

Assessment and Management of People with Behavioural and Psychological Symptoms of Dementia (BPSD)

A Handbook for NSW Health Clinicians



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SHPN (MHDAO) 130007
ISBN 978-1-74187-907-0

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May 2013



The Royal
Australian &
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College of
Psychiatrists

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Handbook overview

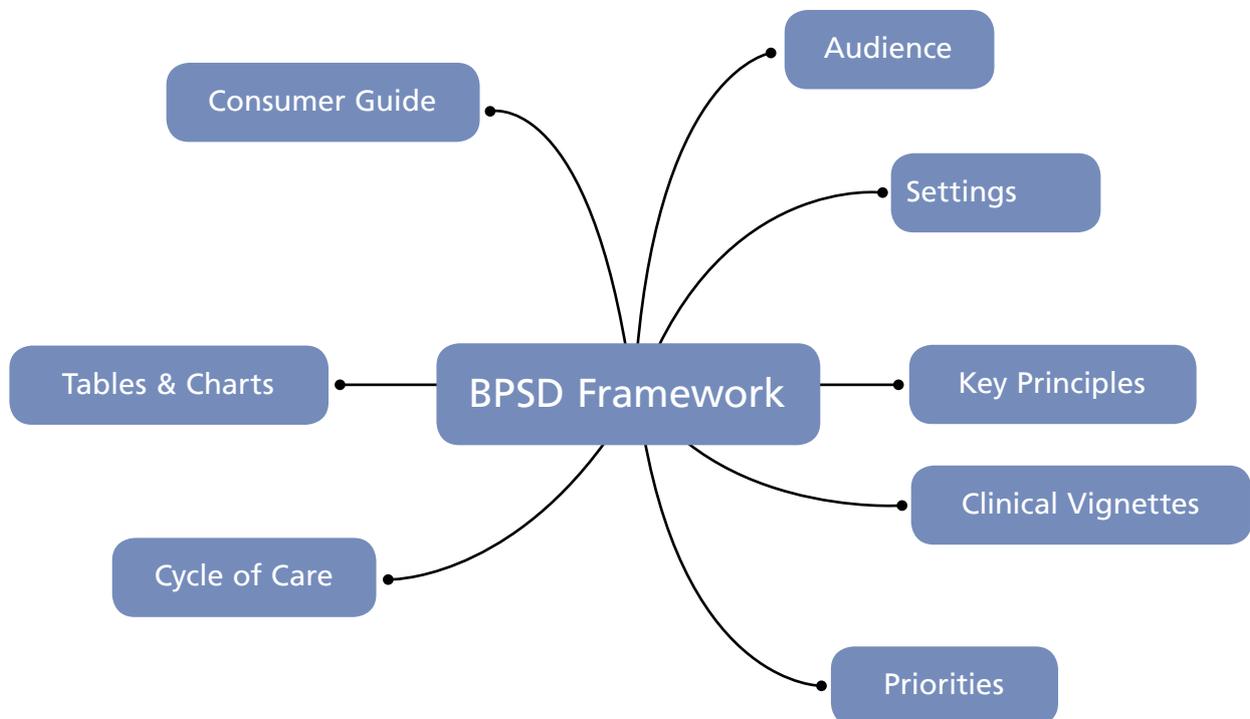
The person with dementia will experience a good quality of life for long periods, but may also experience behavioural and psychological symptoms associated with dementia (BPSD). When BPSD is present, people require care across multiple settings and NSW Health teams. BPSD may be the focus of care or at 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.

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. These are presented in Figure 1 below.

References and further resources are included at the end of each chapter. A bibliography and list of website resources can also be found at the end of the Handbook (pages 69-73).

Figure 1. Main features of BPSD handbook



Audience: NSW Health clinical staff

The Handbook is intended to be a practical handbook and ready reference for NSW Health staff working in settings where they will care for people with dementia and BPSD. Given the wide variety of expertise, disciplines and roles of staff within NSW Health, it is not possible to capture the extent of specialist practice that may be applied by expert practitioners across these disciplines and settings.

Therefore, this Handbook may be used in a variety of ways. For less experienced staff it provides an overview of key concepts and practical resources that they may apply and discuss with their supervisors. More 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 will be cared for in many settings and may be transferred between settings. The settings specifically addressed in this Handbook are Emergency Departments, in-patient units and community settings. Staff providing consultancy to Residential Aged Care Facilities and other community providers should be aware of resources provided for [Dementia Behaviour Management Advisory Services \(DBMAS\)](#) (available at www.dbmas.org.au). GPs should be aware of the [Royal Australian College of General Practitioners \(RACGP\) Dementia Guidelines](#) (available at www.racgp.org.au) and the Department of Health and Ageing Dementia website www.health.gov.au/dementia.

Key principles

A person with dementia and behavioural disturbance may be viewed as 'a difficult or disruptive person', particularly if the clinician has little experience in this area. Although the behaviour may be challenging, the person is 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).
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. All roles are important, so providing optimal care for the person and their carer 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 presents 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 utilises vignettes, which are based on clinical experience to illustrate the application of the BPSD framework. Clinical vignettes include:

Mr K - *an elderly man who is unhappy and confused after being transferred from a hostel to an in-patient setting.* The vignette starts on page 13 and is revisited again on page 52.

Sam - *an elderly man with BPSD who is displaying inappropriate sexual behaviour that is presenting challenges for the nursing staff who are caring for him.* His story is told on page 8.

Valerie - *an 89-year-old woman who is convinced people are stealing her belongings.* Her story is told on pages 18 and 29.

Joanna - *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. Joanna is diagnosed with delirium and dementia.* Her story begins on page 23.

Mrs B - *a 79-year-old woman with a history of mild dementia. Mrs B is admitted to hospital following a fall and is required to undergo survey while an in-patient.* Her story is told on pages 44-47.

Priorities

This Handbook presents five priorities when caring for a person with dementia and BPSD. These priorities are presented in Table 1 below.

Table 1. Priorities

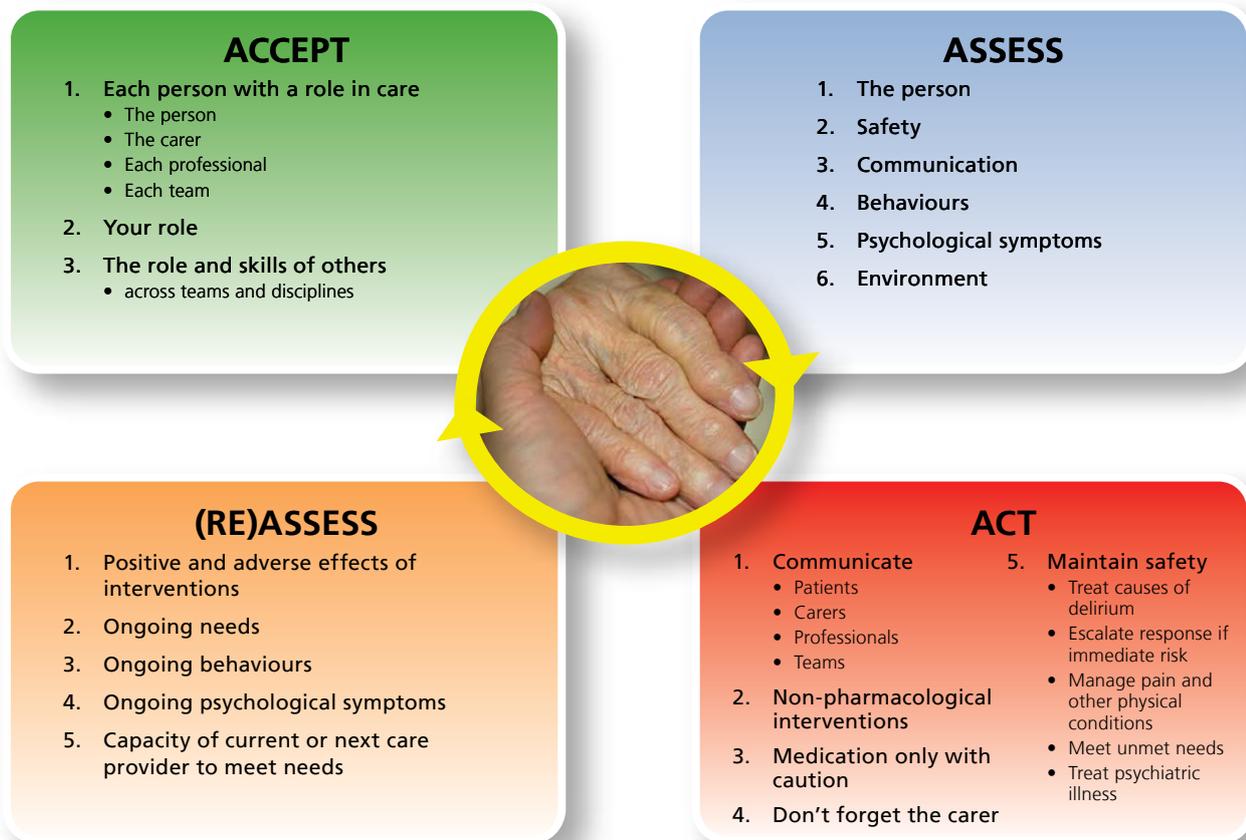
Priority	Examples	References
1. Physical care needs	Is there delirium? Could the person be in pain, need to go to the toilet or have other basic unmet needs?	Chapters 3 and 4
2. Behaviour management strategies	Optimal communication, ABC behaviour modification, reduce noise and distractions, music, sleep hygiene and other psychosocial strategies should be provided, based on an understanding of the person and their needs	Chapter 4
3. Psychological engagement	Is the person distressed and anxious because of separation from loved ones, social isolation, bereavement or frustration?	Chapters 4 and 5
4. Psychotropic medications	Important but limited role, and must be used with caution. Antipsychotics should be limited in use for a period of 12 weeks	Chapter 5
5. Care for the carer	Engage the carer and be mindful of their needs	Chapter 5

The cycle of care

Almost all wards will care for people with dementia and disturbed behaviour. In addition to managing the primary reason for admission (e.g. medical or surgical treatment), ward staff need to incorporate the Cycle of Care for BPSD into the treatment plan. The Cycle of Care involves four stages, depicted in Figure 2 on page vi:

- accept your role, the expertise and roles of others providing care
- assess the person's needs; that is:
 - become familiar with the person's dementia-related needs
 - address any environmental factors that exacerbate or help to calm BPSD
 - develop communication skills to assist in engaging carers and relatives, and
 - know how to obtain professional support that will assist in providing care for the person
- act
- (re)assess the person's needs.

Figure 2. The Cycle of care



7. 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, dieticians, nurses, and social workers are just some of the professions 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.

Table 2. Key clinician tasks

<p>Accept those who may be involved Agree on the roles of each</p>	Assess	Act	Reassess
<p>Person Relatives/carers Medical officer Psychologist Dietitian Nurses Social worker Physiotherapist Occupational therapist Aged Care Assessment Team (ACAT) Aboriginal mental health workers Aboriginal Health Workers Multicultural workers Diversional therapist Other care providers</p>	<p>Ongoing assessment of:</p> <ul style="list-style-type: none"> ■ physical health ■ psychological health ■ cognition ■ behaviour ■ function ■ unmet needs ■ mobility and falls risk ■ social needs ■ carer needs ■ capacity of discharge supports to meet needs. 	<p>Ensure immediate safety. Obtain consent for treatments. Establish rapport with the person and carer. Communicate respectfully, develop a treatment plan. Meet unmet needs:</p> <ul style="list-style-type: none"> ■ physical health ■ discomfort ■ pain ■ loneliness ■ boredom <p>Use non-pharmacological interventions. Start discharge planning early with the person, carer and community providers. Assist family/carers to understand the person’s needs. Only use psychotropic medication if essential for immediate safety and/ or the above interventions have failed.</p>	<p>Reassess regularly. Expect behaviour to fluctuate, not be perfect. Continue to monitor physical health. Monitor for drug side effects. Adapt treatment plan according to response. Ensure discharge supports can continue management.</p>

Key communication points

8. Tables and charts

The Handbook presents many 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.

Table 3. Drug classes used in BPSD

Type of medication	Name of drug class	Example agent (total daily dose)	BPSD Indication	Selected adverse effects
Antipsychotic	Atypical (second generation)	Risperidone 0.25–1mg	Psychosis Agitation Aggression	Falls, confusion, hypotension, multiple neurological and metabolic AEs, QTc prolongation
Cognitive enhancing	Cholinesterase inhibitor (ChI)	Rivastigmine (Exelon Patch) 4.6–9.5mg	Agitation, visual hallucinations in DLB	Exclude bradycardia, gastrointestinal AEs
	NMDA receptor antagonist	Memantine 20mg	Agitation	
Antidepressant	SSRI	Citalopram 10–20mg	Agitation	Hyponatraemia, falls, QTc prolongation in doses > 40mg daily
Anticonvulsant		Carbamazepine 100–400mg	Agitation	Falls, disturbed gait, confusion, hepatic dysfunction, blood dyscrasias
Sedative/ hypnotic	Benzodiazepine	Lorazepam 0.5-1mg	Agitation Nocturnal sedation	Falls, confusion, rebound insomnia
Analgesic		Paracetamol Up to 3g	Agitation	

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 effectiveness for specific BPSD see [‘Behaviour Management - A Guide to Good Practice, Managing Behavioural and Psychological Symptoms of Dementia \(BPSD\)’](#).

9. Consumer and carer resource

The Handbook also includes an outline of a guide for consumers and carers (see 'Making the most of time with a person with dementia and disturbed behaviour or emotions (BPSD)' at the end of the Handbook). It is strongly recommended that if this is to be used locally, it be adapted to local needs with involvement of consumers and carers.

10. 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.

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 below tables.

Figures

No	Title	Brief explanation	Page
1.1	The cycle of evaluation and care for the person with BPSD and their carer	Presents the cycle of evaluation which is used throughout this Handbook	3
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The basics: principles, priorities and cycle of care

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

- Behavioural and Psychological Symptoms of Dementia (BPSD) refers to the non-cognitive presentations of dementia, such as agitation, aggression, psychosis, depression and apathy
- A person with behavioural disturbance should not be viewed as 'difficult' but a person who is unwell and requires help
- Key principles to remember:
 1. Person-centred care
 2. Multidisciplinary and multi-team approach
 3. Legal and ethical responsibilities
- Priorities in care:
 1. Management of physical care needs
 2. Behavioural and environmental management strategies
 3. Psychological engagement
 4. Cautious use of psychotropic medication
 5. Care for the carer

Introduction

The person with dementia will experience a good quality of life for long periods, but may also experience behavioural and psychological symptoms associated with dementia (BPSD). When BPSD is present, people require care across multiple settings and NSW Health teams. Sometimes the BPSD is the focus of care; at other times a co-morbid issue requiring management. In either situation the person with BPSD, and their carers, expect to 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. It should be applied within the context of local policies and procedures.

The term Behavioural and Psychological Symptoms of Dementia (BPSD) refers to the non-cognitive **presentations of dementia**, such as agitation, aggression, psychosis, depression and apathy.

A person with dementia and behavioural disturbance **should not be viewed as 'difficult' and a 'problem to be solved,' but as a person who is unwell and 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 on 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.

Differences in approach to the person increase the likelihood of BPSD, and related adverse outcomes.

This Handbook articulates 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 a given setting will require utilisation of other resources referred to. Universal application of the principles to older people with dementia or cognitive impairment should assist the best 'treatment' of BPSD: 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 person, carer and clinicians work in a partnership to develop a care plan with shared goals based on the person's values and experiences. Physical, psychological and social goals are considered and prioritised. Clinicians focus on the 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 in 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. The clinician has 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 there is incapacity, the 'Person Responsible' (as defined by the Guardianship Act) or the Guardianship Tribunal should be consulted to help guide decisions. In certain situations of clinical urgency, treatment may proceed without consent, for only the period of the emergency. Thereafter, the 'Person Responsible' of the Guardianship Tribunal 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 and other basic physical needs such as thirst, hunger, the need to urinate or defecate.

2. Behavioural and environmental management strategies

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.

3. Psychological engagement

The person may be distressed and anxious because of separation from loved ones, social isolation or bereavement; fearful of a strange environment; frustrated at their disability; or sad about their future. Psychological engagement enables the clinician to assess the particular 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 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
- time limit the use of medication.

5. Care for the carer

Carers, whether a spouse, child, other relative or friend, help manage the person with dementia in the community, and understand the person’s background and precipitants for the development of behaviours. It is essential to engage with the carer, provide general support, education about appropriate techniques for managing behaviours and information on community resources.

The cycle of care

The person with BPSD requires care integrating a **cycle of acceptance, assessment, action and reassessment** (refer to 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 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 patient and carer; and frustrating for all involved. Continuity 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 different health professionals.
- 2. ASSESS:** Assessment of the person's physical and psychosocial care needs.
- 3. ACT:** Development and implementation of an initial care plan.
- 4. REASSESS:** Ongoing assessment of the person and immediate outcomes, and refinement of the care plan.

