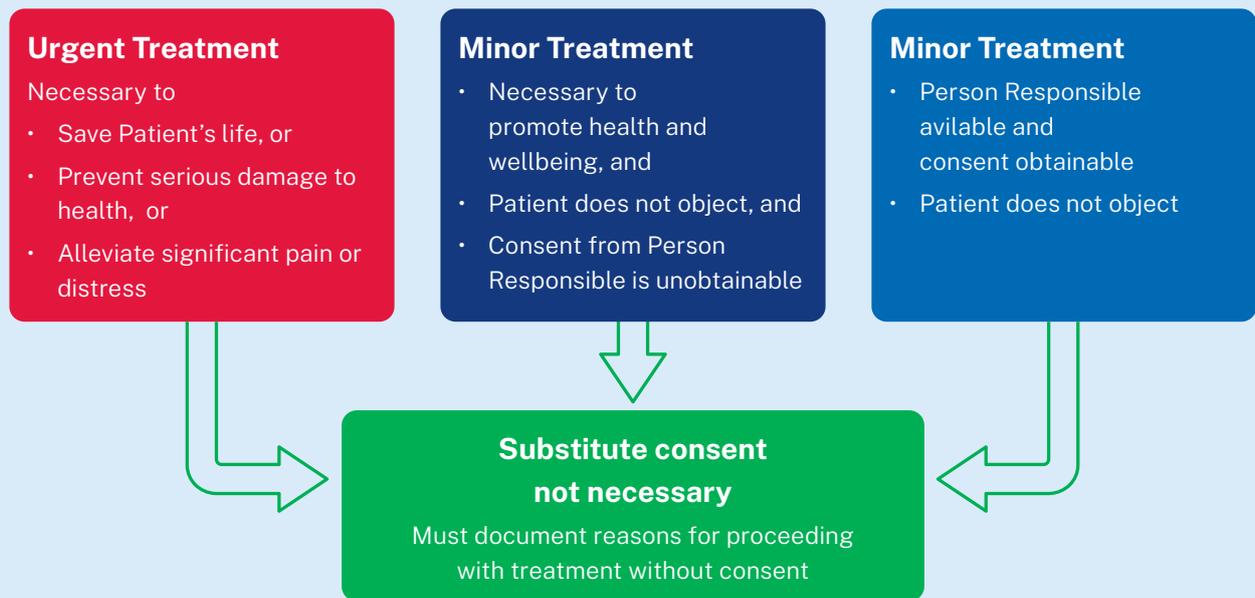
Case vignette continues

Bianca’s colonoscopy noted an early-stage tumour in the bowel, which is best treated by surgical removal. Bianca refused further treatment, even though her niece encouraged her to have surgery.

In making a decision about whether an operation is appropriate, NSW Health staff should consider the stage of dementia, quality of life and previous expectations, if known.

A bowel resection is considered a major treatment by the Guardianship Act. Even though her niece was willing to give substitute consent, as Bianca refused treatment, then consent was required from the Guardianship Division of NCAT. Requests to, and consent from, the Guardianship Division must be in writing.

Figure 8.1. Obtaining substitute consent when the person lacks capacity



Case vignette continues

Bianca returned to living in the community in her own home with significant levels of in-home support: Meals on Wheels, personal support services, and regular visits from the community nursing service.

One night she caused a disturbance at the home of another neighbour, whose home she entered with a knife, saying she was looking for the man who had been stealing all her money.

The neighbour called the GP who placed her under 'schedule' and called the police, who transported Bianca to the local emergency department which is a declared mental health facility for a mental health assessment.

NSW Mental Health Act 2007

The Mental Health Act provides the legislative framework for the voluntary and involuntary treatment of persons with a mental illness/condition in NSW.

The principles for care and treatment of patients under the Mental Health Act require NSW Health staff to make every effort to take into account the person's views and wishes about their treatment, obtain the person's consent for treatment and recovery plans and to support a person who lacks the capacity to consent to understand those plans.

A person with dementia and BPSD may have symptoms that fulfill the criteria of the Mental Health Act as evidence of mental illness or disorder. It may be reasonable to detain a person with dementia under the Mental Health Act if they fulfill the criteria of the Act. If the Mental Health Act is to be used regarding a person with dementia who is outside a declared mental health facility, mental health services should be consulted.

While an authorised medical officer can authorise the medical treatment to a detained person, all reasonable attempts should be made to obtain the consent of the person. However, certain types of treatment require additional consent processes, such as surgical treatment and electro-convulsive therapy (ECT).

Where a person is a voluntary mental health patient, the person's consent must be obtained for any treatment. If the person lacks capacity, consent can be given in accordance with the Guardianship Act. This is the case even where the person is in a declared mental health facility.

The Person Responsible can give consent for most mental health and non-mental health related medical treatment where the person lacks capacity. However, certain types of treatment such as ECT, require additional consent processes.

Further resources

[NSW Health Consent to Medical and Healthcare Treatment Manual 2020](#). Information on consent for adults with and without capacity, consent to medical and dental treatment under the *Mental Health Act*, list of relevant policies and legislation and consent forms.

[Emergency Care Institute \(ECI\) NSW: Clinician Hub: Capacity/Substitute Decision makers/Consent](#).

Information to help ED clinicians providing care to patients with reduced decision-making capacity including people with dementia.

[Capacity Australia](#). Information on decision making capacity including for people experiencing changed behaviour associated with dementia. 'Capacity Mini-legal Kits' developed for use by health care professionals in assessing decision-making capacity are available for NSW, QLD, SA, TAS, VIC and WA.

[NSW Civil and Administrative Tribunal Guardianship Division](#). Forms, fact sheets, videos, information on legislation and guidelines available. Interpreter service: 13 14 50.

[NSW Public Guardian](#). The Public Guardian is appointed by the Guardianship Division of NCAT or the Supreme Court of NSW to make health care, lifestyle and medical decisions for a person who lacks decision-making ability.

[NSW Trustee & Guardian](#). Guardianship and capacity information for medical and health care providers, including dental practitioners.

[Mental Health Review Tribunal](#). A specialist body created under the Mental Health Act 2007 and enabled to conduct mental health inquiries, make and review orders, and to hear some appeals, about the treatment and care of people with a mental illness.

[Mental Health Act \(2007\) Guidebook](#)

[Mental Health Act 2007 No 8](#): Current version for 27 March 2021 to access date 12 Dec 2021.

[Guardianship Act 1987 No 257](#): Current version for 27 March to access date 12 Dec 2021.

CHAPTER 9

Accept: Roles in care of differing professional disciplines, teams and settings



This chapter addresses the team approach to caring for people with dementia in three settings: emergency departments, in-patient wards and community settings.

- **The care of people with dementia who are experiencing BPSD will be managed in many settings**
- **Different professionals may be present in these settings, with roles adapted to local circumstances**
- **The principles in this handbook apply to different settings, but may require adaptation**
- **Guides are provided to assist this for:**
 1. Emergency departments
 2. In-patient wards
 3. Community settings

The person with BPSD commonly requires coordinated interventions from multiple disciplines. In hospital settings these may be involved as part of one, or many, teams. In the community they will often be from different teams. It is essential that there is clear coordination between disciplines and teams, and a clear lead clinician or lead team and a given time responsible for setting goals with the person and the carer.

Common disciplines involved include:

- dietetics
- diversional therapy
- medical specialties, including general practice
- nursing
- occupational therapy
- pharmacy
- physiotherapy
- psychology (both neuropsychology focused on cognitive assessment and clinical psychology focused on behavioural assessments and a range of interventions)
- social work.

Putting it all together: Kenny's vignette

Kenny, aged 89, has been living in a hostel for two years. His wife visits him daily, but he becomes very distressed when she leaves. Residential care nursing staff must intervene to prevent him from leaving with her.

Two weeks ago, he was admitted to hospital following

a myocardial infarction. Staff described his behaviour as "anxious" and "agitated". Although Kenny presents with word-finding difficulties, he repeatedly asks staff if they have seen his wife. He has hit out at nursing staff when they attempt to assist him with showering or getting ready for bed. Kenny accuses people of stealing his personal belongings and other people receiving care often find him disruptive at night when he repeatedly tries to get out of bed. Kenny also presents with low mood and is tearful at times. He does not wish to join in with activities organised by the diversional therapist. On one occasion he told the social worker that he might as well do away with himself.

Kenny has a history of ischaemic heart disease, hypertension, elevated cholesterol and osteoarthritis, which are all treated. Five years ago, his wife was concerned about memory loss and his GP ordered a cerebral CT scan, which showed cerebral atrophy and white matter ischaemic changes. Three years ago he was diagnosed with vascular dementia by a geriatrician.

The social worker obtained more information about Kenny. He is a retired civil engineer. His interests included gardening, fishing and cricket. He had a wide circle of friends and was a member of the local Rotary Club. His wife, Alma, is a retired schoolteacher who is in good health. They have two children and four grandchildren who continue to visit him regularly. Previously, Kenny was friendly and got along well with people. The episodes reported by the nursing staff are unusual and the doctor wonders if these are due to progression of dementia or difficulties he is experiencing in adjusting to the hospital environment.

Multiple professionals are involved in Kenny's care, each bringing their specific professional expertise and different perspective to the situation. All need to be working together to develop a hypothesis about why Kenny's behaviour has changed. Involving Kenny's wife in this process in a meaningful way is essential.

Below are some person-centred changes in environment and communication that might assist Kenny.

Actions that may help Kenny

- making sure Kenny's environment is quiet – avoid competing noises, such as TV or radio when communicating with him
- stay still while talking to him and maintain eye contact – this will make it easier for Kenny to follow what you are saying

- maintain regular routines – this will help minimise confusion and can assist with communication
- keep a consistent approach – it is less confusing for Kenny if all those involved follow the same protocol
- find out what Kenny used to do in the evenings so you can provide him with an explanation that makes sense in that context
- use appropriate non-verbal communication
- use language that is positive and tailored to Kenny's current capacity and strengths
- identify and address sensory deficits
- document key strategies to help engage, settle and reassure.

Figure 9.1. Relating to the person experiencing BPSD: through the clinician's eyes – through the person's eyes

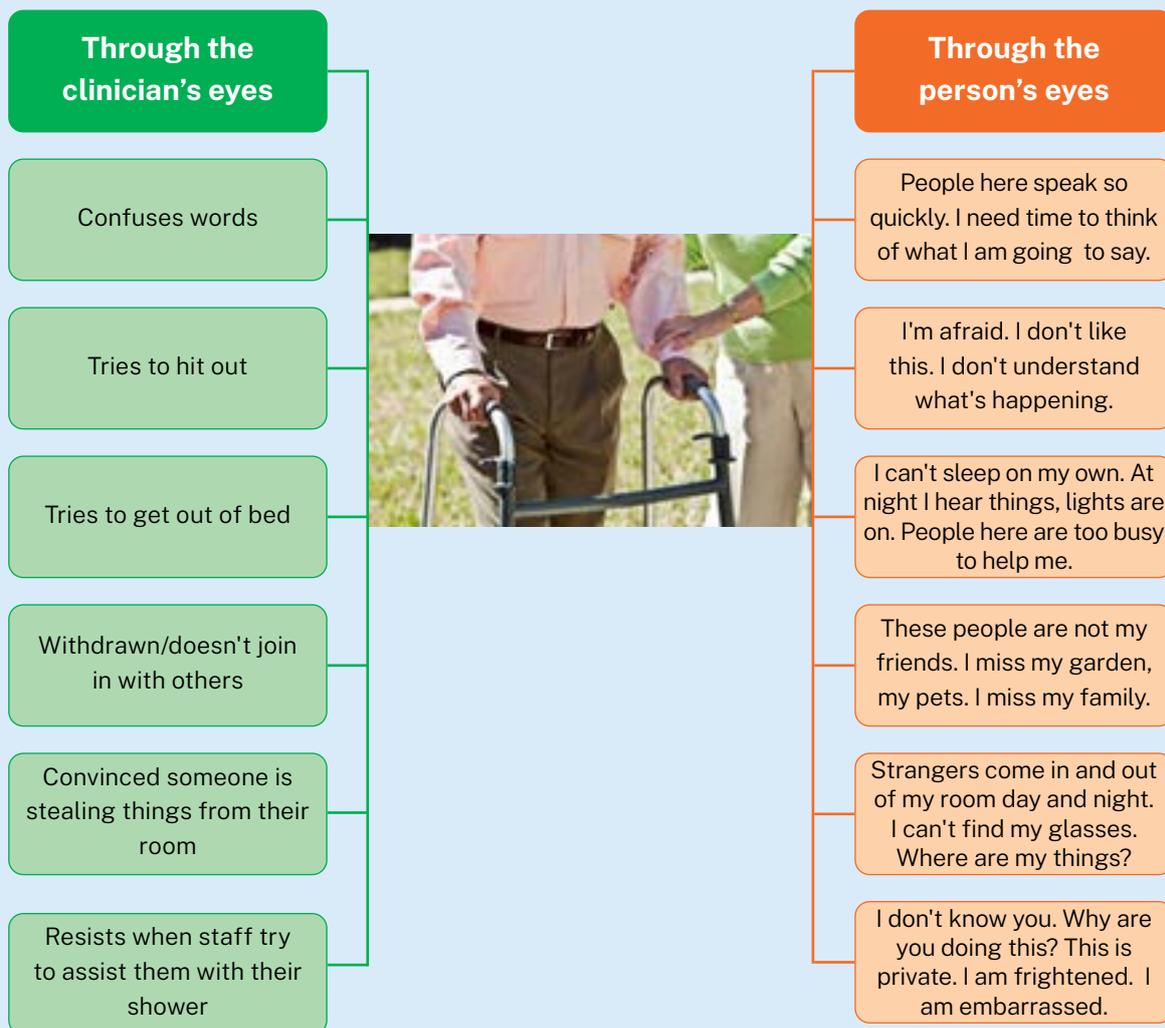
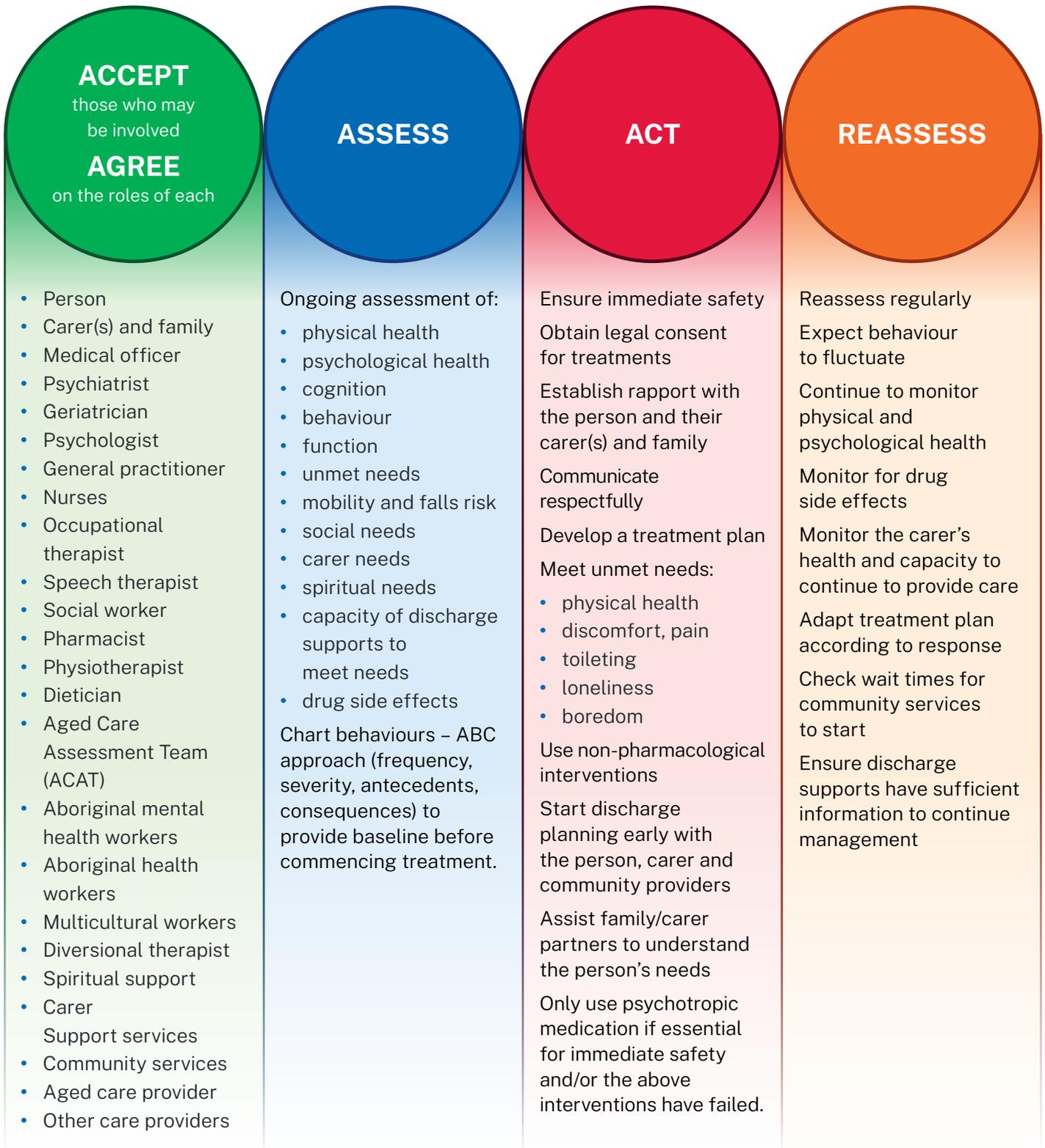


Figure 9.2. A person-centred multidisciplinary approach to care for Kenny and his family



Common disciplines and tasks are presented in Figure 9.3.

Figure 9.3. Key clinician tasks



Some specialised roles are described here:

1. Aboriginal mental health workers and Aboriginal health workers

It is imperative that respectful, responsive and culturally sensitive services are delivered to Aboriginal and Torres Strait Islander people, families and communities. Aboriginal Mental Health Workers and/or Aboriginal Health Workers should be considered an integral part of the multidisciplinary team when caring for Aboriginal and Torres Strait Islander people.

Aboriginal Health Workers and Aboriginal Mental Health Workers bring a unique set of skills that can assist in improving Aboriginal health outcomes. The Aboriginal mental health workforce supports the needs of Aboriginal and Torres Strait Islander peoples across NSW and aims to promote the competencies of non-Aboriginal mental health clinicians who work with Aboriginal and Torres Strait Islander people. Aboriginal Mental Health Workers perform a key role in holistic care of Aboriginal and Torres Strait Islander people with mental illness and play an important role in negotiation of barriers to effective care.

NSW Health Aboriginal Mental Health Workers provide clinical functions such as counselling, therapy and rehabilitation. Aboriginal Health Workers may also provide clinical functions. Aboriginal Mental Health Workers and Aboriginal Health Workers may also provide other health care services, such as advocacy, liaison, health promotion, disease prevention and education.

Clinicians should develop partnerships and work collaboratively with Aboriginal Health Workers and Aboriginal Mental Health Workers to provide culturally appropriate and responsive services.

2. Multicultural health workers and services

It is important to ensure that people from culturally, religiously and linguistically diverse backgrounds have access to quality health services that recognise their linguistic, cultural and religious needs and services and respond in an appropriate way.

Multicultural health workers provide a range of services including research, planning, consultancy,

community development, capacity building, health education, health promotion and training. There are several clinical services which target specific communities and employ bilingual staff to improve access to services, including:

- the Bilingual Counsellor/Clinician Program
- Bilingual Community Educators
- Cultural Support Workers
- Multicultural Health Promotion Officers
- Multicultural Aged Equity Officers
- Diversity Health Coordinators
- Multicultural Workforce Development Officers.

The Health Care Interpreter Service operates across NSW, 24 hours a day, 7 days a week to ensure that non-English-speaking consumers, including those who are hearing impaired, are able to communicate effectively with any health provider of the NSW health system.

The Transcultural Mental Health Centre (TMHC) contributes to a comprehensive NSW Health response to mental health including public health planning and service provision. Its primary goal is to improve the mental health and wellbeing of culturally and linguistically diverse populations. TMHC works in partnership with mental health services to support, build capacity and complement their work with culturally and linguistically diverse consumers across the life course. It provides secondary and tertiary level cross-cultural and culturally responsive face-to-face care and over the phone specialist consultation for health service providers on cultural factors related to mental ill health, mental health and wellbeing.

TMHC also works in partnership with multicultural, ethno-specific and community agencies to reduce stigma related to mental illness and enhance mental health literacy and knowledge on pathways to care for culturally and linguistically diverse community members.