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

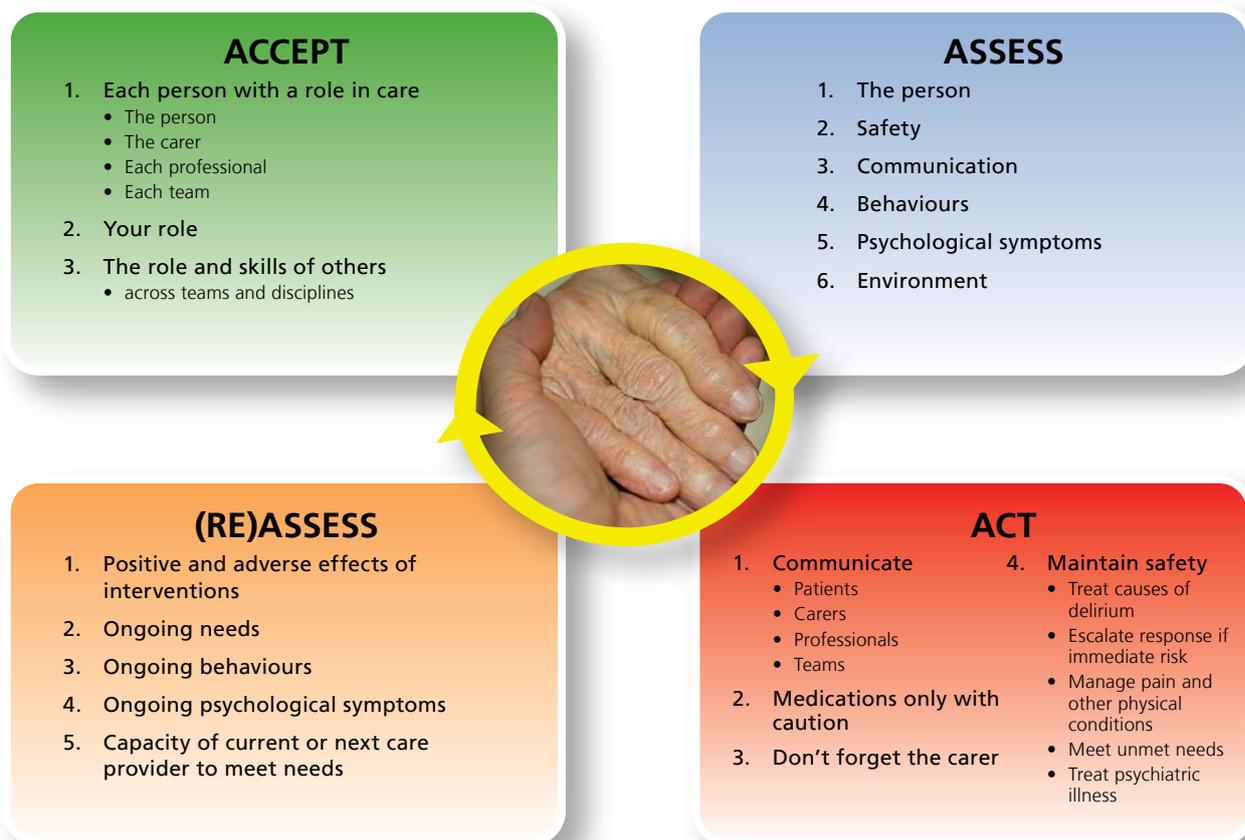
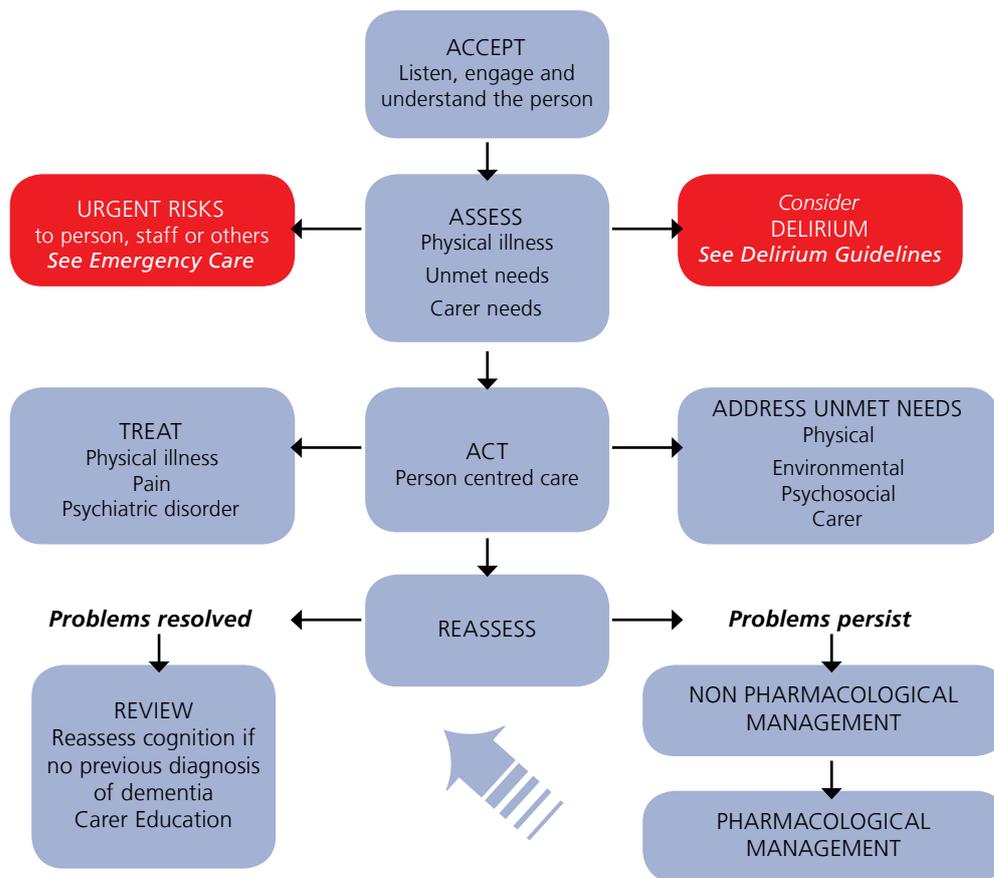


Figure 1.2. Prioritisation of actions with the person with BPSD



Further resources

[Victorian Government Health Information: Best care for older people everywhere, The toolkit](#) (available at www.health.vic.gov.au). A toolkit that puts person-centred care in the context of a ‘cornerstone domain’ of the care of older people.

[Victorian Government Health Information: Dementia Friendly Environments, A guide for residential care](#) (available at www.health.vic.gov.au). Simple guide of the practical implications of person-centred care for people with dementia.

Accept: Overview of dementia and BPSD

This chapter provides an overview of the types and stages of dementia and BPSD. It discusses aggressive behaviour, psychosis, depression and apathy, and introduces Sam – an elderly 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 upon the person and his or her carers
- For people with dementia:
 - cognitive impairment is only one feature
 - behavioural problems such as agitation and aggression occur in up to 60–90%
 - psychological problems such as psychosis and depression occur in up to 25%
 - apathy occurs in 55–90%

Overview of dementia

Dementia is a progressive disease of the brain that impairs a person's intellect, cognitive abilities and personality. However, dementia is not necessarily the terminal condition for each person with dementia. 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. That is, there are approximately 279 000 people with dementia in Australia, including 95 000 in NSW¹.

The rate of dementia may be higher in Aboriginal and Torres Strait Islander people, in whom dementia may present 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 multiple 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 may be associated with some of the above deficits.

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)	15–25%	Fluctuating cognition, visual hallucinations, idiopathic or drug-induced parkinsonism, also REM Sleep Behaviour Disorder
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 examples, Parkinson's dementia (PDD) overlaps with Dementia with Lewy Bodies, and the features of Alzheimer's disease and vascular dementia commonly coexist.

Stages of dementia

There are three main stages of dementia that may be considered very 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 of dementia to another.

In early dementia, the person may be more apathetic, lose interest in hobbies, find more complex tasks difficult, and have 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 may be seen. The person may be disturbed at night, agitated and aggressive. The person will be bedridden in the last few weeks of life².

Behavioural and psychological symptoms of dementia

Although cognitive decline is the hallmark of dementia, non-cognitive symptoms termed "neuropsychiatric" or "behavioural and psychological symptoms of 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 together in a person with dementia.

BPSD typically presents in the later stages of dementia, with 60–90% of people with dementia presenting with at least one BPSD during the course of the disease.³ The frequency of BPSD increases with the severity of dementia. BPSD is associated with carer stress, increased duration of hospitalisation and greater likelihood of placement in a residential aged care facility.

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.

1. 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 (refer to Tables 2.2 and 2.3). Such behaviours may occur for a number of 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 may suddenly become tearful, angry and verbally or even physically abusive. These are usually brief and self-limited episodes caused by acute frustration over reduced capacity to perform simple tasks such as getting dressed, misinterpreting what someone has said or misinterpreting environmental cues. Withdrawal could be a non-aggressive behavioural response to the same context.

Table 2.2. Verbal agitation

Non-aggressive	Aggressive
Constant requests for attention or complaints	Screaming
Expressions of unrealistic fears	Swearing
Repetitive questions or verbalisations	Temper outbursts
Expressions of anxiety	Verbal intimidation or threats
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)	
Inappropriate sexual behaviour (see Figure 2.3)	

2. Psychosis

About 25% of people with dementia will experience psychosis.³

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 caregiver is an imposter, or conviction about infidelity in their spouse. In contrast, delusions in schizophrenia are more bizarre, for instance thinking the Mafia is trying to kill the person’s family.

Hallucinations

Visual hallucinations may be very vivid in Dementia with Lewy Bodies (DLB), such as seeing people in fancy dress having a party in the living room. Auditory hallucinations (“voices”) are uncommon in dementia - their presence should lead to the consideration of a psychiatric disorder. More commonly, auditory illusions may be observed with the person misinterpreting noises and voices, for example, doctors’ and nurses’ discussions about other patients being misinterpreted as a plan to kill people.

Misidentifications

Misidentifications occur when the person with dementia mistakes people or objects for something else, due to perceptual disturbances. Examples include:

- believing someone else is in the house
- thinking that people are not who they are, for example, perceiving familiar people as imposters
- thinking that events on television are happening to them
- being unable to recognise own reflection in the mirror.

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

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

Anxiety

Anxiety occurs in an estimated 16–35% of people with dementia. Common anxieties are:

- fear of being left alone
- unrealistic concerns about finances, future or health
- worries about previously non-stressful events and activities – like not being at home.

4. Apathy

Apathy occurs in 55–90% of people with dementia. A person presenting with apathy has diminished initiative, motivation, and drive, along with reductions in goal-directed behaviour, cognitive activity, and reduced emotional reactivity. For instance, an apathetic person will eat or drink if food is supplied but may make little effort to prepare food spontaneously.

Apathy is distinguished from depressive disorder by the absence of sadness and other features of psychological distress.

Case vignette - Inappropriate sexual behaviour

Sam 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.

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 agitated 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.

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

Various physical and psychological factors may be associated with inappropriate sexual behaviour:

- absence of a 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 carers when assisting with personal hygiene or assisting a person to dress
- the person's sexual behaviour prior to onset of dementia
- dopamine-elevating drugs used to treat Parkinson's Disease
- alcohol use
- mood disorder
- delusions, hallucinations.

Discussion of case vignette

Whilst Sam 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.

It would be important for the community team to explain their concerns about his behaviour and why it is inappropriate. The use of male carers, if available, may help. The place of alcohol in the presentation of his behaviour should be considered and managed appropriately.

Intimate relationships

A related issue is that of a person with dementia engaging in an intimate relationship with someone else, or who may be the object of sexual advances by others.

The salient point here is that the person with dementia should be able to consent to engage in an intimate relationship and there should be no potential for abuse, harm or exploitation of the person with dementia.

To evaluate the ability of a person with dementia to participate in an intimate relationship, certain questions should be addressed:

- what is their awareness of the relationship
- what is their ability to avoid exploitation
- what is their awareness of potential risks
- what kind of relationship do they have – is there a power imbalance or element of coercion
- is there a significant discrepancy between the two people's cognitive capacity
- what pleasure (or otherwise) do they experience in the relationship – are they willing or content for it to continue?

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3. Constantine G. Lyketsos, Martin Steinberg, JoAnn T. Tschanz, Maria C. Norton, David C. Steffens, John C.S. Breitner, Mental and Behavioral Disturbances in Dementia: Findings From the Cache County Study on Memory in Aging. *Am J Psychiatry* 2000; 157:708–714

Further resources

[Alzheimer's Australia](http://www.fightdementia.org.au/) (www.fightdementia.org.au/):

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](http://www.anzsgm.org)
(www.anzsgm.org)

[International Psychogeriatric Association](http://www.ipa-online.org/)
(www.ipa-online.org/)

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

This chapter addresses key communication issues and introduces Mr K who has been admitted to hospital for myocardial infarction and who is exhibiting symptoms of BPSD.

- **Person-centred care:**
 - focuses on helping the person, rather than managing the dementia
 - 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
- **Body language and the tone of your voice provides 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, with or without BPSD. Applying the principles to all people with dementia offers the prospect of reducing the incidence of BPSD.

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

This requires the person, with BPSD, their carer and clinicians to work in a partnership to develop a care plan with shared goals based on the person's values and experiences. Physical, psychological and social goals should be considered and prioritised. Clinicians focus on the development of rapport to enable this partnership. Factors that should guide assessment and treatment include:

- the person's response to their past and current environments
- their personal history, cultural and religious background
- personal likes and dislikes

- interpretation of precipitants for behaviours
- unmet needs.

Clinicians need to not only collect information on each of these factors but also 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 obtain this information.

Person-centred care is individualised, according to the needs of each person. This requires **an understanding of each person as an individual**; that is, recognising their personal strengths and vulnerabilities, life experiences, cultural background, coping resources, and social, family and community networks.

Personal engagement is also required; that is, effective verbal and non-verbal communication tailored to the needs of the person with dementia.

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

In the case of an older Aboriginal 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 place an older Aboriginal 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 people experience. More information may be found in the [Aboriginal Older People's Mental Health Project Report](#) (available at www.health.nsw.gov.au) and [Communicating Positively: A guide to appropriate Aboriginal terminology](#) (available at www.health.nsw.gov.au).

Person-centred care approaches for consumers from culturally and linguistically diverse backgrounds (CALD) should emphasise the role of family and cultural belonging. Alternative approaches may be required for older people from CALD communities experiencing isolation, loneliness and for those who do not have extended family networks for support, are ageing in an unfamiliar cultural environment, and/or are experiencing grief, loss, shame and stigma associated with migration or displacement.

Use of specific workers or agencies focused on Aboriginal or CALD needs may assist management. Further information regarding working with Aboriginal people or people from CALD backgrounds may be found in ['Behaviour Management: A Guide to Good Practice.'](#)

Developing a positive social environment through day-to-day interactions with the person and their family, thereby promoting respect and trust, is important. Do not destroy hope; for example, do not repeatedly tell a person that their spouse is dead.

Communication

Communication is the key to assessing and responding to the person with BPSD. People with dementia will experience a gradual decline in their communication skills, including their capacity for self-expression and understanding of others.

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. Speech may be slurred or slow. They may lose the normal social conventions of conversation, interrupt or ignore a speaker, or fail to respond when spoken to. The person may also have difficulty in expressing emotions appropriately. Writing and reading skills may deteriorate.

People may lose second languages such as English. In such cases:

- healthcare interpreters should be used
- be aware of cultural and communication protocols
- communication boards may be important aids. These and other useful resources can be obtained on the [Centre for Cultural Diversity in Ageing](#) website (www.culturaldiversity.com.au/).

It is important to remember that 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 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
Use a portable hearing amplifier if no hearing aids available	Explain all procedures and activities slowly in simple terms
Ensure hearing aids are functioning and turned on	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 Bill, your green 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 [Alzheimer's Australia](http://www.fightdementia.org.au) (available at www.fightdementia.org.au)

Case vignette

Mr K, 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 have to intervene to prevent him from leaving with her.

Two weeks ago, he was admitted to hospital with a myocardial infarction. Staff described his behaviour as "anxious" and "agitated". He repeatedly asks staff if they have seen his wife. He has hit out at hospital staff when asked to have a shower or get ready for bed. He is tearful and told the social worker that he might as well do away with himself.

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

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

Figure 3.1. Relating to the Person with BPSD



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

Actions that will help Mr K

Examples of actions which may help Mr K include:

- making sure Mr K's environment is quiet – avoid competing noises, such as TV or radio
- stay still while talking to him – this will make it easier for Mr K to follow what you are saying
- maintain regular routines – this will help him minimise confusion and can assist with his communication
- keep a consistent approach – it is much less confusing for Mr K if everyone uses the same style of communication, and repeating the message in exactly the same way is important for him, his family and all his carers
- find out what Mr K used to do in the evenings so you can give an explanation that makes sense in that context
- use non-verbal communication
- use language that is positive and tailored to Mr K's ability
- identify sensory deficits.

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 in concert with a knowledge of the personal history and values of the person (see Chapter 3: Person-Centred Care). They may often 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 work well for BPSD primarily shown in resistance to care (such as bathing or eating).

After identifying strengths, strategies may include:

- task modification
- restructuring daily routines
- facilitating community integration
- equipment prescription and home modification
- risk reduction such as falls prevention.

Such approaches will often utilise the expertise of an Occupational Therapist. More information about the role of the Occupational Therapist in dementia can be found at

[Dementia: Osborne Park Hospital Guide for Occupational Therapists in Clinical Practice](#)

(available at www.library.health.wa.gov.au)

Work with the carer

With appropriate education, the informal or usual carer may be the best able to manage the person with BPSD because they know the person well; particularly, a spouse or relative carer who understands and can share the person's history. It is therefore essential to both support the carer(s) of a person with BPSD, and utilise their expertise in management.