Secondary and tertiary level cross-cultural and culturally responsive health services are provided to support, build capacity and complement their work with culturally and linguistically diverse consumers across the life course.

The NSW Multicultural Health Communication Service (MHCS) works to ensure that culturally appropriate health information and communication initiatives are available for culturally and linguistically diverse communities. It provides advice on multilingual health communication initiatives, undertakes social research with key tertiary institutions and co-designs innovative communication models with culturally and linguistically diverse communities. MHCS provides a translation service and runs a website with health information in 50 languages. It also hosts consultations to identify the ongoing health needs and issues of culturally and linguistically diverse communities in NSW.

The NSW Refugee Health Service aims to protect and promote the health of refugees and people of refugee-like backgrounds living in NSW. The service:

- provides nurse-led health assessments for newly arrived refugees
- provides medical assessments through GP clinics, particularly for asylum seekers
- supports refugee arrivals with a disability or other complex health needs
- educates health service providers on refugee health issues
- provides targeted health education programs for refugees.

For more information see:

[NSW Plan for Healthy Culturally and Linguistically Diverse Communities: 2019-2023](#)

[Interpreters – Standard Procedures for Working with Health Care Interpreters PD2017_044](#)

[Refugee Health Plan 2011-2016 PD2011_014](#)

Multiple teams and settings

In general persons with dementia have a chronic, progressive illness. Their condition will vary over time and if hospitalised may require transfer to different settings within the hospital system. In each setting, the team configuration will change as will the role of specific team members. Even when the person requires acute interventions, these must be adapted to incorporate the specific needs of a person with dementia, especially as the person is likely to become more confused and disorientated with each move.

This chapter presents cycles of care for each of the different NSW Health settings addressed in this Handbook: the emergency department, in-patient ward and the community settings. Each chart is based on the cycle of evaluation and care promoting person-centred care and includes acceptance of the coordinated involvement of professionals of multiple disciplines, and from multiple teams, as essential for care.

Team approach to coordinating care

The complexity of dementia requires a team approach to integrate a wide range of health services delivered across the public and private sectors. In addition, many services are provided by community and voluntary workers. To deliver high standards of care, health practitioners need to know and accept their own role and those of their team members in partnership with the person with dementia and their support network.

In summary the key clinical teams relevant to the management of people with BPSD in the NSW public health services are:

- the emergency department team
- specialist aged care services including geriatric medical teams
- Aged Care Assessment Teams (ACAT) play a key role in assessing the level of residential and community care services the person needs
- general adult psychiatric teams, especially consultation-liaison services
- Older People's Mental Health (OPMH) services including acute and non-acute in-patient units/ services, consultation-liaison and multidisciplinary community services, community OPMH partnership services including residential aged care services and programs
- general community nursing team
- ward teams including surgical, medical and other specialty wards.

Care in the emergency department

The focus within emergency departments is upon timely, accurate assessment of reversible factors that may be precipitating disturbed behaviours, especially delirium. This stage focuses upon diagnosis and emergency interventions to stabilise the person and assessing the person’s needs with respect to ongoing treatment and care. The person may be assessed by several clinicians. Diagnostic tests may be required. The person may be discharged following treatment or admitted to an in-patient ward.

At all times a person-centred approach should be maintained. Emergency departments are disorientating and confusing for people with dementia. Transfer to familiar or more stable environment as soon as practicable.

As mentioned previously many health professionals may be involved in providing care for the person and liaising with family or carers. Table 9.3 on page 74 lists those commonly involved and illustrates the adaption of Assess, Act and Re-assess components of the Care and Evaluation Plan.

Figure 9.4. Cycle of Care – emergency department



Care in the in-patient ward

Almost all adult wards will receive people with dementia and BPSD. In addition to being able to provide care for the primary reason for admission (e.g. palliative care, fractures), ward staff need to incorporate the Cycle of Care for BPSD into the person's treatment plan. This involves:

- becoming familiar with the person's needs related to the dementia and developing communication skills to assist them in engaging the person, their

carer(s) and close family members in the care of the person

- addressing any environmental factors and triggers that exacerbate or help to calm BPSD
- knowing where to obtain professional support that will assist in providing care for the person with BPSD.

Geriatric units or mental health units for older people should aim to support staff by providing resources and training in selected advanced behavioural strategies.

Figure 9.5. Cycle of Care – in-patient ward settings



Care in community settings

The clinician working in the community must be particularly aware of the roles and capacities of other teams and professionals, and develop behavioural strategies that can be implemented through the person's carer and community support workers.

While aiming to manage the person in their familiar environment, clinicians must be alert to the need for change in environment if required due to safety concerns beyond those that the consenting person is willing to tolerate. Such concerns may most frequently relate to the behaviours, medical condition or accidental harm.

Figure 9.6. Cycle of Care – community settings



References

[RANZCP \(2016\) Position statement 50: Aboriginal and Torres Strait Islander mental health workers](#)

[NSW Aboriginal Mental Health Workforce Program](#)

[Aboriginal Older People's Mental Health – Resources for Local Health District SMHSOP 2015](#)

Further resources

[Behaviour Management, A Guide to Good Practice: Managing Behavioural and Psychological Symptoms of Dementia](#)

[Transcultural Mental Health Centre](#)

Glossary

Term	Description
ABC	Antecedent Behaviour Consequence (ABC) approach to behaviour support/management
ACAT	Aged Care Assessment Team
AD	Alzheimer's disease
AEs	Adverse Events
ASET	Aged Services Emergency Team
BMP	Behaviour Management Plan
BSP	Behaviour Support Plan
bvFTD	Behavioural variant fronto-temporal dementia
BPSD	Behaviours and psychological symptoms associated with dementia
CACP	Community Aged Care Packages
CALD	Culturally and Linguistically Diverse
Carer	One who provides ongoing, unpaid support to a person they know well who needs help due to disability, terminal illness, chronic illness, mental illness and/or ageing.
ChEI	Cholinesterase inhibitor medication
DA	Dementia Australia
DBMAS	Dementia Behavioural Management Advisory Service
DLB/LBD	Dementia with Lewy bodies/Lewy Body disease
DSA	Dementia Support Australia
ECG	Electrocardiogram
FTD	Fronto-temporal dementia
GP	General Practitioner
ISB	Inappropriate Sexual Behaviour
LGBTIQ	people who have identified themselves as lesbian, gay, bisexual, transgender, intersex, questioning or queer
MAOIs	Monoamine oxidase inhibitors

Glossary *continued*

Term	Description
MCI	Mild Cognitive Impairment
MDT	Multidisciplinary Team
NCAT	New South Wales (NSW) Civil and Administrative Tribunal
NDIS	National Disability Insurance Scheme
OPMH	Older People's Mental Health services
PBS	Pharmaceutical Benefits Scheme
PCC	Person-centred care
PDD	Parkinson's disease dementia
QTc	time between start of QRS complex and end of the T wave in an ECG (QT interval) corrected for heart rate
RACF	Residential aged care facility
SNRI	Serotonin noradrenergic reuptake inhibitors
SSRI	Selective serotonin reuptake inhibitors
T-BASIS	Transitional Behavioural Assessment and Intervention Service Units
VaD	Vascular dementia: dementia associated with problems of circulation of blood to the brain
YOD	Younger-onset Dementia: onset of dementia in people under the age of 65 and under the age of 50 for Aboriginal and Torres Strait Islander people

APPENDICES



Appendix 1. Rating scales/ measurement tools

Appendix 1 covers a range of rating scales or measurement tools used for assessment including:

- rating scales and proforma provided for use within specialist mental health services
- cognitive dimensions of dementia
- behaviours and psychological symptoms associated with dementia
- delirium
- pain.

Use of rating scales in Dementia

Most of the dementia related measures or scales presented are directly accessible by download with notes on how to use and score each measure on the [NSW Health Agency for Clinical Innovation \(ACI\): Screening and assessment tools for older people](#) resource and/or the [Dementia Outcomes Measurement Suite \(DOMS\)](#), from which the following information has been adapted.

The generic guidelines on administering the scales are a valuable and useful resource for the clinician wishing to employ any of the measures referred to here.

Different measures may be completed by:

- the carer or a family member who knows the person well via self-completion or interview with clinicians
- staff of particular disciplines such as nursing or allied health
- specialist clinicians or neuropsychologists
- a combination of the above.

Most measures are designed to be used via an interview conducted by a clinician with a person and/or informant care partner or by self-completion by a suitably qualified informant care partner. The delivery of most measures is relatively user friendly. Some of the simpler measures, especially for assessment of single behaviours or symptoms, take from one to fifteen minutes to complete and score.

Guidelines for dementia assessment

It is valuable to consult the Guidelines on the [Dementia Outcomes Measurement Suite \(DOMS\)](#) and/or [NSW Health Agency for Clinical Innovation \(ACI\): Screening and assessment tools for older people](#) resource website before using any of the measures presented below.

Consulting the generic guidelines can assist clinicians to conduct a more effective assessment by helping identify appropriate measures for use in the circumstances.

Rating scales and proforma provided for use within specialist mental health services

It is mandatory for all NSW mental health staff to use standardised modules to document care of consumers. [The Mental Health Clinical Documentation Guidelines GL2014_002](#) modules are provided, with guidelines regarding their use. This also includes the Multicultural MH-OAT tool, which should be completed to assist addressing the cultural implications arising in care management for people of culturally and linguistically diverse background. It also defines points at which the data collection using standard assessment tools is required (admission, review and discharge) and guidance regarding their use. Assessment data collection is mandatory within mental health services, and detailed information regarding these is included.

For older people the following assessment tools are included:

Nationally mandated:

- HoNOS 65+ (an alternative version of the HoNOS for people 65 years and over)
- RUG-ADL (Resource Utilisation Groups – Activities of Daily Living Scale)
- LSP (Life Skills Profile)
- K10 (Kessler-10).

Supported in NSW Mental Health documentation suite

- 3MS (with MMSE approximation)
- RUDAS
- Montreal Cognitive Assessment (MoCA).

A) Cognition assessment measures

There are numerous measurement tools or scales for the assessment of cognitive impairments associated with dementia. A range of annotated Cognition Assessment Measures are available for use at the [Dementia Outcomes Measurement Suite \(DOMS\)](#) and the [NSW Health Agency for Clinical Innovation \(ACI\): Screening and assessment tools for older people resource](#).

Choice of tool for assessment of cognitive impairment should be based on several factors including:

- the age of the person
- cultural background
 - people from indigenous communities of a particular region (KICA-Cog)
 - people of cultural and linguistic diversity (RUDAS)
- skills required to administer the assessment measure; for reliable use some measures require specific training (e.g. 3MS or MMSE), professional expertise, (e.g. ADAS-Cog usually performed by a psychologist or neuropsychologist), and
- whether the measure is in the public domain; the measures quoted in this document are all in the public domain and available via the websites mentioned above.

The Kimberley Indigenous Cognitive Assessment tool (KICA-Cog) is developed to assess cognitive performance in older Indigenous Australians living in rural and remote areas.

The KICA also has multiple versions:

- the original KICA-Cog is designed for remote Indigenous populations
- the Modified KICA (mKICA) is tailored for urban and rural Indigenous Australians
- the KICA-Carer is an informant scale
- the KICA-Screen is an abbreviated version of the KICA-Cog.

The KICA-Cog test form and instruction booklet are available from [NSW Health Agency for Clinical Innovation \(ACI\): Screening and assessment tools for older people](#) resource. The mKICA is available through the NSW Health intranet.

Research involving Aboriginal men and women aged 60 years and older from five catchment areas in regional and urban NSW, and conducted through partnership with Aboriginal community-controlled health organisations and guidance from local community Elders and Aboriginal reference group, compared the cultural acceptability and psychometric properties of the Mini-Mental State Examination (MMSE), the Rowland Universal Dementia Assessment Scale (RUDAS) and a version of the Kimberley Indigenous Cognitive Assessment (mKICA) modified for urban settings.

The MMSE, RUDAS and mKICA were found to be valid and culturally acceptable in this population. The MMSE was a good all-round screening tool for Aboriginal Elders in urban areas. The mKICA was suggested for instances where culture, language, and/or literacy limit the appropriateness of MMSE use.

B) Measures for behaviours and psychological symptoms associated with dementia

A range of measures are available for assessment of BPSD. Services that regularly manage people with dementia should consider having agreed relevant measures readily available for staff.

Two broad measures were recommended in the national Dementia Outcomes Measurement Suite (DOMS) which assess a range of behaviours and areas: the Neuropsychiatric Inventory (NPI) and the Behavioural Pathology in Alzheimer's Disease (BEHAVE-AD). The NPI and the BEHAVE-AD are available from the [Dementia Outcomes Measurement Suite](#) and the [NSW Health \(ACI\): Screening and assessment tools for older people](#) resource.

The Neuropsychiatric Inventory (NPI) includes 12 areas:

- delusions
- hallucinations
- agitation/aggression
- depression/dysphoria
- anxiety
- elation/euphoria
- apathy/indifference

- disinhibition
- irritability/lability
- aberrant motor behaviour
- sleep and night-time behaviour disorders
- appetite and eating disorders.

The NPI is designed to be administered to the carer or informant by a trained or specialised clinician. It rates the severity and frequency of the BPSD. An optional scale for measuring carer distress is included for each behaviour. However, a version of the measure, the NPI-NH is designed to be administered in nursing home to formal carers who will not have known the person with dementia prior to onset.

Behavioural Pathology in Alzheimer's Disease (BEHAVE-AD)

Measures behavioural symptoms of Alzheimer's disease via clinician interview with an informant or carer or via self-completion by a clinician or formal carer. It rates severity but not frequency.

Assessing individual BPSD

There are a range of other measures for the assessment of individual BPSD in people with cognitive impairment and/or dementia which focus on aggression, agitation, apathy and depression:

- **Rating Scale for Aggressive Behaviour in the Elderly (RAGE)** a five-minute scale for use by clinicians and regular carers or informants
- **Cohen-Mansfield Agitation Inventory (CMAI)** a ten-to-fifteen-minute clinical rating scale for completion by or with carers or informants to assess the frequency of agitated behaviours
- **Pittsburgh Agitation Scale (PAS)** a one-minute measure for completion by clinical staff during direct observation and documentation
- **Apathy Evaluation Scale (AES)** a 20-minute measure conducted through a semi-structured interview between the clinician and the carer (preferably) or person to quantify and characterise apathy
- **Cornell Scale for Depression in Dementia (CSDD)** clinician conducted interviews of 20 minutes with carer and 10 minutes with person to assess major depression

- **Geriatric Depression Scale (GDS)** a five-to-ten-minute administered or self-complete measure to assess and screen for depression in older people

C) Pain assessment

Assessing someone living with dementia for pain is a fundamental aspect of good care. A thorough pain assessment explores multiple factors including any pain history, medical history, physical examination, physical impact of the pain, social impact of the pain, psychosocial factors related to the pain and a review of medications and treatments.

Knowledge of the person over time is a major factor in detecting pain and making an accurate pain assessment in older people with dementia including individually defined pain cues.

If the person is not able to provide the understanding and long-term knowledge required, the clinician needs to develop a partnership with the person's carer, family and support workers who know the person well. Subtle changes in the behaviour of people with dementia who are in pain may only be detectable by members of staff or at home by the carer or support workers who consistently work with that person. Once the knowledge is available then appropriate scales can be used as a way of guiding the pain assessments.

Pain assessment scales are defined by the capacity of the client to be verbal or non-verbal. Those with communicative capacity typically in the early stages of dementia may benefit by applying both verbal and observational assessment procedures.

The Brief Pain Inventory (BPI)

This is a pain assessment tool, which measures both pain intensity (sensory dimension) and the pain interference (reactive dimension). People rate their pain severity at its worst and least in the last week, on average, and 'right now'. People rate their level of pain interference in seven contexts, i.e. Work, Activity, Mood, Enjoyment, Sleep, Walking and Relationships. The BPI can also assess pain intervention, pain quality, and perception of the cause of pain.

Pain Assessment in Advanced Dementia (PAINAD) Scale

The PAINAD Scale was developed to provide a clinically relevant and easy to use pain assessment tool for individuals with advanced dementia. The tool is an adaptation of the Discomfort Scale for Dementia of the Alzheimer's Type (DS-DAT) and the Face, Legs, Activity, Cry, Consolability (FLACC) scale and includes five items: breathing, negative vocalisation, facial expression, body language and consolability.

Pain Assessment Checklist for seniors with Limited Ability to Communicate (PACSLAC)©

The PACSLAC© Checklist is a tool for a familiar carer or informant to observe and assess both common and subtle pain behaviours. The tool is a checklist with four subscales and a total of 60 items:

- facial expressions (13 items),
- activity/body movements (20 items),
- social/personality/mood (12 items) and
- physiological indicators/eating and sleeping changes/vocal behaviours (15 items).

Further information on the PACSLAC© can be found at the [Geriatric Pain](#) website.

The Abbey Pain Scale

The Abbey Pain Scale was created for the measurement of pain in people with dementia who cannot effectively verbalise their experience of pain. Based on observation and knowledge of a person's usual function and medical history, the person is rated on a four-point word descriptor scale (absent, mild, moderate, severe) across six domains of pain-related behaviour: vocalisation, facial expressions, change in body language, change in behaviour, physiological change and physical changes. The Abbey Pain Scale takes between two and six minutes to administer.

Appendix 2. Clinical support and NSW community services

The exact roles of different services vary across NSW, but general descriptions of roles of services that may assist in meeting the needs of a person with dementia and BPSD are contained in this Appendix. Clinicians should familiarise themselves with the roles and contact details of local services. Types of services include:

NSW Health services

- Specialist geriatric or aged care medical services
- Consultation liaison services (in psychiatry, geriatrics and nursing)
- Older People's Mental Health (OPMH) services including:
 - acute and non-acute in-patient units/services including Transitional Behavioural Assessment and Intervention Services (TBASIS)
 - community OPMH partnership services, including residential services and programs.

Commonwealth-funded services

- Aged Care Assessment Teams (ACAT)
- Dementia Behavioural Management Advisory Service (DBMAS) and Severe Behaviour Response Team (SBRT), both auspiced by HammondCare as Dementia Support Australia (DSA)
- Specialist Dementia Care Program.

NSW Health Services

Specialist geriatric or aged care medical services

These services work in close association with ACAT and provide a range of multidisciplinary specialist assessment and management for older people with complex problems associated with ageing. Service users may include people who present with dementia, with or without behavioural or psychiatric symptoms. The role of OPMH and geriatric services regarding people with dementia is complementary and is determined by local service development. Services may include in-patient and community care.

Consultation-liaison services

Consultation-liaison services are specialist services that provide advice or assistance to another team of clinicians primarily responsible for the care of a person. They often play a key role in supporting care of a person with BPSD who is in hospital for treatment of another acute issue (e.g. a geriatrician providing advice to a surgical team managing the treatment of an older person with a fracture), and in providing assistance in transfer of care.

Consultation-liaison psychiatry

Consultation-liaison psychiatry services provide clinical consultation/liaison support to clinicians in managing the treatment of people with mental health issues. The services assist with acute mental health assessments, consultation, treatment and referral for people with mental health-related issues in non-mental health settings. They also support and provide education for the nursing staff in general hospital wards. Older People's Mental Health (OPMH) may be available in some hospitals. These services particularly focus on the needs of older people. They usually require initial involvement of geriatric or consultation-liaison psychiatry services.

Consultation-liaison geriatric or medical aged care teams

Consultation-liaison geriatric or medical aged care teams provide a range of services including specialist geriatric assessment and clinical consultation/liaison for clinicians managing the treatment of older people with delirium and dementia. Services may include access to geriatricians and/or dementia clinical nurse consultants.

Consultation-liaison nurses

Nursing consultation liaison may be available from nurses who specialise in psychogeriatric, dementia, aged care or geriatric nursing. These may inform and assist in planning care for dementia and BPSD, and provide a link between mental health, medical and surgical services. They may also provide a link between hospital and community settings, including various community support organisations. They also assist other clinicians to develop skills and confidence caring for people with mental health problems by providing support, education, mentoring and a role model.

Older People's Mental Health (OPMH) services

NSW OPMH services provide public specialist mental health clinical care generally to people aged 65 years and over. People under 65 years old, including Aboriginal people aged 50 years and older, can also use this service if it is suitable for their needs. OPMH services are delivered by a range of health professionals with skills and expertise in mental health problems affecting older people and people with age-related frailty including people who present with severe behavioural or psychiatric symptoms associated with dementia or other long-standing organic brain disorders.