Using the carer's expertise

The presence of an appropriate family member may be an effective intervention in settling behaviour and distress. In particular, a carer can provide information on how to avoid triggering inappropriate behaviours and how to best deal with difficult behaviours.

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

- strategies that keep the person reassured and settled
- situations that may cause distress
- signs that indicate need
- set routines and rituals that help the person settle (see *Figure 3.2* at the end of the chapter for an example of a proforma for such information).

Other strategies that are likely to improve outcome 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 start of care
- ensuring plans for managing BPSD can be continued with appropriate supports after discharge.

Supporting the carer

Interventions that may assist the carer, and thereby the person with BPSD include:

- collaboratively determining the **social, economic and healthcare 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 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 tribunal applications
- direct support for the carer’s stress or mental health.

Carers may experience chronic fatigue, anger, depression, frustration, isolation, changes in physical health, and financial strain.

■ **education about dementia and BPSD**

[Alzheimer’s Australia](#) in particular has many useful resources including factsheets, web site, national helpline (1800 100 500) and training/ support groups. The NSW DBMAS 24-hour Telephone Advisory Line may also offer support (1800 699 499).

■ **training** in how to utilise strategies found to assist the person’s BPSD. This is important for both family carers, and non-NSW Health staff who may be involved.

The implications of the following must be considered in assisting with the above issues:

- living in rural or remote areas
- the presence of other disabilities in the person or their carer
- belonging to an Aboriginal or cultural and linguistically diverse community.

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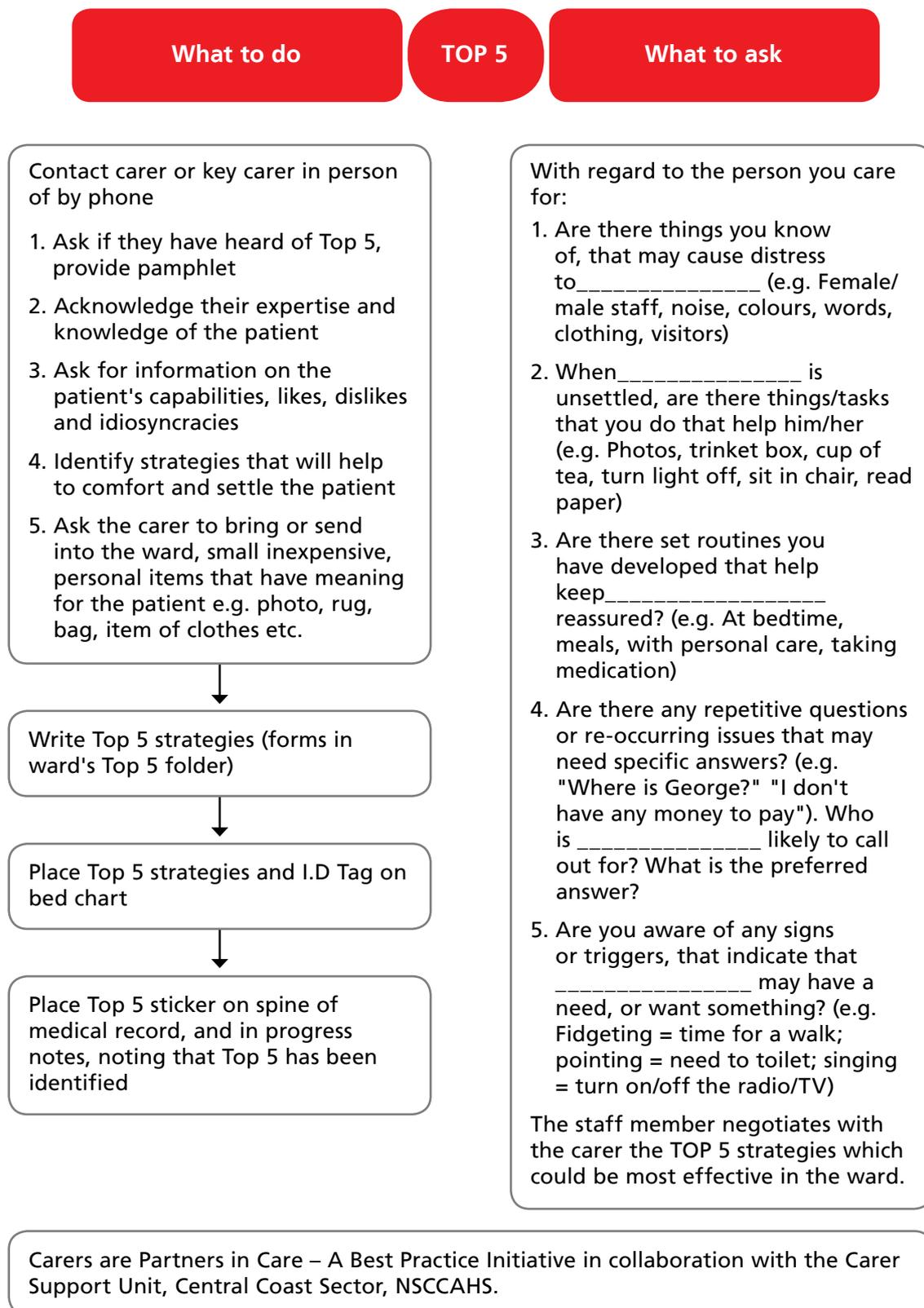
Further resources

[Victorian Government Health Information: Best care for older people everywhere, The toolkit](#) (available at www.health.vic.gov.au) puts person-centred care in the context of a ‘cornerstone domain’ of the care of older people

[Alzheimer’s Australia](#) (www.fightdementia.org.au/) A wealth of resources for clinicians, carers, and people with dementia. National Dementia Helpline 1800 100 500

[Dementia: Osborne Park Hospital Guide for Occupational Therapists in Clinical Practice](#) (available at www.library.health.wa.gov.au)

Figure 3.2. Top 5 strategies to reassure a person with cognitive impairment



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 Valerie, an 89-year-old woman who has been admitted to a general medical ward in a rural hospital.

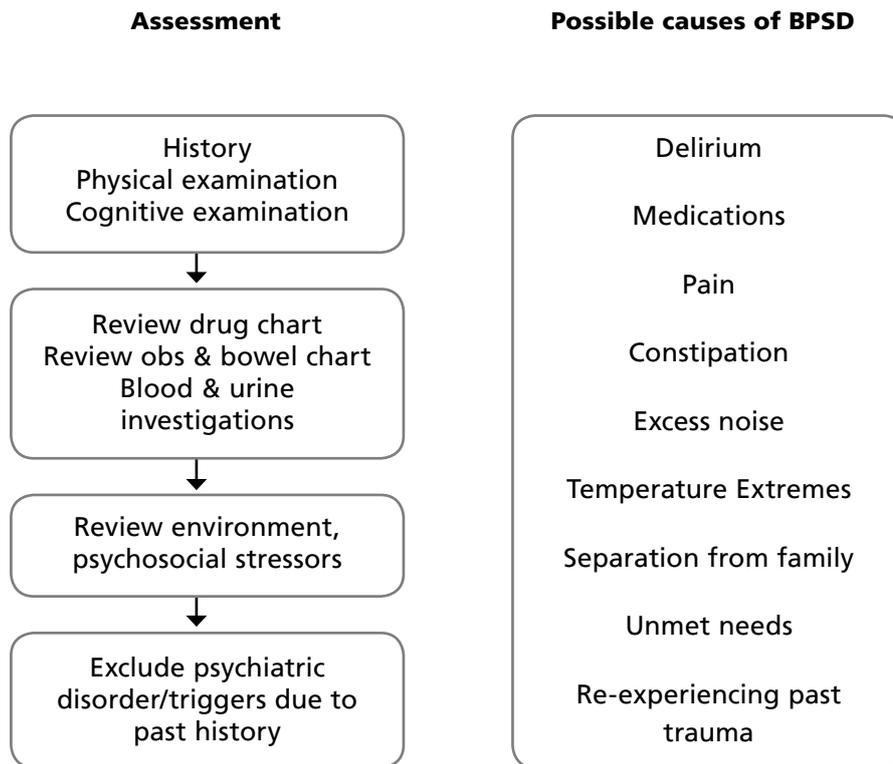
- The following factors require assessment:
 1. The person (for delirium, pain, unmet needs or other physical problems)
 2. Safety
 3. Communication
 4. Environment
 5. Psychological symptoms
 6. Behaviours
- The person may have:
 - Communication problems so that unmet needs may be expressed through behaviour, rather than specific complaints
 - Personality and cultural factors, and past experiences that influence presentation
- If dementia has not been diagnosed previously, determine if a diagnosis of BPSD is appropriate after acute physical and psychiatric problems have resolved

Introduction

This chapter focuses on identifying problems the person with BPSD may have but it is equally important to be identifying residual strengths and how these may be utilised in management. Carers may be particularly important in identifying strengths, but other areas to consider include residual cognitive and functional capacities and support networks.

Assessment of the person with BPSD must cover multiple domains, as shown in Figure 4.1.

Figure 4.1. Assessment of BPSD



Case vignette – Introduction to assessment of BPSD

Valerie, 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 wandered into other patients’ rooms. On one occasion when a nurse tried to take her back to her bed, Valerie 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.

Valerie’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 have a tendency 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.

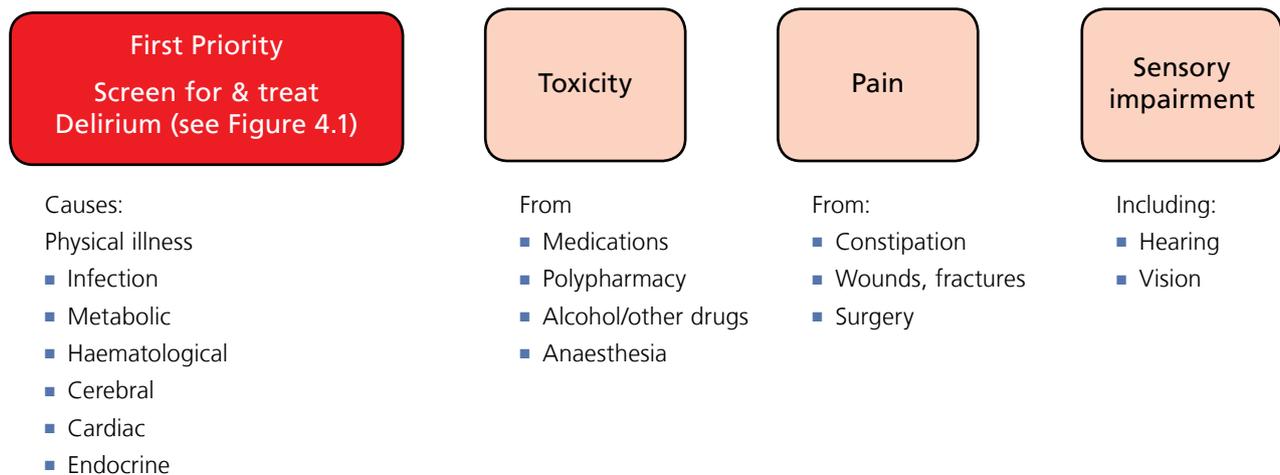
This is a common presentation of someone with dementia and agitation, both of which have been noted in the community for some time. The delusion of theft is new. Although dementia may account for the worsening in her agitation and onset of psychosis, it is essential that other causes are excluded in the assessment of BPSD.

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



1. Delirium

Dementia may be considered as a chronic confusional state, whereas delirium is an acute confusional state. The two conditions often occur together and in fact 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. Information on potential causes and investigations for delirium is included 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 thoughts and disorganised.

The Confusion Assessment Method can assist clinicians in identifying and rating these issues. This is available in the Dementia Outcomes Measurements Suite.

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 Mid-stream urine, chest X-ray
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
Drug toxicity, especially agents with strong anti-cholinergic activity (tricyclic antidepressants, oxybutynin, benztropine, olanzapine chlorpromazine, antihistamines) Opiate medications Anaesthetic agents	Review all medications – check digoxin, lithium, anticonvulsant levels
Sensory decline	Check aids for hearing and vision
Sleep deprivation	

For detailed information on the management of delirium refer to [Delirium Care Pathways](http://www.health.gov.au) (available at www.health.gov.au)

Other resources include the [Medical care of older persons in residential aged care facilities](#) (silver book) (available at www.racgp.org)

2. 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 upon 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. There may be a number of non-specific, non-verbal expressions of distress due to pain, such as 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 and constipation ■ Cancer ■ Bowel disease ■ Fractures ■ Vascular disease ■ Dental ■ Pain in genital/anal area due to thrush, haemorrhoids ■ Bony protrusions due to weight loss ■ Pressure or other skin ulcers ■ Gastro-oesophageal reflux 	(Damage to peripheral or central nervous system) <ul style="list-style-type: none"> ■ Neuropathy ■ Sciatica ■ Phantom limb pain ■ Trigeminal neuralgia

There are a number of other physical problems that are associated with BPSD, which should be assessed. For example:

- impaired vision (check that prescription glasses are available and worn)
- impaired hearing (check that hearing aids are available and worn)
- thirst or hunger
- assessment of nutrition (formal review by dietitian, also referred to as clinical nutritionist)
- constipation and faecal impaction
- urinary retention.

Safety

Assessment of safety in a person with BPSD must be considered in the context of developing a 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.

Table 4.3. Key risks to consider in a person with BPSD

Harm to self	Harm from others	Harm to others	Other
Delirium	Physical responses to intrusive behaviours	Verbal Aggression	Accommodation loss
Medical illness	Adverse effects of interventions	Physical Aggression	Carer stress
Falls	Elder abuse	Sexual disinhibition	Social isolation
Wandering			Hazardous environment
Accidental injury			
Malnutrition			
Undetected co-morbidity (e.g. drug and alcohol misuse)			
Suicide (esp. in delirium or early stages dementia)			

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.

Communication

Chapter 3 provided information regarding how to communicate with the person with dementia and BPSD. However communication involves the interaction between the person and others. Therefore 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. A lot of these may be assessed by a range of clinicians, but speech therapy or other specialist assessment may be appropriate at times for both 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, and attention ability can fluctuate significantly. Common reasons for communication difficulties with a person with BPSD are outlined in Table 4.4.

Table 4.4. Common reasons for communication difficulties with a person with BPSD

Individual	Environmental
Hearing impairment (including reversible)	Excessive background noise
Visual impairment	Excessive visual activity/ stimuli
Disturbed language (written and/or verbal) function:	Use of different language to person's
■ Expressive dysphasia and/or	Written material too small, or too far away
■ Receptive dysphasia	Inadequate time for communication
■ Dysarthria	

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 look at opportunities to develop their own cultural competency skills.

The environment

Environmental factors which may contribute to the behaviour are included in Table 4.5 below.

Table 4.5. Common environmental factors impacting on a person with BPSD

Noise (such as TV or music played loudly, 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

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 carers
- family or friends absent, or changes in availability.

Even if the person with BPSD is not aware, they may react to changes in the behaviours of other around them in response to a stressor, such as the death of a family member.

Psychiatric disorder, both new presentations and recurrence of long-standing disorders may mimic BPSD. As in all psychiatric and medical assessments a careful history often provides the most information to guide assessment, complemented by careful direct assessment of the patient and consideration of investigation results.

Agitated associated with severe depression may in particular 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'
- frequent 'don't know' answers and/or patient self-highlighting of 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 depression, but may be a difficult differential diagnosis. Figure 4.3 outlines some considerations for assessment of mental health.

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

Case vignette

Joanna is an 82-year-old woman who was born in Germany and has 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 only spoke in German and was not cooking or eating properly now. A UTI and dehydration were treated, and she was then noted to have stable chronic renal failure. Her behaviour in hospital did not change over the next two months; however, she was noted to be responding to voices, giggling at times, believed the Gestapo was going to kill her children, and remained restless at night. She was discharged to a residential aged care facility with diagnoses of dementia and BPSD, and was on 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, Joanna 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 Joanna at the facility. The psychiatrist assessed her with her daughter-in-law and an interpreter present. Knowledge of the history of Germany 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 mental health

Assess and treat psychiatric illness

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

Schizophrenia/ Delusional Disorder

- More bizarre delusions
- Auditory hallucinations
- Past history

Mania

- Persistent physical overactivity
- Rapid speech
- Irritability/disinhibition

Depressive disorder

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

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

Further resources

Delirium

[Delirium Care Pathways](http://www.health.gov.au) (available at www.health.gov.au)

Other resources include the [Medical care of older persons in residential aged care facilities](#) (silver book) (available at www.racgp.org)

NSW Health suicide assessment protocols

(available at www.health.nsw.gov.au)

[Framework for Suicide Risk Assessment and Management for NSW Staff](#)

[Suicide Risk Assessment and Management Protocols, General Community Health Service](#)

[Suicide Risk Assessment and Management Protocols, General Hospital Ward](#)

[Suicide Risk Assessment and Management, Emergency Department](#)

Pain

[Therapeutic Guidelines Analgesic version 5](#) (available at www.tg.org.au)

[Australian and New Zealand College of Anaesthetists and Faculty of Pain Medicine](http://www.fpm.anzca.edu.au/) (www.fpm.anzca.edu.au/)

[Acute Pain Management: Scientific Evidence](#) (available at www.anzca.edu.au)

[Alzheimer's Australia](http://www.fightdementia.org.au) (www.fightdementia.org.au)

Assessing mental health needs

[Assessing the mental health needs of older people](#) (available at www.scie.org.uk). Although this includes UK policy context, this provides material for the non-mental health clinician regarding assessing the mental health needs of older people.

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 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 management and palliative care
- Consider the following specific non-pharmacological therapies
 - behaviour management
 - aromatherapy
 - music
 - validation and reminiscence therapy
 - sleep hygiene
- As a general rule, the person should be cared for in an environment that is free of restraints
- Work with the carer

The person with dementia and BPSD should be managed within a model of person-centred care. This chapter outlines specific and non-specific non-pharmacological strategies that may be used. Restraint is not considered a therapeutic intervention. As a general rule, the patient should be cared for in an environment that is 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.
2. Escalate response if there is an immediate risk.
 - a. good, calm communication combined with a 'safe space' and time will often assist an agitated person with BPSD to calm
 - b. this may require, when possible, modifying the person's environment, staff routines, or the location of other patients
 - 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.

Modify the environment

A person-centred assessment guides appropriate modification of a person's environment.

Priorities, and the ability, to do this may be quite 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
- 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 room to one closer to main nurse activities, or away from 'triggers' (including other patients)
- night lighting matching past preferences
- 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 a 'safe area for the person to 'wander' in
- changing night lighting
- removing, or covering mirrors.

Further information on the environment and dementia can be found at [Alzheimer's Australia](http://www.alzheimer.org.au) (available at www.fightdementia.org).

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 particular BPSD while at the same time meeting needs for meaningful activity and stimulation and social contact. This should help to prevent boredom and frustration, enhance cognition and quality of life.

The following figure may be used by clinicians to highlight the individual's previous likes and dislikes. **Figure 5.1 on the next page, or Figure 3.2 may be utilised to facilitate person-centred care.**

Figure 5.1. Identifying key personal preferences

KNOWING ME

I like to be called

(Insert preferred name)

I can speak English (circle option)

Yes

No

I prefer to speak

(Insert preferred language)

Commenced: (Insert date)	Ceased: (Insert date)
Signature:	Signature:

	I like (or need)	I do not like
For communication		
Occupations and activities I used to:		
My main goals are		
Topics to talk about		

Prepared by (Insert name)	Signature	Date
Assisted by (e.g. person/carer) (Insert name)	Signature	Date

Adapted from Braeside Hospital, Hammond Healthcare

Hospital in-patient units may ask carers to bring in materials, or develop a set of local resources in conjunction with their 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, individualised program or specific equipment may be required. Wards often having people with BPSD within them may wish to develop a set of appropriate equipment and/or clear mechanisms to assist carers to obtain them in a timely manner.

Examples of diversion activities are presented Table 5.1 below by category. However, they clearly will often meet needs in more than one category, and different activities will be suitable for different settings. More information can be found through websites such as [Golden Carers](http://www.goldencarers.com) (www.goldencarers.com).

Table 5.1. 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, Hanukah, 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

Specific Non-pharmacological treatments

A number of psychological and alternative therapies have been researched in dementia, although the number of studies is small and small samples have been used.^{1, 2} There are a number of such therapies that may be used, each with the advantages of being associated with few adverse effects, and the need for little additional training or resources. For this reason, dementia care mapping and multisensory stimulation are not recommended because of the greater training and resources needed.

Units caring for people with dementia should consider which of the following therapies are to be resourced and used. Note that services with access to Australian Government funded DBMAS support may be able to request utilisation of brokerage funding to support appropriate interventions.

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.

1. Behavioural assessment and management

Behavioural assessment and management involves structured and systematically applied interventions, such as using an individualised ABC approach³. This can be applied by a variety of health professionals, although 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 this chapter.

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
- 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.

The following figures and table illustrate the use of the *ABC approach* to the assessment of the wandering and intrusive behaviour exhibited by Valerie.

Figure 5.2. Current ABC assessment

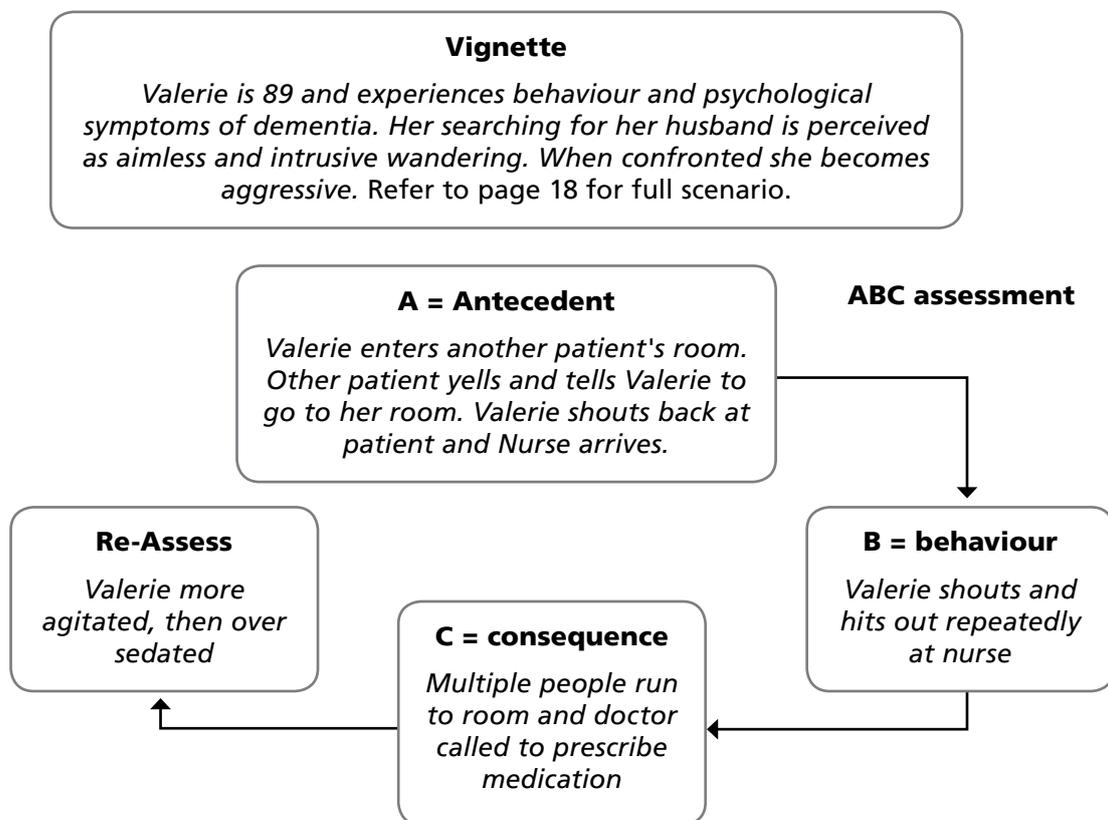
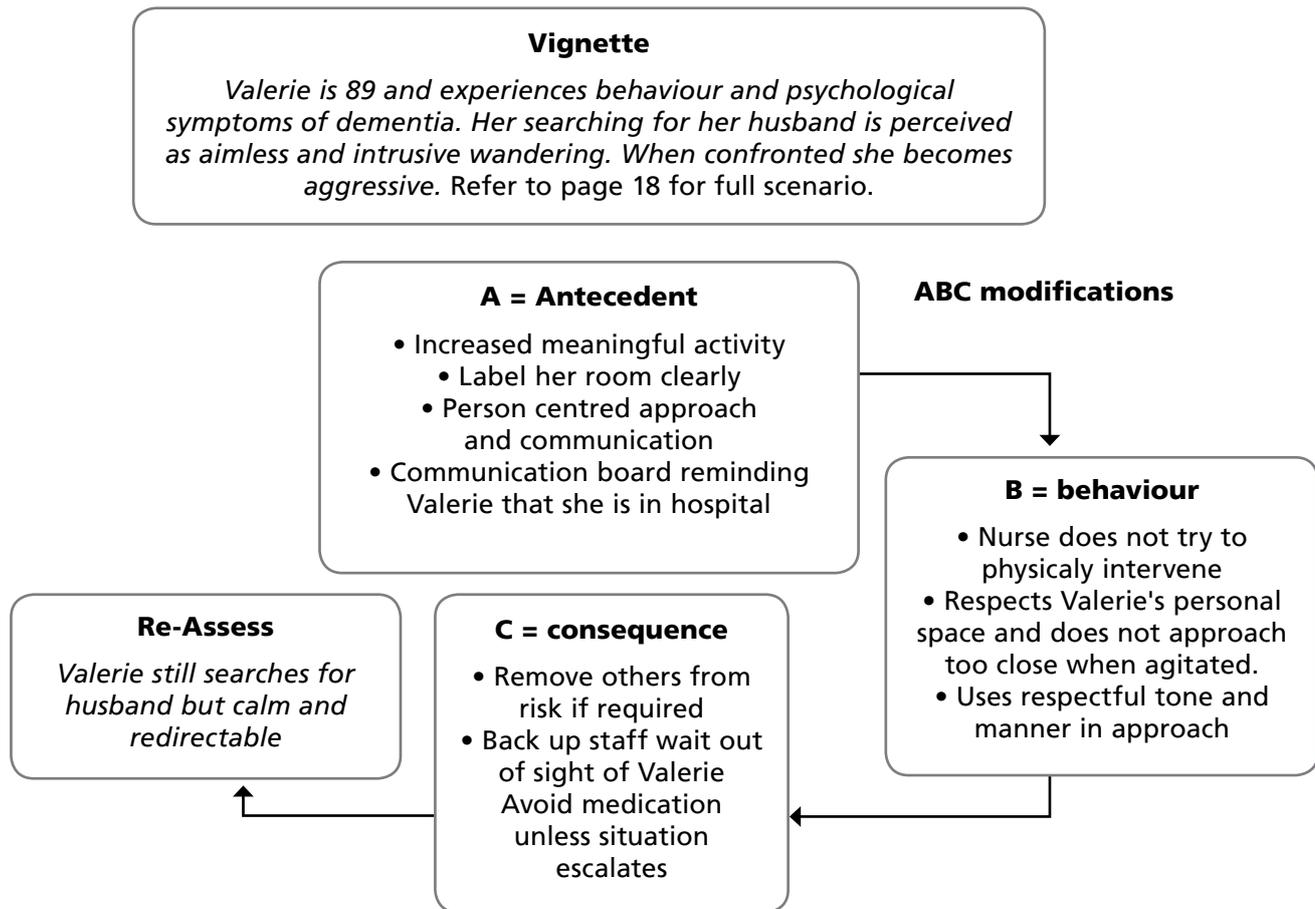


Table 5.2. ABC chart entry

Date / Time	Antecedent (what happened before the behaviour)	Behaviour (provide details)	Consequence	Re-assess/ Comment
25/12	Entered room 12 Other patient yelled to leave; Valerie yelled back.	Ongoing shouting. When nurse arrived, hit her 4 times with closed fist.	All nurses ran to aid. Doctor called. Increasing agitation Medication given.	26/12. Patient slept 12 hours. Unsteady when she woke.

Figure 5.3. Modified ABC assessment



Adapted from [ABC of behaviour management](#), Bendigo Health (available at www.dementiamanagementstrategy.com)

2. Aromatherapy and hand massage

The use of lavender oil and, in particular, Melissa oil (lemon balm), applied to the wrists and/or forearms, may reduce agitation^{4, 5}. The advantages of aromatherapy include being well tolerated and easy to administer. The additional use of hand massage/therapeutic touching may also be a positive non-verbal communication.

Note individual allergic reactions or dislike for aroma should be monitored.

3. Music therapy

When personalised to what is the person's preferred style, music is most effective⁵. If a person's preference is unknown or music is to be played to a group, classical music should be used.

4. Psychological interventions^{7, 8}

All interventions should be applied within a person-centred framework and 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 the actual reality. 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 some past personal event such as marriage, children or work. Alternatively, it may be about a song or singer of their era, major local and international events.

Orientation therapy aims to re-orientate the person by presenting information about time, place and important others. This requires the use of clocks, personal mementos, and regular visits from close family or friends. In addition, light should be bright during daylight hours and a night light may help reduce confusion and restlessness.

5. Sleep hygiene

Most people with dementia experience sleep difficulties that are associated with worsening of cognition, mood and behaviour. In particular, there may be disruption of the sleep-wake cycle due to environmental changes or physical problems.

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

- pain
- urinary symptoms
- Restless Legs Syndrome (RLS)
- sleep disorders, such as REM Sleep Behaviour Disorder or Obstructive Sleep Apnoea.

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

- going to sleep and waking at regular times
- avoiding sleeping 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.

Further information can be found at [Alzheimer's Australia](http://www.fightdementia.org) (available at www.fightdementia.org)

Other considerations

Apathy

Apathy is associated with increased disability, frustration 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. Continuation of effects once therapies cease is particularly difficult to determine from available evidence.

Revising timing of activities

The timing of activities, especially personal care is important. If the person is not cooperative with personal care, consider flexibility to allow tasks (such as showering) to be undertaken at a later stage.

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 close 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 and provide non-pharmacological management.

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

- the potential for absconding
- 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, carers and family members may be able to provide a similar role, within the scope of locally agreed practice.

Restraint

Physical restraint is the intentional restriction of a person's voluntary movement or behaviour by the use of a device or physical force. Physical restraints may include lap belts, tabletops, wrist restraints, bedrails, deep chairs or other devices used to restrict movement. Caution must be exercised when using physical restraints to minimise the risk of injury to the patient.

There may be rare instances in which restraint is required. In determining whether to restrain a person physically, the following principles should apply:

1. The risks associated with the person being unrestrained must outweigh the risks associated with restraint.
2. The use of restraint should be viewed as a temporary solution and only as a last resort.
3. The least restrictive form of restraint should be used.

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

- [Policy Direction, Aggression, Seclusion & Restraint in Mental Health Facilities in NSW](#) (available at www.health.nsw.gov.au)
- [Guideline, Aggression, Seclusion & Restraint in Mental Health Facilities – Guideline Focused Upon Older People](#) (available at www.health.nsw.gov.au); and
- [Decision Making Tool: Responding to issues of restraint in aged care](#) (available at www.health.gov.au)

Palliative approach vs palliative care

The distinction between a palliative approach and palliative care is often poorly recognised. A person-centred approach that attends appropriately to consent and clearly identifies the goals of treatment as well as potential side effects should help inform this distinction.

Dementia refers to a group of neurodegenerative disorders with overlapping but variable, symptoms and patterns of progression. It is very difficult to predict the time course of progression for a particular person. However this should not prevent recognition, and sensitive discussion, of the irreversible nature of dementia.

Whilst there are no treatments that 'cure' dementia, interventions that aim to cure 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 good 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 a palliative care approach should involve a senior medical clinician. Clinicians should be familiar with [NSW Ministry of Health policy regarding advanced care planning and decision making](#) (available at www.health.nsw.gov.au) and encourage the discussion of related issues whilst the person can express their views.

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Further resources

[Bendigo Health Regional Dementia Management Strategy - Pathway Overview](#)

(available at www.dementiamanagementstrategy.com)

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

(available at www.dementia.unsw.edu.au)

[Australian and New Zealand Society for Geriatric Medicine, Position Statement 20: Sleep and the Older Person](#) (available at www.anzsgm.org)

[Golden Carers](#) (www.goldencarers.com)

ACCEPT

ASSESS



(RE)ASSESS

ACT

ACT 2: Pharmacological management

The chapter provides information on the use of antipsychotic medications, cholinesterase inhibitors, memantine, antidepressants, anticonvulsants, benzodiazapines and other sedatives and analgesics in people with dementia and BPSD.

- The essentials of prescribing psychotropic medication to the person with BPSD are:
 - Ensure consent is present (see Chapter 7)
 - Use the 3T approach to prescription, namely
 - Target behaviours or symptoms that do potentially respond to psychotropics
 - Titrate carefully: start at a low dose and increase slowly
 - Time limit the use of psychotropics
- The use of multiple psychotropics is not generally recommended
 - Review the ongoing use and dose of each psychotropic at least every 12 weeks
- Stop if there has been no response or adverse effects are present
 - Antipsychotics are associated with potentially life-threatening adverse effects, so planned review with view to withdrawal should occur within 12 weeks
- Depot antipsychotics should not be used

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. Whilst the methodological quality of psychotropic drug trials is high, many studies are of 6–12 weeks' duration so that the benefits of some drugs in the medium to long term are unclear. Most trials have used subjects diagnosed with Alzheimer's disease (AD), so that it may be inappropriate to extrapolate the results to people with vascular dementia (VD), and the frontotemporal dementias (FTD).

The results of trials suggest modest benefits and the potential for clinically significant adverse effects.

There is evidence that in nearly two-thirds of people, anti-psychotics can be withdrawn after three months with stable or improved behaviours¹.

The prerequisites for prescribing psychotropics to manage BPSD are:

- a thorough physical assessment
- an understanding of the behaviour or psychological symptoms
- that previous trials of behavioural and psychological therapies have not been of adequate benefit
- consent has been obtained correctly.

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.

There are some behaviours, in particular 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 with dementia who screams repeatedly may require treatment for pain, or the person who wanders may have akathisia (severe restlessness) from the effects of anti-psychotic medication.

Pharmaceutical benefits scheme (PBS indications)

The only psychotropic medication that has a specific PBS indication for the treatment of BPSD is Risperidone.

Cholinesterase inhibitors are indicated for the cognitive symptoms of mild to moderate Alzheimer's disease (Mini Mental State Examination score 10+), and Memantine for the treatment of cognitive symptoms of severe Alzheimer's disease (Mini Mental State Examination score 10–14), rather than BPSD per se.