The role of OPMH and geriatric services for people with dementia is complementary and determined by local area service development. Services generally include in-patient and community care. For more information see [GL2017_022 NSW Older People's Mental Health Services SERVICE PLAN 2017-2027](#)

In-patient services focused on care of people experiencing BPSD

OPMH acute in-patient services provide specialist mental health care for people who present with acute, severe symptoms of mental illness. Acute mental illness in older people may be accompanied by co-existing physical health or medical issues and is sometimes complicated by delirium. These services may be discrete facilities or sub-units within acute mental health facilities or acute hospitals.

OPMH acute in-patient services provide multidisciplinary assessment of a person's mental and behavioural status, including physical health and psycho-social issues, and short-term clinical treatment (voluntary or involuntary) for the acute phase of an illness which cannot be managed in the community.

Non-acute mental health in-patient services provide specialist clinical assessment, treatment and rehabilitation where people experiencing BPSD are not able to be managed in the community. It is an expectation that people experiencing BPSD will improve sufficiently for discharge to a mainstream service or community setting with additional support from OPMH Community Services and other services. Strong links with residential and community services are important in these services.

Specialist interim care in-patient facilities provide multidisciplinary assessment, care planning and intensive treatment for older people with severe behavioural and psychological symptoms of dementia (BPSD). This includes iterative behavioural assessment and treatment, such as medication planning, psychosocial interventions and environmental approaches. The Transitional Behavioural Assessment and Intervention Services (T-BASIS) Units are included in this category. T-Basis units are short to medium stay transitional/non-acute in-patient units providing intensive behavioural assessment and intervention for older people with severe BPSD. For more information see [Older People's Mental Health \(OPMH\) services](#).

Commonwealth-funded services

Specialist Dementia Care Program (SDCP)

The Commonwealth funded [Specialist Dementia Care Program](#) is progressively establishing 9-bed Special Care Dementia Units in each Primary Health Care Network. They will provide care for up to eight persons with severe BPSD who are unable to be managed in residential or community care for approximately 12 months. The aim is to ameliorate the presenting behaviours and return the person to mainstream services. The ninth bed will be available for recently discharged persons whose behaviour relapses.

Dementia Support Australia (DSA)

[Dementia Support Australia](#) provides support for people living with dementia, care workers, health professionals and family carers who are supporting a person with dementia experiencing behaviours and psychological changes that are impacting their care. There are different streams:

[Dementia Behavioural Management Advisory Services \(DBMAS\)](#)

DBMAS is an Australian Government-funded program in every state and territory. Each state has its own network managed through a central agency.

DBMAS 24-Hour Telephone Assistance Line 1800 699 799.

DBMAS provide services to support staff and carers in community, residential aged care, acute and primary care settings with expertise, advice and short-term

case management interventions. Services include:

- clinical support, information and advice
- tailored information and education workshops
- assessments, short-term case management and care planning
- clinical supervision, mentoring and modelling
- linkages and partnerships.

[Severe Behavioural Response Teams \(SBRT\)](#)

When a person with BPSD requires more intense support the SBRT provide timely, in person assessments of the person living with dementia and their environment to assess the causes of the behaviours.

[Needs Based Assessment Program \(NBA\)](#)

The NBA Program provides nationally consistent assessment for eligibility into the Specialist Dementia Care Program (see above).

[Behaviour Support Plans \(BSP\)](#)

It is a legal requirement for aged care providers to use Behaviour Support Plans (BSPs). The DSA website and behaviour support resources provide a guide to the behaviour support process and how to create a good BSP.

Aged Care: a quick guide (updated 30 April 2021)

[Aged care: a quick guide](#) is a publication of the Parliament of Australia. The quick guide provides a brief overview of aged care in Australia. It describes the types of care provided, the people who use aged care, the process for accessing care, the organisations that provide care, and the regulatory arrangements for ensuring quality care. In addition, this quick guide includes a brief overview of the Royal Commission into Aged Care Quality and Safety. It does not describe care that is provided outside of the formal aged care system, such as care provided by family members or accommodation in retirement villages.

Aged care assessment teams (ACAT)

ACATs are multidisciplinary clinical teams whose primary role is to assess independently and comprehensively the care and support needs of frail older people, and to facilitate access to available care services appropriate to their long-term care needs

whether at home or in residential aged care. They provide assessment, information, referral advice and assistance to frail older people and determine and approve eligibility for government subsidised aged care services.

They aim to:

- focus on the needs and preferences of the client and carers
- refer to a range of services as appropriate to the needs of the client
- seek equity of access whenever practicable.

While there are many assessments of older people undertaken by a variety of health care and community service teams across NSW, an ACAT assessment is a definable event and not an aspect of usual care. It encompasses holistic client/carer assessment and care planning governed by set guidelines and procedures that must be followed when undertaking assessments.

An ACAT assessment includes the evaluation of a client's restorative potential and physical health, mental health, social (including carers' needs) and economic status, functional status and environmental characteristics. It may lead to a formal approval of a person as a care recipient eligible to access Commonwealth subsidised aged care services under the [Aged Care Act 1997](#). The Secretary of the Australian Department of Health and Ageing (DoHA) delegates powers to ACATs for the purpose of conducting assessments under the Aged Care Act 1997. Decisions made by ACAT delegates to approve or not approve a person as a care recipient are reviewable decisions under the Aged Care Act 1997.

ACATs are located either in hospitals or in community health centres. Their services are available in all LHDs. Further information on services by locality may be obtained from [My Aged Care](#).

Community support services

A range of community services is available to assist the person with dementia, their family, informal and formal carers. Key services include:

- [NSW Health Aboriginal and Torres Strait Islander Liaison Services](#) Liaison Officers provide support to Aboriginal and Torres Strait Islander people and

their families, facilitate better understanding of the health system and procedures, provide cultural and social support and advice on other services in the community, and talk with clinicians at the person's request

- [NSW Health Carer Support Services](#) In NSW, all Local Health Districts have a Carer Support Service. Contact your local team to find out what services they provide for carers
- [Aged Care Guide](#) (previously titled DPS Guide to Aged Care) Digital publication and directory of residential aged care, in-home and community support options, retirement villages and products & services
- [Commonwealth Home Support Programme \(CHSP\)](#) (previously titled Home and Community Care (HACC)) Program for people aged 65 and older and Aboriginal and Torres Strait Islander peoples aged 50 and over, and for; people who are 50 years or older (45 years or older for Aboriginal and Torres Strait Islander people) and on a low income, homeless, or at risk of being homeless
- [Home Care Packages Program](#) Where a person needs a coordinated approach to the delivery of support at home because help with many everyday tasks is required or care needs are more complex they may qualify for a Home Care Package
- [National Disability Insurance Scheme \(NDIS\)](#) The NDIS is a national scheme that provides funding for people under the age of 65 with a permanent and significant disability and people living with younger-onset dementia may be eligible to receive this funding
- [Disability Support for Older Australians \(DSOA\) Program](#) The DSOA program supports older people with disability who received specialist disability services from the Continuity of Support (CoS) Programme but were not eligible for the National Disability Insurance Scheme (NDIS)
- [Extended Aged Care at Home – Dementia \(EACH-D\) top-up supplement for aged care](#) This supplement is for people who had an EACH-D package before transferring to a home care level 4 package plus dementia and cognition supplement and is paid to providers on behalf of eligible care recipients who received an EACH-D package before 1 August 2013

- [The National Dementia Support Program \(NDSP\)](#)
Australian Government initiative to fund information, education, services and resources to improve awareness and understanding about dementia and empower people living with dementia and carers and families to make informed decisions
- Residential Aged Care Facilities.

The following section provides general descriptions of services relevant to the care of people with dementia and BPSD.

[Dementia Australia](#)

[Dementia Australia](#) have offices in NSW and offer a range of sensitive and flexible services to support people with dementia or who are caring for someone with dementia. Services include:

- National Dementia Helpline (below)
- counselling support
- support for people recently diagnosed
- support of those with younger onset dementia
- social support programs
- programs to keep the person's mind active
- information about safety in the home and outside the home
- educational programs for people living with dementia, their carers, close family members, health professionals and the general community
- a National library service providing access to a comprehensive collection of print and digital resources about dementia including books, articles, audio resources, eBooks, DVDs, and an online video library offering informational videos in several community languages.

[National Dementia Helpline](#)

Free call: 1800 100 500 Monday to Friday from 8am to 8pm. Webchat: dementia.org.au/helpline/webchat

Email: helpline@dementia.org.au

[Forward with dementia](#)

[Forward with dementia](#) is a website with practical guides for people with dementia, carers and health care practitioners focusing on the first 12 months after diagnosis. It includes information about BPSD.

[The NSW Falls Prevention and Healthy Ageing Network](#)

The key focus of the [NSW Falls Prevention and Healthy Ageing Network](#) is to reduce the incidence of falls and harm from falls among older people. More than one in three people aged 65 years or over fall at least once per year and many fall more often. Fall injury is a major cause of injury-related hospitalisations and loss of independence among people aged 65 years and over in NSW.

For falls, 58% of hospitalisations and 94% of deaths were in people aged 65 years and over. The very old are at greatest risk of a serious fall injury. In-hospital falls represent a significant high cost, high volume hospital acquired condition within NSW hospitals. Falls in hospitals increase length of stay, require additional diagnostic investigations and impact on the person's treatment resulting in increased cost to the system. Having had a recent fall is one of the leading reasons for premature admission to permanent residential aged care.

The NSW Falls Prevention and Healthy Ageing Network seeks to promote a comprehensive, systemic approach to falls prevention and to reducing fall-related injury within NSW. The program involves collaboration between the NSW Ministry of Health, the Clinical Excellence Commission, the Agency for Clinical Innovation, Ambulance NSW and the local health districts.

The NSW Falls Prevention and Healthy Ageing Network share falls prevention knowledge, expertise and resources to those working in the hospital, community and residential aged care sectors. The Network is funded by the Clinical Excellence Commission and is hosted by Neuroscience Research Australia. The NSW Falls Prevention and Healthy Ageing Network implements a range of strategies for preventing falls in hospital, community and residential aged care settings.

Key strategies for preventing falls in the hospital sector include:

- systematic screening to identify people at risk of falls
- assessment and tailored implementation of strategies to reduce risk of falls
- implement post-fall guideline following a fall in hospital

- report and monitor fall incidents and provide feedback to ward staff.

Key strategies for preventing falls in the community sector:

- form links with agencies to build a network of exercise programs (community and home-based) with a focus on balance and strength training
- identify falls risk factors and implement strategies to care for people at risk that includes referral to suitable programs by community health teams, GPs, Ambulance Service NSW and community service providers.