The use of antidepressants for depression and antipsychotics for delusions, associated with dementia are reasonable. Clinicians should be aware, however, that the use of anticonvulsants for agitation is 'off label.' It is recognised that such use may be essential for adequate patient care, in particular when non-pharmacological and other pharmacological treatments have been ineffective.

1. Antipsychotic medication

There are a number of risks associated with the use of antipsychotics that tend to be a class rather than specific drug effect:

- i. Increased mortality, which is higher in typical antipsychotics.^{2, 3}
- ii. Increased risk of stroke and other cerebrovascular events.⁴
- iii. Confusion and decline in cognition: – olanzapine and quetiapine may be particularly associated with confusion because of their anticholinergic activity and are therefore not recommended as a first-line anti psychotic.
- iv. Neurological adverse effects:
 - (a) akathisia: subjective motor restlessness, manifesting as an inability to sit down and pacing
 - (b) parkinsonism including tremor, stooped gait, limb rigidity
 - (c) falls
 - (d) neuroleptic malignant syndrome (NMS) – severe parkinsonism (rigidity), autonomic instability, confusion, elevated white cell count and CK enzymes.
- v. Metabolic adverse effects:⁵
 - (a) weight gain
 - (b) hyperglycaemia
 - (c) hypercholesterolaemia.

- vi. 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.

There are two types of antipsychotic medications.

Typical (first generation) antipsychotics

There is modest evidence for the use of haloperidol for aggression. Typical antipsychotics such as haloperidol are associated with greater neurological adverse effects and depression, and are therefore not recommended as a first-line antipsychotic.

Atypical (second generation) antipsychotics

There is modest evidence for the use of risperidone 0.5–2 mg daily in aggression, but limited evidence for benefits in other agitated behaviours⁶.

In the management of psychosis in Alzheimer's disease, there is modest benefit for risperidone at 1mg daily, and a statistically non-significant trend towards benefit for olanzapine 2.5–7.5mg daily ⁷.

Aripiprazole may also be beneficial in the treatment of agitation/aggression in Alzheimer's disease, but there is no evidence for other antipsychotics ⁷.

Two studies of quetiapine in Dementia with Lewy Bodies and Alzheimer's disease, respectively, did not show any benefits in the treatment of agitation ^{8,9}. In the latter study, quetiapine was associated with significantly greater cognitive decline compared to placebo. In a study of psychosis in Alzheimer's disease, quetiapine was no better than placebo, although risperidone and olanzapine were ¹⁰.

2. Cholinesterase inhibitors

There are three ChIs – donepezil, galantamine and rivastigmine – that are similar in efficacy. Their main effects are in preventing emergent BPSD rather than treating existing BPSD.

A meta-analysis showed a small but significant benefit for the ChIs in the treatment of BPSD¹¹. ChIs seem most effective in:

- depression and dysphoria
- anxiety
- apathy and indifference.

It should be noted that most studies did not target patients with BPSD. The ChIs do not appear to be effective for treating acute agitation and aggression.

Withdrawal of ChIs does lead to worsening of behavioural problems within six weeks¹².

In contrast, rivastigmine is of significant benefit in BPSD associated with Dementia with Lewy Bodies, in particular for visual hallucinations and agitation^{13 14}. Other ChIs may be as effective for this indication but have not been studied.

3. Memantine

Meta-analysis and pooled analysis shows that memantine is effective in the treatment of irritability, agitation, aggression and psychosis over 3 to 6 months in Alzheimer's disease¹⁵.

There may be a modest benefit for BPSD in Vascular Dementia but not in Dementia with Lewy Bodies¹⁶.

4. Antidepressants

Citalopram, a Selective Serotonin Reuptake Inhibitor (SSRI), has been found to be effective in the treatment of aggression and agitation with comparable efficacy to risperidone in one study¹⁷ and superior to the typical antipsychotic perphenazine in another¹⁸.

The quality of the trials of antidepressants in depression associated with dementia is limited. There is only weak evidence for the benefits of antidepressants in depression associated or with dementia, including negative results from a recent large randomised controlled trial using Sertraline and Mirtazapine¹⁹.

Clinicians should use non-pharmacological strategies for treating depression associated with dementia and consider anti-depressants when these fail or in more severe cases, such as with risk of self harm.

Tricyclic antidepressants such as amitriptyline, dothiepin and doxepin, should not be used because of the risk of increased confusion.

5. Anticonvulsants

A meta-analysis of carbamazepine at 100-300mg daily, showed significant improvement in agitated behaviours.²⁰

Although there have been some studies showing a benefit in aggression, meta-analyses have shown no evidence for the efficacy of sodium valproate²¹.

6. Benzodiazepines and other sedatives

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

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 short term only.

Lorazepam (0.5–1mg daily) may be considered in the short-term management of agitation.

7. Analgesics

A recent RCT demonstrated a significant reduction in agitation in nursing home residents with moderate to severe dementia, using a systematic approach to pain management²². In this protocol, 70% received paracetamol (maximum 3g daily) and 20% received buprenorphine patch (maximum dose 10 microgm/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.

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Table 6.1. Drug classes used in BPSD

For a more detailed review of the evidence for effectiveness for specific BPSD see 'Behaviour Management – a Good Practice Guide

Type of medication	Name of drug class	Example agent (total daily dose)	BPSD indication	Selected adverse effects
Antipsychotic	Atypical (second generation)	Risperidone 0.25–1mg		Falls, confusion, hypotension, multiple neurological and metabolic AEs QTc prolongation
Cognitive enhancing	Cholinesterase inhibitor (ChI)	Rivastigmine (Exelon Patch) 4.6–9.5mg	Agitation, visual hallucinations in DLB	Exclude bradyarrhythmias – need ECG 20% gastrointestinal AEs
Antidepressant	NMDA receptor antagonist	Memantine 20mg	Agitation	Hyponatraemia, falls
Anticonvulsant	SSRI	Citalopram 10–20mg	Agitation	QTc prolongation in doses > 40mg daily
Sedative/hypnotic	Benzodiazepine	Carbamazepine 100–400mg Lorazepam 0.5–1mg	Agitation	Falls, disturbed gait, confusion, hepatic dysfunction, blood dyscrasias.
Analgesic		Paracetamol, up to 3g	Agitation Nocturnal sedation	Falls, confusion, rebound insomnia

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 effectiveness for specific BPSD see '[Behaviour Management – a Good Practice Guide](#)'.

Further Resources

Behaviour Management a Guide to Good Practice: Managing Behavioural and Psychological Symptoms of Dementia (BPSD) (available at www.dementia.unsw.edu.au)

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



Emergency care

This chapter discusses safety issues and emergency management. Any situation in which the physical safety of the person, carers and other patients is potentially seriously compromised is considered an emergency. 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
- 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 staff in the immediate environment

Any situation in which the physical safety of the person, carers and other patients is potentially seriously compromised is considered an emergency.

Whilst immediate action must be taken, it is still essential to consider the cause of the behaviour – such as delirium or unmet needs – and to use non-pharmacological actions that help prevent the behaviour escalating.

Apart from trying to engage the person as discussed earlier, consider the following non-pharmacological actions:

1. Prevent self-harm, such as keeping the person away from open windows, balconies, electric cords and other equipment.
2. Remove from the immediate environment others who may be at risk.
3. Move the person so that continuous direct observation is possible, or to a secure unit where available.
4. Involve family or other carers.
5. Consider one to one staffing.

Consent

No consent is required from the person or a substitute decision maker if:

- the medical practitioner, carrying out or supervising the treatment, considers the treatment necessary as a matter of urgency
- there is a risk to the person's life, a risk of serious damage to their health, or the person is suffering significant pain or distress.

The following chapter will consider capacity and consent in more detail.

Medication

The following acute sedation protocol may be followed if medication is essential to immediately reduce risks to the person, other patients and staff in the immediate environment.

1. Remember the principles of communication, especially body language and tone of voice.
2. Remember that the person with dementia will be afraid and confused.

3. Oral medication should always be offered first.
4. Intramuscular (IM) medication can aggravate the person's distress and should only be used if the person cannot be calmed with oral medication. Depot antipsychotics such as Acuphase, Clopixol, Modecate and Haldol should never be used in this context.

Table 7.1 includes information on medication in in-patient behavioural emergencies.

Table 7.1. Medication in in-patient behavioural emergencies

Older Person's Route	Medications		Initial Dose	Maximum Dose in 24 Hours	Caution
ORAL	BENZODIAZEPINE (preferred)	Lorazepam	0.5 - 1.25mg	Max dose 7.5 mg (total per event)	Respiratory depression, confusion, ataxia
	And/or ANTIPSYCHOTIC ¹	Olanzapine wafer OR	2.5 - 5mg	Max dose 10 mg (total per event)	Confusion, hypotension, bradycardia, ataxia
		Risperidone	0.5 - 1 mg	Max dose 4 mg (total per event)	Hypotension, sedation, ataxia
IM ⁷	ANTIPSYCHOTIC	Olanzapine ²	2.5 mg	2.5 mg increments to max dose of 7.5mg (total per event). DO NOT use if delirious; seek specialist advice	Confusion, hypotension, bradycardia, ataxia

Precautions:

¹ Benztropine 2 mg IV or IM should be used to manage acute dystonia caused by antipsychotics. Note: Use with caution in the elderly as benztropine may cause an anticholinergic delirium.

² Do not use Olanzapine IM within tow hours of parenteral benzodiasepines due to the risk of respiratory depression.

References

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Further resources

[Guideline, Aggression, Seclusion & Restraint in Mental Health Facilities – Guideline Focused Upon Older People](#) (available at www.health.nsw.gov.au). Useful information about de-escalation and prevention of disturbed behaviour; as well as procedures for appropriate use of restraint where it cannot be avoided.

[Mental Health for Emergency Departments – A Reference Guide](#) (available at www.health.nsw.gov.au)

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, substitute consent must be obtained from a 'person responsible' or the NSW Guardianship Tribunal for 'major treatment'
 - 'Minor treatment' can proceed without consent if the 'person responsible' cannot be contacted or is unwilling to decide, and if the clinician documents this appropriately in the medical file
- Document consent and treatment decisions

Determining capacity to consent

Consent is a key element of all healthcare – the person has to be made aware of the benefits and risks of a treatment proposed by the practitioner, as well as the risks of not accepting care, so that an informed decision about accepting the treatment can be made.

The clinician has a responsibility to 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. arrive at a choice.

Principles of capacity assessment

Every adult is presumed to have capacity. The degree of certainty required about the person's capacity to consent to treatment should be consistent with the gravity of the decision the person is required to make. That is, the more serious the decision, the greater the certainty regarding capacity must be.

There are some key principles of capacity assessment:

1. Always presume a person has capacity.
2. Capacity is specific to each decision.
3. Assess the person's decision-making ability, not the decision they make.
4. Substitute decision-making allows for consent when capacity is lacking.

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.

A person with dementia may be capable of making some decisions (for example, simple decisions about taking an antibiotic), but not others (such as a more complex decision about an operation). A person with delirium may recover their ability to make decisions once the delirium has resolved.

Family, carers or friends with regular contact with the person may be approached for information to assist with the assessment of a person's decision-making capacity. In the event of current incapacity, they should be asked what the person's views or expectations about the proposed management strategy might have been, and about their own expectations of the management strategy. The role of the 'Person Responsible' is discussed further below.

Further information is available in the [Capacity Toolkit](#) (available at www.lawlink.nsw.gov.au).

Case vignette – Mrs B

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

The hospital contacted Mrs B's GP who advised the doctor that she did have tests two years ago for memory loss. She was diagnosed with mild dementia but has been managing well with community supports. She has had no previous hospital admissions. Mrs B appears agitated when told she will need to be admitted for treatment and further tests.

When admitted to the ward, the nurse settled Mrs B into her bed around 10pm. At 3am the nurse on duty discovered Mrs B 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.

Mrs B's vignette presents clinical staff with two problems. The most important is whether she should be allowed to act as she pleases; that is, to go home.

When capacity is not present

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

- a) they are incapable of understanding the general nature and effect of the treatment, or
- b) they are incapable of indicating whether or not they consent to the carrying out of the treatment.

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

Mrs B had been managing well at home but the circumstances of her admission suggest that she is physically unwell and confused. The working diagnosis is delirium due to dehydration, a urinary tract infection and anaemia, on a background of dementia. It cannot be assumed, however, that she lacks the judgment to make decisions about her care, in particular to understand the risks to herself of leaving hospital, so her capacity must be tested. Initial evidence of lack of capacity is that Mrs B was unable to believe the nurse's statement that she was unwell or follow directions to maintain her safety.

The second question is – if Mrs B is not capable of providing consent – who can legally provide that consent?

Case vignette continues

The on-call intern was paged and attended Mrs B, who has become more agitated and insists on leaving without further treatment. The intern formed the opinion Mrs B was incapable of giving consent for treatment in hospital because she could not describe where she was, that she was unwell or that she was in danger if she left the hospital without treatment in the middle of the night, and

is incapable of understanding the general nature of the treatment. Two nurses and the intern walked Mrs B back to her bed; the intern prescribed diazepam 2.5mg stat, commenced IV fluids and trimethoprim for a presumed UTI on the advice of the consultant physician.

1. Substitute consent in urgent situations

If the patient lacks capacity, treatment should be given in accordance with the Guardianship Act.

Diazepam is a sedative and therefore is major medical treatment. To give major medical treatment without the consent of the substituted decision maker, the treatment needs to be necessary, as a matter of urgency, to:

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

Although the diazepam is not necessary to save Mrs B's life, it was considered required as a matter of urgency, to allow the administration of IV fluids and antibiotics, thereby preventing serious damage to the patient's health. It is also seen as preventing significant ongoing distress.

2. Substitute consent in non-urgent situations

After ten days, Mrs B's agitation settled considerably after treatment of her dehydration and urinary tract infection. During that period, regular risperidone 0.25mg BD was started and continued. Although Mrs B willingly took all her medications, consent still needed to be sought either from Mrs B (if she had recovered sufficient capacity) or if incapable, from a substitute decision-maker as the clinical situation was no longer urgent.

Person responsible

In non-urgent situations, when the person is unable to give consent to treatment, and the treatment involves minor or major medical treatment, consent must be sought from a **'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. a guardian (including an enduring guardian) who has the function of consenting to medical treatments or, 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 or, if there is no spouse or de facto spouse

3. an unpaid carer who is now providing support to the person or provided this support before the person entered residential care or, if there is no carer
4. a relative or friend who has a close personal relationship, frequent personal contact and a personal interest in the welfare of the person, on an unpaid basis.

If the identified person responsible is unavailable or cannot be located, and the proposed treatment is a 'major treatment,' as defined below, substitute consent must be obtained from the Guardianship Tribunal before the treatment may be carried out lawfully. If the proposed treatment is a 'minor treatment,' as defined below, treatment may be carried out without consent if the requirements set out under 'minor treatment' below are complied with.

If a person identified as being a 'person responsible' declines in writing to exercise the function of 'person Responsible,' or a medical practitioner or other qualified person certifies in writing that the person identified as 'person responsible' is not capable of carrying out those functions, then the person next in the hierarchy **becomes** the 'person responsible'

The Guardianship Act has strict provisions relating to the information that must be provided to the person responsible as well as the matters the person responsible must consider before consenting on the patient's behalf. In addition, the Guardianship Act generally requires the request and consent to be in writing, or if not practicable, later confirmed in writing. The provisions in the Guardianship Act must be complied with.

A person responsible cannot consent to special medical treatment. If special medical treatment is proposed, consent must be sought from the Guardianship Tribunal.

Further information about the substituted consent process under the Guardianship Act can be found in the NSW Health's policy [Consent to Medical Treatment – patient information](#) (available at www.health.nsw.gov.au)

Case vignette continues

The medical team determined that the 'person responsible' for Mrs B 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 Mrs B's niece. As Mrs B was not objecting, her niece gave written consent to the use

of risperidone. It must also be noted that the use of psychotropic drugs like risperidone is a 'major treatment'.

Major treatment

Major treatment refers to any treatment that involves:

- Medication 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 a substantial risk to a patient (e.g. resulting in death, or brain damage, or paralysis, or permanent loss of function of any organ or limb, or permanent and disfiguring scarring, or exacerbation of the condition being treated, or unusually prolonged period of recovery, or detrimental change of personality, or high level of pain or stress).
- 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.
- Any treatment involving the testing for HIV.
- Other major treatments that are identified at the NSW Health's policy [Consent to Medical Treatment – patient information](#). (available at www.health.nsw.gov.au)

If there was no person responsible available, or if Mrs B objected to risperidone and there was no appointed guardian to override her objection, then an application to the Guardianship Tribunal would have been necessary.

Case vignette continues

Mrs B's haemoglobin continued to decline and rectal bleeding was noted. She was told that a colonoscopy and gastroscopy were necessary. Mrs B 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 the medical records.

As they are considered necessary to promote or maintain the Mrs B's health, gastroscopy and colonoscopy are considered by the Guardianship Act to be 'Minor Treatments'.

Minor treatment

Minor treatment refers to any treatment that is not major or special medical treatment:

- 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 is, given when required, according to the patient's needs) that may be given not more than 3 times a month, or
 - given for sedation in minor medical procedures.

In this case, a person responsible was available and could provide substitute consent. However there is no requirement for substitute consent being sought for minor treatment when the person responsible cannot be found, is unwilling or unable to make a decision, or there is no person responsible, and the patient does not object.