Key strategies for preventing falls in residential care:

- support the residential care sector to implement the Australian Safety and Quality Commission falls best-practice guidelines for residential aged care facilities
- access services of occupational therapists, physiotherapists and nurses to assist with falls assessment, prevention planning and support.

NSW Health is supporting older people to live active and healthy lives, with improved physical and mental wellbeing. NSW Health is developing, implementing and funding a range of state-wide, evidence-based initiatives to support active living.

- The [Active and Healthy website](#) is an online directory of physical activity programs, including those with a falls prevention component, for older adults
- NSW Health funds the *Stepping On* program which is delivered across the state by local health districts. *Stepping On* is an evidence-based falls prevention program to assist older people to reduce their risk of falling. See the [Stepping On website](#) for more information about the program, or visit the [Active and Healthy website](#)
- NSW Health funds the *Healthy and Active for Life Online* program. This is a home-based physical activity and healthy lifestyle program for adults aged 60 years and over. The online program includes home exercise, online education modules and phone support, and aims to build participants' fitness, knowledge, skills and confidence to lead active and healthy lives. See the [Healthy and Active for Life website](#) for more information about the program.

Information on respite services

If the person living with dementia is aged 65 or over call [My Aged Care](#) on 1800 200 422 or contact [Carer Gateway](#) on 1800 422 737.

My Aged Care may be able to arrange community or residential respite care for the person living with dementia. The care partner and the person will be assessed for eligibility for respite care. Consumers can talk with the assessor about and make decisions about which services would best suit their individual situation.

If the person living with dementia is younger than 65 years of age, call the National Disability Insurance Scheme (NDIS) on 1800 800 110.

An NDIS package may include support for respite care for a person living with dementia. The person living with dementia and/or their care partner can discuss this option with their NDIS planner.

Culturally responsive services for Aboriginal and/or Torres Strait Islander people

It is important that all clinicians provide culturally responsive care for people living with BPSD. All services should work with Aboriginal and Torres Strait Islander clinicians and services to facilitate their understanding of local Aboriginal and/or Torres Strait Islander communities and facilitate culturally responsive services.

Discharge planning for an Aboriginal and/or Torres Strait Islander person with dementia requires liaison with the appropriate:

- Aboriginal hospital liaison officer (AHLO)
- Aboriginal health and mental health workers/practitioners
- Aboriginal Community Controlled Health Services (ACCHSs)
- Aboriginal Medical Service (AMS)
- housing support services
- transport support services, ComPacks, AMS, Medicare locals, Supplementary care
- support with ongoing medication needs, [Closing the Gap \(CTG\)](#) prescription requirements, need for blister packs, carer education.

Multicultural Health Services Information

[NSW Health Care Interpreting Services \(HCISs\)](#). In any health care situation where communication is essential, health practitioners must engage professional health care interpreters for persons receiving care and their families and carers who are not fluent in spoken English or who are hearing impaired. The policy [Interpreters - Standard Procedures for Working with Health Care Interpreters](#) must be adhered to by all staff across NSW Health.

The responsibility to book an interpreter lies with the health practitioner who is seeing the person with BPSD. There are five Health HCIS in NSW. Health practitioners should contact these services first for any interpreting needs.

Some HCISs also have an emergency priority line that is only available for targeted or critical facilities such as Emergency Departments and Intensive Care Units. Clinicians in these units should enquire with their local HCIS about their emergency hotline or using the [Translating and Interpreting Service \(TIS National\)](#) as a back-up service.

[NSW Refugee Health Service \(RHS\)](#) provides clinical services across local health districts in metropolitan Sydney. The RHS provides medical assessments through GP clinics for community-based asylum seekers and support to refugee arrivals with a disability or other complex health needs.

[Transcultural Mental Health Centre \(TMHC\)](#) works with health professionals and communities across NSW to support positive mental health for people from culturally and linguistically diverse communities. The TMHC is hosted by Western Sydney Local Health District.

[NSW Multicultural Health Communication Service](#) provides culturally appropriate health information and communication initiatives for culturally and linguistically diverse communities.

Residential aged care services

Residential aged care services provide housing and care for people with dementia for whom it is no longer practical to live at home. Levels of care differ between and within aged care facilities. Many include separate dementia care units within the facility to cater for residents with behaviours requiring extra care. Specialised dementia care options may also be available as are a range of multicultural aged care facilities with different community languages.

Access to nursing home care requires approval by ACAT, which determines the level of care and the way in which it can be funded, including the cost and any subsidy afforded. Key resources for selection of residential aged care facilities are the [My Aged Care](#) website (or call 1800 200 422), and the [Aged Care Guide website](#).

Peak industry bodies are [Aged & Community Care Providers Association](#) and [Leading Age Services Australia \(LASA\)](#).

Appendix 3. Project methodology and consultation

Method

In 2013 the NSW Ministry of Health released a handbook for NSW Health clinicians in collaboration with the Royal Australian and New Zealand College of Psychiatrists (RANZCP) entitled Assessment and Management of People with Behavioural and Psychological Symptoms of Dementia resource (the BPSD Handbook). The Handbook provides guidance for acute care clinicians supporting persons with dementia experiencing BPSD across multiple care settings. Developments in the field since the document was released meant updates were required to ensure clinicians have access to the best available evidence to assist in managing BPSD and to ensure persons presenting with BPSD and their family/carer partners receive the highest quality of care possible.

In 2021, the NSW Ministry of Health commissioned the University of NSW (UNSW Sydney) to update the BPSD Handbook, with advice from an expert reference group convened by the Health Education and Training Institute (HETI) and in consultation with people living with dementia and carers; and to work with the Health Education and Training Institute (HETI) to ensure the revised Handbook and the content of the Dementia Training Project were aligned. The NSW Health project partners (Health and Social Policy Branch and Mental Health Branch, NSW Ministry of Health; Agency for Clinical Innovation and HETI) oversaw the project.

The process for compiling the BPSD Handbook included a systematic search of the relevant literature, using PubMed MEDLINE, Embase, Psychinfo and Cochrane databases. The Handbook update was informed by the best available literature evidence with focus on the most recent systematic reviews, meta-analyses and intervention studies published April 2020 - July 2021 as well as relevant clinical practice guidelines, consensus and position statements on the assessment and management of dementia, Alzheimer's disease and BPSD. The update was also informed by an ongoing systematic review of evidence regarding biological/pharmacological and non-pharmacological interventions published 2013-2021.

The aim of the Handbook update was to reflect best practice approaches to use of medications and other key areas where evidence and/or best practice guidance has changed since the Handbook's release in 2013, and to incorporate and align with recently created or updated NSW Health policy and guidelines current at the time of publication. Recommendations for good clinical practice are based on review of the literature and clinical experience, rather than prescriptive recommendations according to specific levels of evidence.

Consultation

The BPSD Handbook was developed through extensive consultation with key stakeholder groups including consumer and carer representatives, NSW Health frontline clinicians, and representatives from NSW Health agencies supporting health care professionals. The NSW Ministry of Health and the UNSW Sydney project team thank all those involved for volunteering their time, insights and expertise to this project, and gratefully acknowledge the generosity of their contribution during the COVID-19 pandemic.

Expert Reference Group

The Expert Reference Group (ERG) included clinicians from a range of professional colleges, associations, research centres and a carer representative with an interest in the care of people living with dementia and their carers and family members. The ERG members were consulted extensively to provide input and comment into the structure, form and contents of the updated BPSD Handbook.

Consumer and Carer and NSW Health Clinician focus groups

People living with dementia and carers who had experience of using NSW Health services in settings including emergency departments, in-patient settings and in community settings participated in virtual focus groups and provided their perspectives on key messages and concepts to be included in the Handbook update. NSW Health frontline staff who worked directly with people living with dementia and their carers and family members provided insights into

existing care practice, reviewed the 2013 Handbook and provided feedback on changes to content and structure.

UNSW Sydney project team

The UNSW project team led by Professor Henry Brodaty collaborated with participating NSW Health teams, drafted the updated Handbook, consulted with key stakeholders including members of the ERG and members of both the Consumer and Carer and the NSW Health Clinician focus groups. Members of the UNSW Sydney project team were:

Dr. Anne-Nicole Casey, BSc Psych (Hons), PhD Research Officer, Dementia Centre for Research Collaboration (DCRC) Sydney/Centre for Health Brain Ageing (CHeBA), Faculty of Medicine and Health, Discipline of Psychiatry and Mental Health, UNSW Sydney

Kim Burns, BPsych (Hons), RN Knowledge Translation (KT) Fellow, DCRC/CHeBA, Faculty of Medicine and Health, Discipline of Psychiatry and Mental Health, UNSW Sydney

Professor Dr. Brian Draper MB BS MD UNSW, FRANZCP Conjoint Professor, Faculty of Medicine and Health, Discipline of Psychiatry and Mental Health, UNSW Sydney; Clinical Lead, Academic Department for Old Age Psychiatry, Prince of Wales Hospital, Sydney; DCRC, UNSW Sydney; Honorary Senior Research Fellow Neurosciences Research Australia

Scientia Professor Dr. Henry Brodaty, AO, MBBS, MD, DSc, FRACP, FRANZCP, FAHMS Director of the DCRC Sydney and Co-Director of CHeBA, Faculty of Medicine and Health, Discipline of Psychiatry and Mental Health, UNSW Sydney; Scientia Professor of Ageing and Mental Health, UNSW Sydney; Consultant Psychogeriatrician, Older People's Mental Health Service, Prince of Wales Hospital

NSW Ministry of Health project leadership

NSW Health commissioned the update of the 2013 *Assessment and Management of People with Behavioural and Psychological Symptoms of Dementia (BPSD)* resource ("the Handbook") and provided funding for the update. NSW Health established a Project Steering Committee that met regularly for the

duration of the project to guide project development and convened the Expert Reference Group including representatives from Aged Health Nursing, Geriatric Medicine, Old Age Psychiatry, Older People's Mental Health Nursing, Older People's Mental Health Allied Health Clinicians, Aged Health Allied Health Clinicians, and Emergency Medicine. NSW Health reviewed all drafts of the revised Handbook text and completed graphic design and layout of the revised Handbook text and final graphic design of all tables, figures and graphics in the Handbook as well as all health education, training and other resources associated with the updated Handbook.