Before the treatment is given without substitute consent, however, the medical practitioner carrying out or supervising the minor treatment must certify in the patient's medical record that:

1. The treatment is necessary.
2. The treatment is the form of treatment that will most successfully promote the patient's health and well-being.
3. The patient is not objecting to the treatment.

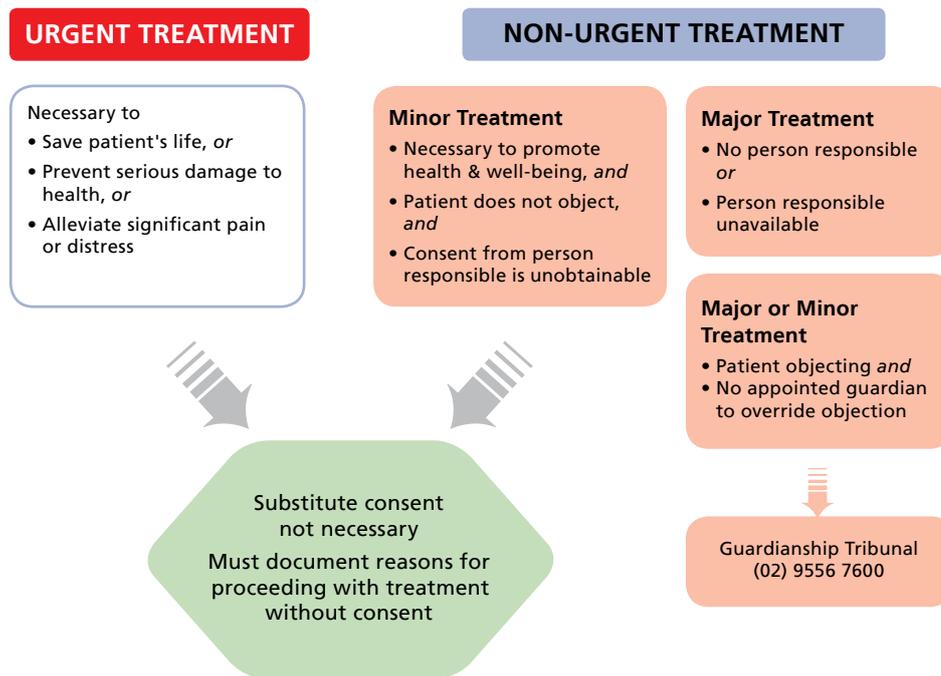
Special treatment

Special medical treatment includes:

- Treatment that involves the use of androgen reducing medication for the purpose of behavioural control.
- Any treatment that involves the use of an aversive stimulus, whether mechanical, chemical, physical or otherwise.
- Other special treatments that are identified at the NSW Health's policy [Consent to Medical Treatment – patient information](#) (available at www.health.nsw.gov.au).

Only the Guardianship Tribunal can consent to special treatment.

Figure 8.1. Obtaining substitute consent when patient lacks capacity



Case vignette continues

The colonoscopy noted an early stage tumour in the bowel, which is best treated by surgical removal. Mrs B has refused any further treatment because she believes there is nothing to worry about and wants to be left alone, even though her niece has encouraged her to have surgery. In making a decision about whether an operation is appropriate, the treating clinician should consider the stage of dementia, quality of life and previous expectations, if known.

A bowel re-section is considered a Major Treatment by the *Guardianship Act*. Even though her niece is willing to give substitute consent, as Mrs B is refusing treatment, then consent must be obtained from the Guardianship Tribunal. The request to, and consent from, the Tribunal must be in writing.

Mrs B returns to living in the community in her own home with significant levels of in home support: meals on wheels, personal care 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 Mrs B to the local Emergency Department which is a declared mental health facility for a mental health assessment.

NSW Mental Health Act 2007

While it may be reasonable to transfer a person with dementia to hospital for further assessment under the *Mental Health Act*, it is important to note that a patient may generally only continue to be detained under the Act in a declared mental health facility. However, if a patient has been scheduled as a mentally ill person or mentally disordered person and is liable to be detained in a declared mental health facility, the person can be managed in a general ward if it is necessary to provide treatment or care for an illness or condition unrelated to their mental illness or mental condition.

As 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 also be reasonable to detain a person with dementia under the *Mental Health Act* if they fulfill the criteria of the Act. If it is thought that the *Mental Health Act* should be used in regard to a person with dementia who is outside a declared mental health facility, mental health services should be consulted.

In order for a person to be detained or treated as a mentally ill person under the *NSW Mental Health Act 2007*:

1. the person must have a mental illness, which means a condition that seriously impairs, temporarily or permanently, the mental functioning of a person and is characterised by the presence of delusions, hallucinations, serious disorder of thought form, severe disturbance of mood, or sustained irrational behaviour indicating the presence of the aforementioned symptoms; and
2. the person or others require protection from serious harm.

The *Mental Health Act* also has mentally disordered provisions for short-term detention, which outside a declared mental health facility should only be used in conjunction with mental health service consultation.

A person under guardianship may be admitted to a mental health facility as a voluntary patient if the guardian makes a request to an authorised medical officer. A person under guardianship must not be admitted as a voluntary patient if the guardian objects, and must be discharged as a voluntary patient at the request of the guardian, unless the treating team decides that the involuntary provisions of the Mental Health Act must be used. Such action, contrary to a guardian's wishes, should only occur with consultation with a senior clinician.

Further resources

[Public Guardian](http://www.lawlink.nsw.gov.au) (www.lawlink.nsw.gov.au)

[The NSW Guardianship Tribunal](http://www.gt.nsw.gov.au) (www.gt.nsw.gov.au)

[Mental Health Act 2007](http://www.health.nsw.gov.au)
(available at www.health.nsw.gov.au)

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.

- People with dementia and 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:
 - Emergency Departments
 - In-patient Wards
 - Community Settings

The person with BPSD will most commonly require coordinated interventions from disciplines of multiple disciplines. This may be to deliver the non-pharmacological interventions described in Chapter 5, or to provide other care. In hospital settings these may be involved as part of one, or many, teams. In the community they will often be from differing 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 (in alphabetical order) include:

- dietitian
- diversional therapist
- medical specialists, including GPs
- nursing disciplines
- occupational therapist
- pharmacist
- physiotherapist
- psychologist (both neuropsychologists focused on cognitive assessment and clinical psychologists focused on behavioural assessments and a range of interventions)
- social worker.

Common disciplines and tasks are presented in Table 9.1.

Table 9.1. Key clinician tasks

Accept those who may be involved Agree on the roles of each	Assess	Act	Reassess
Person Relatives/carers Medical officer Psychologist Dietitian Nurses Social worker Physiotherapist Occupational therapist Aged Care Assessment Team (ACAT) Aboriginal mental health workers Aboriginal Health Workers Multicultural workers Diversional therapist Other care providers	Ongoing assessment of: <ul style="list-style-type: none"> ■ physical health ■ psychological health ■ cognition ■ behaviour ■ function ■ unmet needs ■ mobility and falls risk ■ social needs ■ carer needs ■ capacity of discharge supports to meet needs 	Ensure immediate safety. Obtain consent for treatments. Establish rapport with the person and carer. Communicate respectfully develop a treatment plan. Meet unmet needs: <ul style="list-style-type: none"> ■ physical health ■ discomfort ■ pain ■ loneliness ■ boredom. Use non-pharmacological interventions. Start discharge planning early with the person, carer and community providers. Assist family/carers to understand the person's needs. Only use psychotropic medication if essential for immediate safety and/or the above interventions have failed.	Reassess regularly. Expect behaviour to fluctuate, not be perfect. Continue to monitor physical health. Monitor for drug side effects. Adapt treatment plan according to response. Ensure discharge supports can continue management.

Some disciplines that may be overlooked, and whose role is therefore described further, include:

1. Aboriginal mental health workers and Aboriginal health workers

It is imperative that respectful, responsive and culturally sensitive services are delivered to Aboriginal 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 people¹.

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 communities across NSW, and also aims to promote the competencies of non-Aboriginal mental health clinicians who currently work with Aboriginal people². Aboriginal

Mental Health Workers perform a key role in holistic care of Aboriginal 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. Both 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 services³.

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 which respond in an appropriate way.

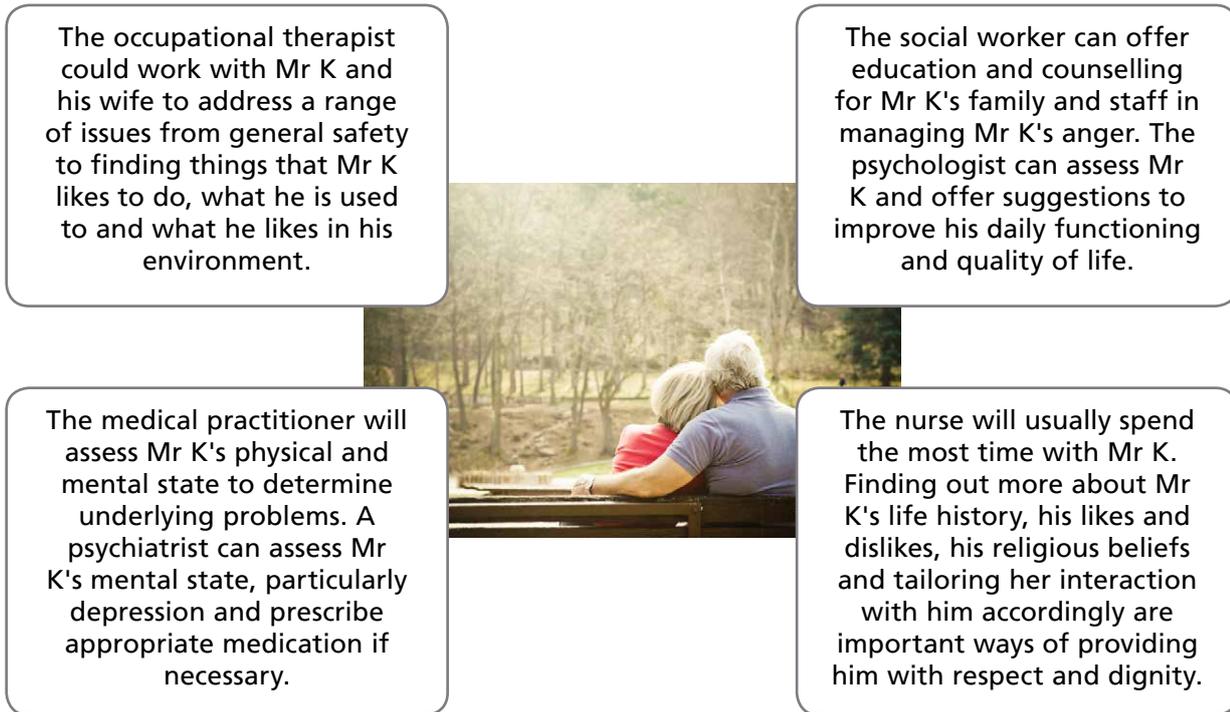
Multicultural health workers provide a range of services including direct health care, research, planning, consultancy, community development capacity building, health education, health promotion and patients. There are a number of clinical services which target specific communities and employ bilingual staff to improve access to services, including:

- The Bilingual Counsellor Program
- Bilingual Community Educators
- Multicultural Access Workers / Multicultural Aged Equity Officers
- Diversity Health Coordinators
- Multicultural Workforce Development Officers.

The Transcultural Mental Health Centre (TMHC) Clinical Consultation and Assessment Service provides clinical consultation and assessment services for individuals and families from culturally and linguistically diverse communities with mental health issues and has a pool of bilingual workers including psychiatrists, psychologists, social workers, mental health nurses and occupational therapists, who speak over 50 languages.

The Health Care Interpreter Service operates across NSW, 24 hours a day, 7 days a week to ensure that non-English speaking patients / clients are able to communicate effectively with any health provider of the NSW health system.

Figure 9.1. Mr K vignette continued



Putting it all together: Continuing Mr K's care

We have previously met Mr K in [Chapter 3](#).

At this point there are several people involved in trying to decide what needs to be changed and monitored in Mr K's care plan: the doctor, the nursing staff and Mr K's wife who has been upset by the recent changes in his behaviour. Each will be grappling with the following considerations but from different perspectives. The doctor will want to find out whether the behaviour is caused by delirium or another physical cause such as pain caused by arthritis. The nurse will want to know what to do and to reassure Mr K's wife that her husband is receiving good care. Other professionals such as psychologists, dietitians, occupational therapists, social workers will bring to Mr K's care plan their specific professional expertise. All should be working together to develop a working hypothesis about why the behaviours are occurring.

In Mr K's case, this requires taking time to learn about his life story and being sensitive to his religious beliefs and cultural identity. It means making attempts to tailor his activities and care.

Multiple teams and settings

The person with dementia has a chronic, progressive illness and their condition will vary over time requiring 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.

This chapter presents cycles of care for each of the different health settings addressed by the 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 and the roles of their team members in partnership with the person, their relatives and carers.

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 and Aged Care Assessment Teams (ACAT).
The ACAT plays a key role in assessing the level of residential and community care services the person needs
- general adult psychiatric teams, especially consultation-liaison services
- Special Mental Health Services for Older People (SMHSOP) teams including in-patient, consultation-liaison and community services
- general community nursing team
- ward teams including surgical, medical and other specialty wards.

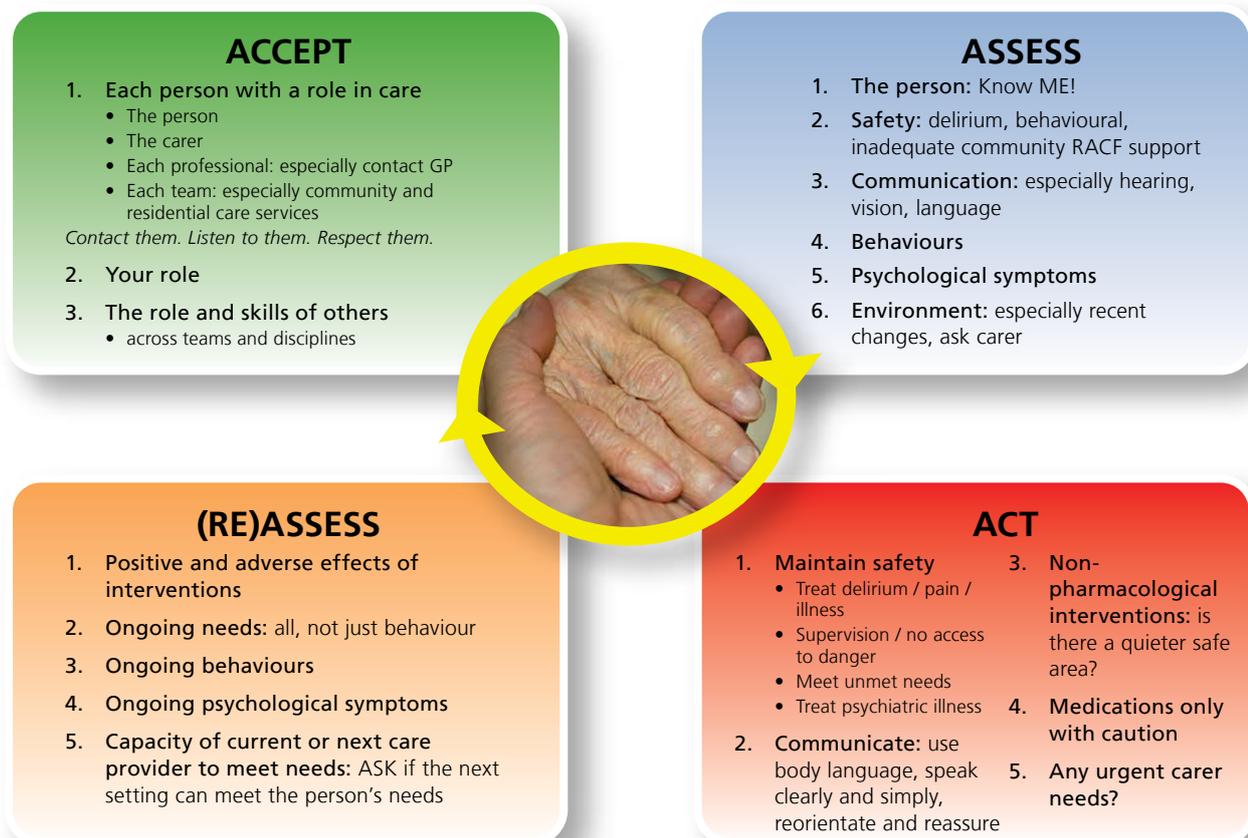
Care in the emergency department

The focus within Emergency Departments is particularly 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 a number of clinicians. Diagnostic tests may be required. The person may be discharged following treatment or they may be admitted to an in-patient ward.

At all times a person-centred approach should be maintained to minimise and/or manage behavioural problems that are associated with dementia.

As previously mentioned many health professionals may be involved in providing care for the person and liaising with family or carers. Table 9.1 on page 50 lists those commonly involved and illustrates the adaption of Assess, Act and Re-assess components of the Care and Evaluation Plan.