NSW Ministry of Health Project Partners

Health and Social Policy Branch (Aged Care Unit), Ministry of Health

Mental Health Branch (Older People's Mental Health Policy Unit), Ministry of Health

Agency for Clinical Innovation (Aged Health Network)

Health Education and Training Institute (Mental Health Program)

NSW Health Handbook update project advisors

Dr. Kate Jackson, Director, Older People's Mental Health Policy Unit (OPMPHU), Mental Health Branch

Christian Prusiak, Policy Officer, Older People's Mental Health Policy Unit (OPMHPU), Mental Health Branch

Dr. Roderick McKay, OPMH Clinical Advisor, Mental Health Program (MHP)/Health Education Training Institute (HETI)

Glen Pang, Manager, Aged Health Network, Agency for Clinical Innovation (ACI)

Samantha Simmons, Aged Care Unit (ACU), Health and Social Policy Branch (ACU, HSPB)

Maria Passarello, Aged Care Unit (ACU), Health and Social Policy Branch (ACU, HSPB)

Table A1. Memberships of the Expert Reference Groups for the update and for the original version of the BPSD Handbook

Version	Member	Role
Update		
Chair	Adjunct A/Prof Rod McKay	Old Age Psychiatrist and OPMH Clinical Adviser, Mental Health Branch
	Kath Sizer	Consumer/Carer
	A/Prof Faye McMillan	Indigenous advisor, Consumer/Carer Associate Professor, Aboriginal and Torres Strait Islander Health, UNSW Sydney
	Dr. Marian Lee	ED Staff Specialist at Prince of Wales Hospital Emergency
	A/Prof Chanaka Wijeratne	Old Age Psychiatrist through RANZCP Faculty of Psychiatry of Old Age
	Professor Susan Kurrle	Geriatrician: NS Hornsby Rehab and Aged Care Department
	Dr Gayatri Majumdar	VMO Geriatrician: Kenmore Dementia Specific Unit, Goulburn Staff Specialist Geriatrician, Fairfield Hospital
	Claudia Woolf	Clinical Neuropsychologist: OPMH, St Vincent's Health Network
	Erica Tarlinton	Bulli Hospital Physiotherapy Site Clinical Lead & Illawarra Shoalhaven Local Health District Allied Health Clinical Stream Leader for Aged Care
	Linda Uslu	CNC: Community Dementia, Western Sydney Local Health District
	Rosina Shekhar	CNC: Aged Health In-patient/Community Dementia/Delirium
	Allyson Waird	CNC: Aged Care, Delirium and Dementia, Royal North Shore Hospital and Ryde Hospital
	Angela Nelson	CNC: Aged Services Emergency Team, Tamworth Rural Referral Hospital ED
	Kellee Barbuto	CNC: Sutherland Hospital, South Eastern Sydney Area Health Service
Nicole Britten	Senior OT: Aged Services Emergency Team, Wollongong Hospital	
Original		
Chair	A/Prof Chanaka Wijeratne	Old Age Psychiatrist through RANZCP Faculty of Psychiatry of Old Age
	Ms Elizabeth Brandis	CNC
	Ms Gail Daylight	Aboriginal Health Manager
	Professor Brian Draper	Old Age Psychiatrist
	Ms Christine Duffy	Community CNC Dementia - Rural and Remote
	Mr Alan Grochulski	Senior Clinical Consultant, Cultural and Linguistic Diversity
	Dr Susan Hertzberg	Emergency Physician
	Mrs Judith Howe	Carer/Consumer
	Ms Anne Kelly	CNC, Aged Services in Emergency Team
	Dr Lisa Kelly	Geriatrician

Version	Member	Role
	Ms Cheryl-Ann Pollack	Policy Officer, Ministry of Health
	Dr Sarah Visser	Clinical Psychologist
	Dr Tom White	Knowledge Translator, Dementia Collaborative Research Centre
	Mrs Eesa Witt	Clinical Nurse Consultant

Table A2. Memberships of the Consumer/Carer and Clinician Focus Groups

Group	Member	Role
Consumer/ Carer		
Chair	Professor Henry Brodaty	UNSW Sydney Project Team
	Kath Sizer	Consumer/Carer representative
	Dr. David and Fay Keegan	Consumer/Carer representatives
	Susan Burgess	Consumer/Carer representative
	David Brown	Consumer/Carer representative
	Mireille	Consumer/Carer representative
Clinician		
Chair	Professor Henry Brodaty	UNSW Sydney Project Team
	Dr. Dimity Pond	GP: Emeritus Prof, University of Newcastle
	Maree Gallop	CNC: Specialist dementia care program, Mater Hospital, Hunter New England Local Health District
	Barbara Lewis	Manager: Carer Support Service, Royal North Shore Hospital, Northern Sydney Local Health District
	Megha Mulchandani	Clinical Director: OPMHS, Mater Hospital, Hunter New England Local Health District
	Lesley Elder	CNS: Behaviour Management Support – Dementia/Delirium, South Eastern Sydney Local Health District
	Mel O'Reilly	Team leader: Dementia Outreach Service, Ballina, Northern NSW Local Health District
	Paul Woodford	CNC: Psychogeriatrics, Aged Care Assessment Team, Ballina, Northern NSW Local Health District
	Kellee Barbuto	CNC: Dementia-Delirium, South Eastern Sydney Area Health Service, Sutherland Hospital
	Chloe Weaver	OT: Geriatric Medicine, Westmead Hospital, Western Sydney Local Health District

Consultative Draft

A consultative draft of the Handbook was made available for comment to:

- Key stakeholders including people living with dementia and family/care partners, and individual health care professionals
- NSW Health Mental Health Branch, Older People's Mental Health Policy Unit
- NSW Agency for Clinical Innovation Aged Health Network
- NSW Health Education and Training Institute
- NSW Clinical Excellence Commission
- NSW Ministry of Health (MoH), Older People's Mental Health (OPMH) Services Advisory Group.

Ratification

Pre-final draft of the BPSD Handbook was provided for input and ratification to NSW Health project partners (Health and Social Policy Branch and Mental Health Branch, NSW Ministry of Health; Agency for Clinical Innovation and HETI).

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Dr. Lynn Chenoweth, Professor of Nursing, CHeBA, UNSW Sydney contributed to the development of Chapter 3 Person-centred care, communication and working with the carer. Dr. Simon Bell, Professor and NHMRC Dementia Leadership Fellow, Centre for Medicine Use and Safety, Monash University advised on current evidence regarding use of psychotropic medications for people with dementia. Dr. Jacqueline Close, Conjoint Professor and Clinical Director of the Falls Balance and Injury Research Centre, NeuRA, UNSW Sydney advised on information regarding the [NSW Falls Prevention and Healthy Ageing Network](#).

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Making the most of time with a person who is living with dementia and experiencing changed behaviour or emotions

Dementia involves the loss of brain function and is typically progressive. It is different for every person, but can involve problems with:

- Memory
- Ability to understand or speak language, especially languages learned later in life
- Carrying out coordinated tasks such as dressing
- Recognising objects or a familiar face
- Planning and organising tasks
- Abstract thinking (such as understanding irony)
- Activities of daily living and social functioning.

Behaviours and **P**sychological **S**ymptoms associated with **D**ementia (**BPSD**) refer to other symptoms and changes in behaviour that may be experienced by people living with dementia. These include verbal and physical agitation, aggression, anxiety, apathy, depression, disinhibition, psychosis and sleep disturbances.

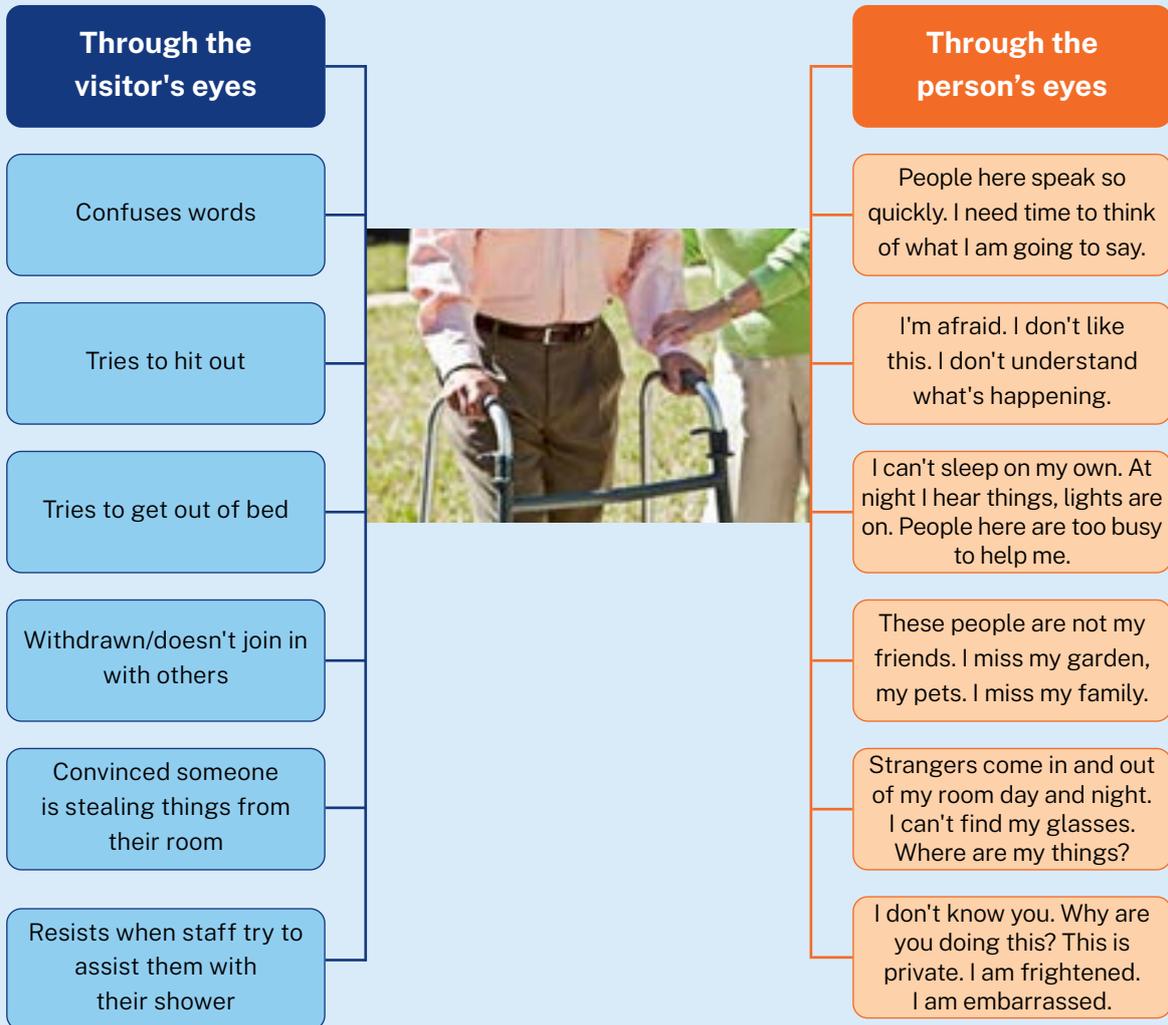
Clinicians understand that a person with dementia who is experiencing BPSD is a person who is communicating a need. The person may be unwell and requires care.

Often the person and those around them see things quite differently. For example, a person who appears agitated or aggressive may be feeling frustrated or anxious or fearful. Your knowledge about the person may help their care team to understand the person's experience and help describe this to others.

If you are visiting a person with dementia who is experiencing BPSD...

Ask the staff if they need to know anything about the person and check whether there is anything the staff need to tell you so that you can help the person.

Relating to the person who is experiencing BPSD



Five things you can do to make the most of time with your family member/friend

Some health care settings provide tools that help the care team learn more about the person living with dementia and their carer and other family members and friends. The care team use these tools to collect, display and communicate information that can help others get to know the person living with dementia throughout their care experience.

The following are things that you can do to help the person's care team and to make the most of the time you spend with your family member/friend who is receiving care.

1. Use what you know about the person.
This might include:
 - What they like to be called
 - What is important to know about their social and cultural background
 - What may cause them distress
 - What may help them to settle
 - Whether they have set routines
 - Whether they ask repeated questions that require specific answers
 - Whether there are signs or triggers that indicate that they have an unmet need.
2. Become involved; talk to the person and staff, find out activities you can do with them and make your own observations about what helps
3. Don't be afraid to ask staff questions or tell them if you know of situations or actions that may either help or upset the person
4. Use these tips to help communication:
 - Remember that body language is most important
 - Minimise background noise and distractions
 - Stay calm and still while talking and communicate at eye level
 - Check that prescription glasses are available and worn
 - Ensure that any hearing aids are functioning and turned on
5. Use short sentences and simple words
 - Talk in a gentle tone
 - Use simple, calm hand gestures and facial expressions
 - Allow time for what you say to be understood
 - Allow plenty of time for the person to reply
 - Clarify what they have said – repeat back to them if you are unsure
 - Stick to one idea at a time
 - Explain what is happening slowly and in simple terms
 - Break down tasks into smaller steps.
5. Modifications to the environment— you may not be able to make major changes, but little ones can make a big difference:
 - Adjust lighting or music/TV/radio choice or volume level
 - Where available, put personal objects where the person can see them
 - Write key words in the person's primary language, use pictures to assist care
 - Minimise risk of injury, e.g. ask staff if the person needs help to prevent falls.

Making the most of one-to-one (1:1) staff time while providing care for a person who is experiencing behaviours and psychological symptoms associated with dementia

Dementia is a syndrome that involves the loss of brain function. Most (but not all) dementias are progressive. It is different for every person, but can involve problems with:

- Memory
- Ability to understand or speak language, especially languages learned later in life
- Carrying out coordinated tasks such as dressing
- Recognising objects or a familiar face
- Planning and organising tasks
- Abstract thinking (such as understanding irony)
- Activities of daily living and social functioning.

Behaviours and Psychological Symptoms associated with Dementia (BPSD) refers to the non-cognitive presentations of dementia such as verbal and physical agitation, aggression, anxiety, apathy, depression, disinhibition, psychosis and sleep disturbances. While a convenient term, BPSD is not a diagnosis; each behaviour requires individual description and understanding.

1:1 care for a person who is experiencing BPSD may be used for several reasons. Typically, it is used to increase the safety of the person and/or those around them. This flyer does not offer instructions on how to provide 1:1 care but does offer some helpful hints to make the most of such time.

It is essential that anyone providing care clarify their role and duties with other care team members

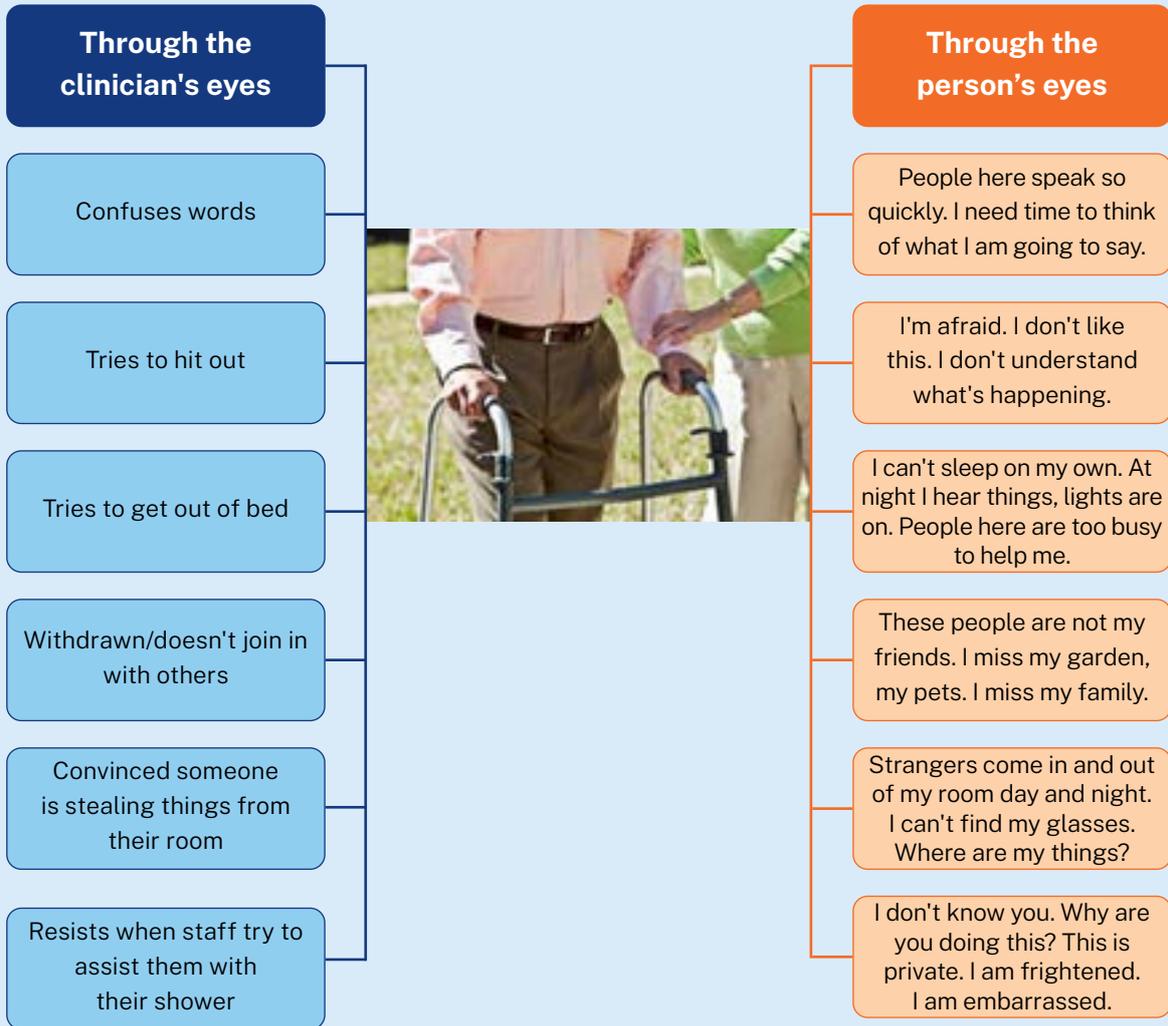
A person with dementia who is experiencing BPSD **is a person who may be communicating a need and may be unwell; the person requires care.** Often the person and those around them see things quite differently.

Many people prefer to use the terms 'changed behaviours' or 'responsive behaviours' when referring to non-cognitive symptoms. Clinicians may see 'agitation' or 'aggression' when the person with

dementia is trying to express a physical or social need and/or may be feeling frustrated, sad, worried or afraid.

A professional providing 1:1 care must be aware of this and try to both understand the person's experience and help describe this to others involved in their care.

Relating to the person who is experiencing BPSD



Five things you can do to get to know the person and their carer and provide person-centred care

The 'Sunflower Tool', 'Top 5' toolkits and related resources exist to help care teams collect and display similar information. Your workplace may have its own resource for collecting and displaying information and to allow consistent communication to others in the person's care team.

1. Respectfully ask the person or someone who knows them well
 - What the person likes to be called
 - What is important to know about their social and cultural background
 - What may cause them distress
 - What may help them to settle
 - Whether they have set routines that help them to settle
 - Whether they ask repeated questions that require specific answers
 - Whether there are signs or triggers that indicate that they have an unmet need.
2. Become involved: talk to the person and their carer and family, find out activities you can do with the person, make your own observations
3. Communicate with other staff about what is helpful/unhelpful and document these
4. Strategies that may help communication:
 - Remember that body language is most important
 - Minimise background noise and distractions
 - Stay calm and still while talking and communicate at eye level
 - Check that prescription glasses are available and worn
 - Ensure that any hearing aids are functioning and turned on, use a hearing amplifier if needed
 - Use short sentences and simple words
 - Talk in a gentle tone
 - Use simple, calm hand gestures and facial expressions
 - Allow time for what you say to be understood
 - Allow plenty of time for the person to reply
 - Clarify what they have said – repeat back to them or reword
 - Stick to one idea at a time
 - Explain all procedures and activities slowly and in simple terms
 - Break down tasks into smaller steps
 - Use personal references: e.g. “your son Yichén”, “your pink jumper”, “your favourite music”, “this photo of your granddaughter”, etc.
5. Modifications to the environment— you may not be able to make major changes, but little ones can make a big difference:
 - Adjust lighting or music/TV/radio choice or volume level
 - Where available, put personal objects where the person can see them
 - Have family write key words in the person's primary language, use pictures to assist care, and/or contact NSW Multicultural Health Communication Service and your closest NSW Health Care Interpreting Services (HCIS) for assistance.

More information can be found in Assessment and Management of Behaviours and Psychological Symptoms associated with Dementia (BPSD): A Handbook for NSW Health Clinicians providing services for people experiencing BPSD, and the online resource NSW Health Agency for Clinical Innovation – Get to know your patients – “Get to know you” systems.



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