Figure 9.2. Cycle of Care – Emergency Department



Care in the in-patient ward

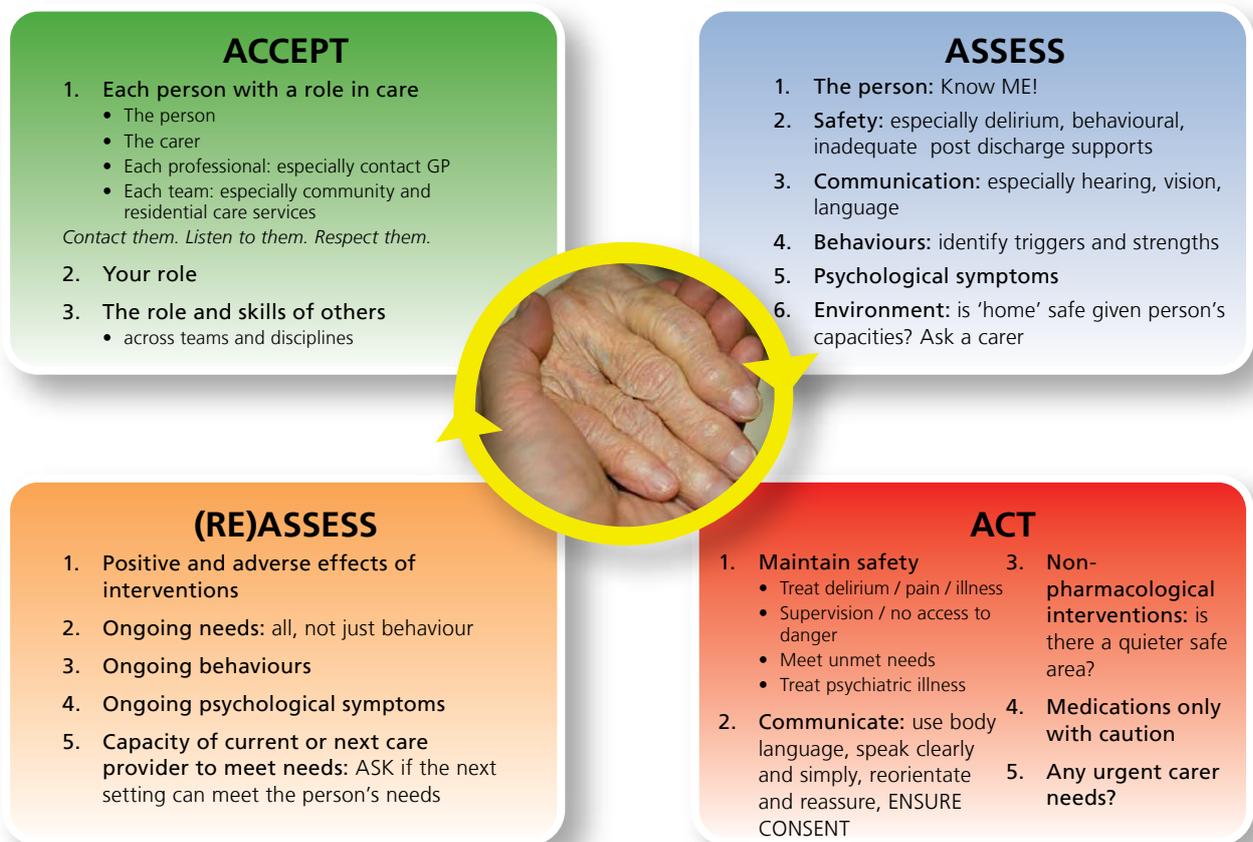
Almost all wards will receive people with dementia and BPSD. In addition to being able to provide care for the primary reason for admission (e.g. palliative care, fractures), ward staff need to incorporate the Cycle of Care for BPSD into the person's treatment plan. This involves:

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

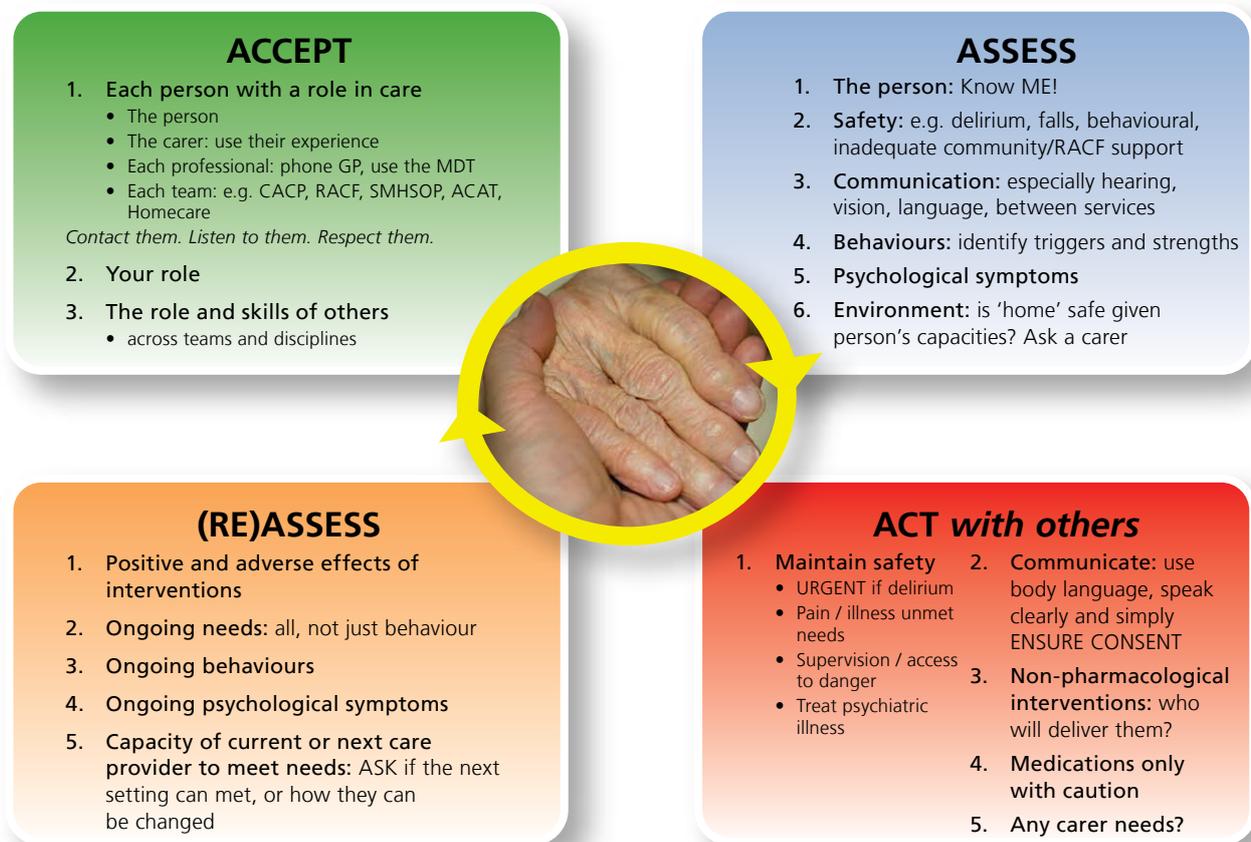
Figure 9.3. Cycle of Care – In-patient ward settings



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 carers*. 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 the consenting person is willing to tolerate. Such concerns may most frequently relate to the behaviours, medical condition or accidental harm.

Figure 9.4. Cycle of Care – Community settings



References

1. [Royal Australian & New Zealand College of Psychiatrists \(2009\). *Position Statement 50: Aboriginal and Torres Strait Islander Mental Health Workers*: http://www.ranzcp.org/getattachment/Policy-and-advocacy/Indigenous-health/50-PS-2012-Aboriginal-and-Torres-Strait-Islander-Mental-Health-Workers-GC-2012-3-R36.pdf.aspx](http://www.ranzcp.org/getattachment/Policy-and-advocacy/Indigenous-health/50-PS-2012-Aboriginal-and-Torres-Strait-Islander-Mental-Health-Workers-GC-2012-3-R36.pdf.aspx)
 2. [NSW Aboriginal Mental Health Workforce Program. http://www.healthinfonet.ecu.edu.au/key-resources/programs-projects?pid=139](http://www.healthinfonet.ecu.edu.au/key-resources/programs-projects?pid=139)
 3. [NSW Department of Health \(2012\). *Aboriginal Older People's Mental Health Project Report* \(http://www.health.nsw.gov.au/resources/mhdao/pdf/aboriginal_older_peoples_.pdf\)](http://www.health.nsw.gov.au/resources/mhdao/pdf/aboriginal_older_peoples_.pdf)
- [Dietitians Association of Australia](http://www.daa.asn.au/) (www.daa.asn.au/)
- [Diversional Therapists Australia](http://www.diversionaltherapy.org.au/) (www.diversionaltherapy.org.au/)
- [Occupational Therapy Australia](http://www.otaus.com.au) (www.otaus.com.au)
- [The Psychogeriatric Nurses Association Australia Inc](http://www.pgna.org.au/) (www.pgna.org.au/)
- [Royal Australian College of General Practitioners](http://www.racgp.org.au/) (www.racgp.org.au/)
- [Royal Australian and New Zealand College of Psychiatrists](http://www.ranzcp.org/Home.aspx) (www.ranzcp.org/Home.aspx)

Further resources

(In alphabetical order)

[Australian Association of Social Workers](http://www.aasw.asn.au/)
(www.aasw.asn.au/)

[Australian College for Emergency Medicine](http://www.acem.org.au/)
(www.acem.org.au/)

[Australian and New Zealand Society for Geriatric Medicine](http://www.anzsgm.org/)
(www.anzsgm.org/)

[The Australian Clinical Psychology Association](http://www.acpa.org.au/)
(www.acpa.org.au/)

[Australian Physiotherapy Association](http://www.physiotherapy.asn.au/)
(www.physiotherapy.asn.au/)

[Australian Psychological Society](http://www.psychology.org.au/) (www.psychology.org.au/)

[The College of Nursing](http://www.nursing.edu.au/) (www.nursing.edu.au/)

[Dementia Behaviour Management Advisory Service \(DBMAS\), *Behaviour Management, A Guide to Good Practice, Managing Behavioural and Psychological Symptoms of Dementia*, page 9-11. Cultural competencies specifically Aboriginal and Torres Strait Islander people and Multicultural Health Workers'](http://www.dementia.unsw.edu.au/) (available at www.dementia.unsw.edu.au/).

[The Society of Hospital Pharmacists of Australia](http://www.shpa.org.au/)
(www.shpa.org.au)

[Transcultural Mental Health Centre](http://www.dhi.health.nsw.gov.au/tmhc/default.aspx)
(www.dhi.health.nsw.gov.au/tmhc/default.aspx)

Glossary

Term	Description
ACAT	Aged Care Assessment Team
AD	Alzheimer's disease
BASIS	Behavioural Assessment and Intervention Service
BPSD	Behavioural and Psychological Symptoms of Dementia
ChI	Cholinesterase inhibitor medication
DBMAS and BASIS	Dementia Behavioural Management Advisory Service / Behavioural Assessment and Intervention Service
FTD	Fronto-temporal dementia
LBD	Dementia with Lewy bodies
MAOIs	Monoamine oxidase inhibitors
PDD	Parkinson's disease dementia
SMHSOP	Specialist Mental Health Services for Older People
SNRI	Serotonin noradrenergic reuptake inhibitors
SSRI	Selective serotonin reuptake inhibitors
VaD	Vascular dementia

Appendix 1. Rating scales/ measurement tools

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

- Rating scales and proforma provided for use within specialist mental health services
- Cognitive dimensions of dementia
- Behavioural and Psychological Symptoms of 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 *Dementia Assessment website* ³⁴ (available at www.dementia-assessment.com.au), from which the following information has been adapted.

The generic guidelines about how to administer are a valuable and useful resource for the clinician wishing to employ any of the measures referred to here.

Completion of different measures may be by:

- caregivers or family informant 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 conducted through an interview conducted by a clinician with a person and/ or informant care giver or by self completion by a suitably qualified informant care giver.

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 Assessment website before using one of the measures presented below.

Health professionals often begin with the measurement tool and work backward. Consulting the Generic Guidelines can assist the clinician 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 the consumer. [The Mental Health Clinical Documentation – Redesigned GL2008_016. Standardised Mental Health Clinical Documentation](#) 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 the management of people of CALD 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–16 (an abbreviated version of the Life Skills Profile) K10+–LM or K10–L3D (two versions of the Kessler–10).

Supported in NSW Mental Health documentation suite

- 3MS (with MMSE approximation)
- RUDAS

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 Cooperative Research Centre Cognition Assessment Measures](#) web page (available at www.dementia-assessment.com.au).

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

- the age of the person

- cultural background. There are tools specifically adapted for:
 - 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), particular professional expertise, (e.g. ADAS-Cog usually performed by a psychologist or neuropsychologist)
- whether the measure is in the public domain: the measures quoted are all in the public domain and available via the dementia assessment website.

B) Measures for behavioural and psychological symptoms of 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, and are available on the Australian Government Dementia Assessment website which assess a range of behaviours and areas, the Neuropsychiatric Inventory (NPI) and the Behavioural Pathology in Alzheimer's Disease (BEHAVE-AD).

(i) The Neuropsychiatric Inventory includes ten behavioural and two neurovegetative 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

It is designed to be administered to the caregiver by a trained or specialised clinician.

However, there is a version of the measure, the NPI NH designed to be administered to caregivers who will not have known the person with dementia prior to its onset.

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

Measures behavioural symptoms of Alzheimer's Disease via clinician interview with an informant caregiver or through self-completion by a clinician caregiver.

There are a range other measures for the assessment of individual BPSD for people with cognitive impairment and/or dementia which **focus upon Aggression, Agitation, Apathy and Depression:**

- **Rating Scale for Aggressive Behaviour in the Elderly (RAGE)** a five-minute scale for use by nurses and regular caregivers.
- **Cohen-Mansfield Agitation Inventory (CMAI)** a ten-to-fifteen minute clinical rating scale for completion by caregivers to assess the frequency of manifestations of agitated behaviours
- **Pittsburgh Agitation Scale (PAS)** a one-minute measure for completion by clinical staff during the course of direct observation and documentation.
- **Apathy Evaluation Scale (AES)** a 20-minute measure conducted through a semi-structured interview between the clinician and the person to quantify and characterise apathy in adults.
- **Cornell Scale for Depression in Dementia (CSDD)** two 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 interview requiring no training to assess and screen depression in elderly people.

¹ There are many complex needs of older Indigenous people with dementia and other health-related issues. The lack of a culturally appropriate assessment tool has previously hindered the evaluation of cognitive impairment in the Indigenous community. The Kimberley Indigenous Cognitive Assessment tool (KICA) was developed and validated in a number of Indigenous communities in the Kimberley region of Western Australia. The full tool can be found at: <http://www.kamsc.org.au/research/downloads/KICA%20Tool%202006.pdf>

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 themselves is not able to provide the understanding and long-term knowledge required, the clinician needs a partnership with family and friends and long-term care givers. Subtle changes in the behaviour of people with dementia who are in pain may only be detectable by members of staff or at home carers who consistently work with that same 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. Residents with borderline communicative capacity (that is, early stages of dementia) may benefit by applying both verbal and observational sets of 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 the 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 Pain Assessment in Advanced Dementia (PAINAD) Scale was developed to provide a clinically relevant and easy to use pain assessment tool for individuals with advanced dementia (Warden et al, 2003). The tool is an adaptation of the DS-DAT and the FLACC 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 Pain Assessment Scale for seniors with Severe Dementia (PACSLAC) is a tool for the familiar caregiver 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](http://www.geriatricpain.org) website (available at www.geriatricpain.org).

The Abbey Pain Scale (Abbey et al, 2003)

The Abbey Pain Scale was created for the measurement of pain in people with dementia who cannot verbalise. Based on observation and knowledge of a resident's usual function and medical history, the resident 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:

- Consultation liaison services (consultation liaison services in psychiatry, geriatrics and nursing)
- Specialist geriatric or aged care medical services
- Specialist Mental Health Services for Older People (SMHSOP)
- Dementia Behavioural Management Advisory Service and Behavioural Assessment and Intervention Services
- Aged Care Assessment Teams (ACAT)
- Community Support services
- Residential Aged Care services.

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. Specialist Mental Health Services for Older People liaison (SMHSOP) services 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 being a role model.

Specialist mental health services for older people (SMHSOP)

SMHSOP provide specialist assessment and management for older people (usually 65 years or older) with mental health problems requiring specialist input. This includes people who present with severe behavioural or psychiatric symptoms associated with dementia or other long-standing organic brain disorders who would be optimally managed with input from SMHSOP. The role of SMHSOP and Geriatric services in regards to people with dementia is complementary, and determined by local area service development. Services *may* include in-patient and community care; including Behavioural Assessment and Intervention Services (BASIS).

Specialist behavioural management services

Behavioural Assessment and Intervention Services (BASIS)

BASIS are NSW-funded specialist community based services for older people with behavioural and/or psychological symptoms of dementia or mental illness. BASIS clinicians are part of Specialist Mental Health Services for Older People (SMHSOP) community teams across NSW. Functions include information, advice, assessment, case management, care planning, mentoring and clinical support, and training. These are intended to complement, and collaborate with, DBMAS services.

Dementia Behavioural Management Advisory Service (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 care workers, aged care service providers and carers of people with dementia who receive support through Australian Government funded aged care services. 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.

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 SMHSOP and Geriatric services in regards to people with dementia is complementary and is determined by local service development. Services *may* include in-patient and community care.

Aged care assessment teams (ACAT)

ACATs are multidisciplinary clinical teams whose primary role is to independently and comprehensively assess 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. ACATs facilitate access to available care services appropriate to the client's needs. 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 services 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 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 can be obtained from [Aged Care Australia](#) (available at www.agedcareaustralia.gov.au)

Community support services

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

- DPS Guide to Aged Care
- [Commonwealth Home and Community Care Program \(HACC\)](#) (available at www.health.gov.au)
- Aboriginal and Torres Strait Island Communities - information and liaison
- [Aged Care Australia, Community Aged Care Package \(CACP\)](#) (available at www.agedcareaustralia.gov.au)
- [The National Respite for Carers Program \(NRCP\)](#) (available at www.health.gov.au)
- [Extended Aged Care at Home \(EACH\)](#) (available at www.health.gov.au)

- [Extended Aged Care at Home-Dementia \(EACH-D\)](#) (available at www.eldercare.net.au)
- The National Dementia Support Program (NDSP)
- Low and High Care residential facilities
- Dementia Help Line.

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

Dementia Advisory Services

(available at www.adhc.nsw.gov.au)

Dementia Advisory Services are funded by Ageing, Disability and Home Care through the Ageing Grants Program and the Home and Community Care (HACC) Program, to promote local awareness of dementia, provide information, education and support and to link people to assessment and support services.

This is a network of over thirty organisations that deliver counselling services by phone or in person throughout NSW on a range of issues related to dementia, including:

- adjusting to a diagnosis
- understanding dementia and its impact
- caring for someone with dementia
- finding appropriate services or practical assistance responding to changed and challenging behaviours
- family issues
- loss and grief
- planning for the future
- the move into residential care.

[NSW Falls Prevention Program](#)

(available at www.cec.health.nsw.gov.au)

The key focus of the NSW Falls Prevention Program is to reduce the incidence of falls and harm from falls among older people.

Between one in four and one in three community dwelling people aged 65 years or over report at least one fall per year and many fall more than once. Fall injury is a major cause of injury-related hospitalisations and loss of independence among people aged 65 years and over in NSW.

Patient falls are the most common adverse event reported in acute care settings, affecting between 2% to 10% of annual hospital admissions. In-hospital falls represent a significant high cost, high volume hospital acquired

condition within NSW hospitals. Patient falls in hospitals increases length of stay, requires additional diagnostic investigations and impacts on patient treatment resulting in increased costs to the system. Having had a recent fall is one of the leading reasons for premature admission to permanent residential aged care.

NSW Falls Prevention Program implements a range of strategies for preventing falls in hospital, community and residential aged care settings in the hospital sector, the community sector and in residential care.

Key strategies for preventing falls in the hospital sector:

- Screen for people at risk for falls.
- Assess and implement strategies to care for people at risk.
- Implement post-fall guideline following a fall in hospital.
- Report and monitor fall incidences, 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 early any 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.

[Alzheimer's Australia NSW](#)

(www.fightdementia.org.au)

Alzheimer's Australia NSW offers a range of sensitive and flexible services to support people with dementia or who are caring for someone with dementia.

[National Dementia Helpline](#)

(www.fightdementia.org.au) Contact: 1800 100 500 Monday to Friday from 9am to 5pm

NSW – Counselling and support

(www.fightdementia.org.au)

Provides:

- professional consultants for people to talk with about dementia, discuss needs and connect to a range of programs and services
- understanding and support for people with dementia, their family and carers
- practical information & advice
- up-to-date written material about dementia
- information about other services
- details of the full range of services provided by Alzheimer's Australia.

NSW – Living with Memory Loss program

For people living with early stage dementia or who are a family carer for someone with dementia, there is an early intervention program. People are able to get information and support by sharing experiences with a small group of others in a similar situation.

NSW – Community awareness

Alzheimer's Australia offers a range of services to increase awareness of dementia in the community and highlight the importance of brain health and dementia risk reduction.

NSW – Rural and regional services

Alzheimer's Australia NSW has a number of regional offices and partnerships across NSW offering dementia support services designed to meet your needs in your local community.

NSW – Social and therapeutic activities

Alzheimer's Australia NSW provides a selection of single event and ongoing activity programs for recreation, therapy and social support. Many activities are conducted in partnership with local community groups around the state and most are free of charge.

NSW – Library and information service

The service supports family carers, people with dementia, health professionals and community care workers in NSW by providing access to quality dementia-related consumer health information and resources.

NSW – Support Groups

Support Groups give people with dementia and carers an opportunity to meet with others in a similar situation to share experiences, learn new ideas for skills for living with dementia and engaging in mutual problem solving.

NSW – Safely Home

Enables carers and family members to have peace of mind by knowing a wandering person can be rapidly and accurately identified and returned home when located. Safely Home is a joint program run by Alzheimer's Australia NSW and the NSW Police Service.

NSW – Safe2Walk

This GPS-based personal alert and location service provides increased independence for people living with dementia and peace of mind to family carers

Directory of Parliamentary Services (DPS) Guide to Aged Care (available at www.agedcareguide.com.au)

A key resource is the publication DPS Guide to Aged Care, which lists the number of places provided by each service in each region including Community Aged Care Packages, Extended Aged Care at Home, Extended Aged Care at Home – Dementia and for residential care Aboriginal and CALD specific facilities.

Aged care and Disability Services HACC Program and Other Community Service

[The Home and Community Care \(HACC\) Program](http://www.health.gov.au) (available at www.health.gov.au) is a joint Australian, State and Territory Government Initiative.

The HACC Program provides a range of services designed to enable older Australians, younger people with a disability and their carers to be more independent. Services include:

- nursing care
- allied health care
- meals and other food services
- domestic assistance
- personal care
- home modification and maintenance
- transport
- respite care
- counselling, support, information and advocacy
- assessment.

The Program provides a basic level of support to recipients.

An ACAT assessment and approval is required before people can access residential aged care, Community Aged Care Packages (CACPs) or Extended Aged Care at Home (EACH) Packages. Services can be purchased on a private basis or can be allocated on the basis of the need as established by the ACAT.

For more information or to find a service please use the contact information below:

Sydney Metropolitan: 1800 350 792

Rural Areas and Central Coast: 1300 881 144

Aboriginal Access and Assessment Team: 1300 797 606

Family and Community Services, Ageing and Disability & Homecare, [Home Care Services](#)
(available at www.adhc.nsw.gov.au)

Commonwealth Respite and Care Link Centres

Commonwealth Respite and Carelink Centres provide a single point of contact for information on community aged care, disability and other support services. The Centres can also assist with information about costs for services, assessment processes and eligibility criteria.

Each Commonwealth Respite and Carelink Centre has extensive regional networks and maintains a comprehensive database containing community aged care, disability and other support services.

Shopfronts are operated by organisations that already provide established services within their region.

Contact nearest [Commonwealth Respite and Carelink Centre](#) (available at www.health.gov.au) on Freecall™ 1800 052 222

Culturally responsive services for Aboriginal people

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

For discharge planning for an Aboriginal with dementia it is essential to liaise with the:

- [Aboriginal Medical Service and Aboriginal Home Care](#) (available at www.health.nsw.gov.au)
- [Aboriginal Home Care Service Development Unit, NSW Health](#)
(available at www.directory.nsw.gov.au):
Email: AboriginalRAC@dhs.nsw.gov.au; Telephone: 1300 797 606
- Aboriginal Specific brochure [Worried About Your Memory?](#) (available at www.fightdementia.org.au)

Multicultural Health Services Information

[Policy Directive, Standard Procedures for Working with Health Care Interpreters](#), NSW Health
(available at www.health.nsw.gov.au)

[Diversity Health Institute](#) (www.dhi.gov.au) and
[Transcultural Mental Health Centre](#)
(www.dhi.health.nsw.gov.au/tmhc/default.aspx)

[NSW Multicultural Health Communication Service](#)
(www.mhcs.health.nsw.gov.au/)

Residential aged care services

Residential aged care services provide the key manner of housing and caring for people with dementia for whom it is no longer practical to live at home.

There are two key types of care High Care (previously referred to as 'nursing home') and Low Care (previously referred to as 'hostel'). Within each of these types of care there are a range of levels and types of care. A range of 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 is 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.

A key resource for selection of residential aged care facilities is the [DPS Guide to Aged Care](#) (available at www.agedcareguide.com.au), which is generally available.

Peak industry bodies in NSW are the [Aged & Community Services Association of NSW & ACT Inc](#) (www.agedservices.asn.au/) and [Leading Age Services Australia NSW-ACT](#) (www.acaansw.com.au/)

Appendix 3. Project methodology and consultation

Method

The process for compiling the BPSD Handbook included an electronic search of the relevant literature, using Medline, Psychinfo and Cochrane databases, published between 2006 and 2011, in particular review papers, clinical practice guidelines, consensus and position statements on the assessment and management of dementia, Alzheimer's disease and BPSD.

The aim of the Handbook was to provide recommendations for good clinical care, based on this literature review and clinical experience, rather than prescriptive recommendations according to specific levels of evidence.

Project management

The Project was managed by the RANZCP Practice, Policy and Projects division, under the supervision and direction of Dr Chanaka Wijeratne, the Project Clinical Leader. Management oversight was provided by the Bi-National Faculty of Psychiatry of Old Age, via the BPSD Handbook Project Working Group including Faculty Chair Dr Roderick McKay (NSW), Associate Professor Jeff Looi (ACT),

Associate Professor Stephen MacFarlane (Victoria) and Dr Wijeratne. The Working Group included support from RANZCP staff including General Manager Practice, Policy and Projects, Dr Anne Ellison, and Project Officer, Mr Tim Sussman.

The initial draft of the Handbook was written by Dr Wijeratne and Mr Sussman. This was redrafted and edited by Dr Wijeratne and Dr McKay with the assistance of Dr Ellison and Claire Bellett (RANZCP Executive Assistant to Dr Ellison).

Consultation

The BPSD Handbook was developed through extensive consultation with key stakeholders from agencies supporting health professionals and from other projects working with dementia listed.

Expert reference group

An 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 who have dementia. The ERG members were consulted extensively to provide input and comment into the structure, form and contents of the BPSD Handbook.

Table A3. Membership of the Expert Reference Group

Member	Vocational group or role
Dr Chanaka Wijeratne	Old Age Psychiatrist (Clinical Leader)
Ms Elizabeth Brandis	Clinical Nurse Consultant
Ms Gail Daylight	Aboriginal Health Manager
Professor Brian Draper	Old Age Psychiatrist
Ms Christine Duffy	Community Clinical Nurse Consultant 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	Clinical Nurse Consultant, Aged Services in Emergency Team
Dr Lisa Kelly	Geriatrician
Ms Cheryl-Ann Pollack	Policy Officer, Ministry of Health
Dr Sarah Visser	Clinical Psychologist
Dr Tom White	Knowledge Translator, Dementia Research Cooperative Centre
Mrs Eesa Witt	Clinical Nurse Consultant

Consultative Draft

A Consultative Draft of the Handbook was made available for comment to:

- Key stakeholder professional societies and individual professionals
- Chairs of Bi-National Committee and NSW Branch of the Faculty of Psychiatry of Old Age (FPOA), Royal Australian and New Zealand College of Psychiatrists (RANZCP) (Drs McKay and Peisah)
- NSW Local Health District Mental Health Directors
- NSW Agency for Clinical Innovation Aged Health Network
- NSW Health Education and Training Institute
- NSW Clinical Excellence Commission
- NSW Ministry of Health (MoH), Special Mental Health Services for Older People (SMHSOP) Advisory Group
- NSW MoH Mental Health Clinical Advisory Council (CAC)
- NSW MoH Older People's Mental Health Working Group
- NSW MoH Aboriginal Older People's Mental Health Working Group
- NSW MoH CALD Older People's Mental Health Working Group
- Chair of the International Psychogeriatric Association BPSD Taskforce (Dr Draper).

Ratification

Pre-Final draft of the BPSD Handbook was provided for input and ratification to the NSW Mental Health Clinical Advisory Committee, the NSW Mental Health Program Council, Agency for Clinical Innovation Aged Health Network and the Bi-National Committee, The General Council and Faculty of Old Age Psychiatrist's of the Royal Australian and New Zealand College of Psychiatrists.

Funding

The BPSD Handbook was supported by funding from the NSW Ministry of Health, Mental Health and Drug and Alcohol Office.

Conflicts of Interest

Dr Wijeratne has received honoraria to speak at educational meetings from Pfizer and Novartis.

Acknowledgements

Associate Professor Carmelle Peisah and Mr Nick O'Neill contributed to the development of Chapter 8 ('Ethical and Legal Obligations').

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Community Care Settings

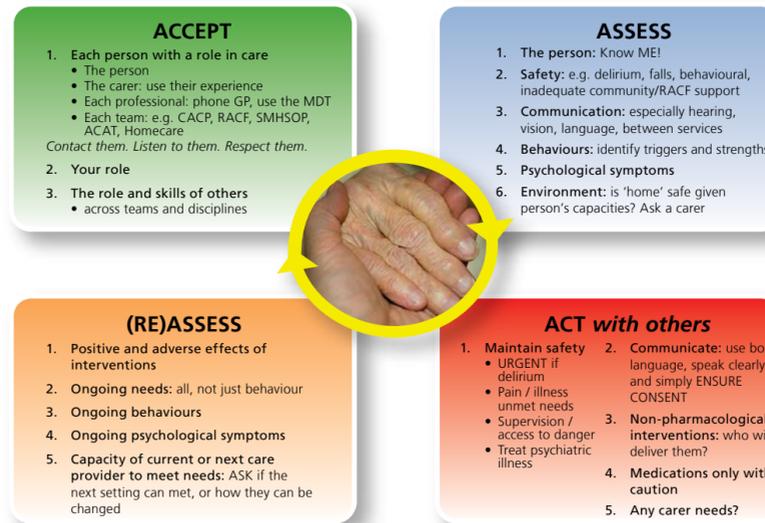
Assessment and Management of People with Behavioural and Psychological Symptoms of Dementia

Behavioural and Psychological Symptoms of Dementia (BPSD) refers to the non-cognitive presentations of dementia, such as agitation, aggression, psychosis, depression and apathy. Almost all services will care for people with dementia and disturbed behaviour. In addition to managing the primary reason for referral, staff need to incorporate the Cycle of Care for BPSD into the treatment plan. The Cycle of Care involves four stages, three care principles and five care priorities.

A person with dementia and behavioural disturbance should not be viewed as 'a difficult or disruptive patient' but a person who is unwell and requires care.

Complete the Cycle of Care

- **Stage 1:** Accept your role, the expertise and roles of others providing care
- **Stage 2:** Assess the person's needs; that is:
 - become familiar with the person's dementia-related needs
 - address any environmental factors that exacerbate or help to calm BPSD
 - develop communication skills to assist in engaging carers and relatives, and
 - know how to obtain professional support that will assist in providing care for the person
- **Stage 3:** Act
- **Stage 4:** (Re)Assess the person's needs



Principles of Care

- **1. Ensure Person Centred Care**
 - Working in partnership with the person, carer and other clinicians
 - Apply knowledge about *the person*, not just their illness
- **2. Multi-disciplinary and Multi-team Approach**
 - Each clinician should respect the expertise of other disciplines and teams as of equal value in the care of the person with BPSD and aim to *minimise disruption* during *transfers of care* and at *discharge*
- **3. Meet legal and ethical responsibilities**
 - The clinician has a responsibility to determine whether the person is able to understand and accept their diagnosis and recommended treatment, balance the potential benefits and risks of treatment, and arrive at a 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 decisions

Care Priorities

- **1. Management of physical needs**
- **2. Behavioural and environmental management strategies**
- **3. Psychological engagement**
- **4. Cautious use of psychotropic medication**
- **5. Care for the carer**

KEY CLINICIAN TASKS

Accept those who may be involved Agree on the roles of each	Assess	Act	Reassess
Person Relatives/carers Medical officer Psychologist Dietitian Nurses Social worker Physiotherapist Occupational therapist Aged Care Assessment Team (ACAT) Aboriginal mental health workers Aboriginal Health Workers Multicultural workers Diversional therapist Other care providers	Ongoing assessment of: <ul style="list-style-type: none"> ■ physical health ■ psychological health ■ cognition ■ behaviour ■ function ■ unmet needs ■ mobility and falls risk ■ social needs ■ carer needs ■ capacity of discharge supports to meet needs 	Ensure immediate safety. Obtain consent for treatments. Establish rapport with the person and carer. Communicate respectfully develop a treatment plan. Meet unmet needs: <ul style="list-style-type: none"> ■ physical health ■ discomfort ■ pain ■ loneliness ■ boredom. Use non-pharmacological interventions. Start discharge planning early with the person, carer and community providers. Assist family/carers to understand the person's needs. Only use psychotropic medication if essential for immediate safety and/or the above interventions have failed.	Reassess regularly. Expect behaviour to fluctuate, not be perfect. Continue to monitor physical health. Monitor for drug side effects. Adapt treatment plan according to response. Ensure discharge supports can continue management.

KEY COMMUNICATION POINTS

Body language and the tone of your voice provide most communication.

The actual words used are less important, so that a warm smile, laughter or touch, where appropriate, may be more effective than conversation.

Non-verbal actions	Verbal actions
<ul style="list-style-type: none"> ■ Minimise background noise ■ Stay calm and still while talking, in the person's line of sight ■ Use a portable hearing amplifier if no hearing aids available ■ Ensure hearing aids are functioning and turned on ■ Break down tasks into smaller steps ■ Communicate at eye level ■ Use simple, calm hand gestures and facial expressions ■ Allow plenty of time for the person to reply 	<ul style="list-style-type: none"> ■ Talk in a gentle tone ■ Use short sentences and simple words ■ Explain all procedures and activities slowly in simple terms ■ Allow time for what you say to be understood ■ Clarify what they have said - repeat or reword ■ Use personal references where available, e.g. your son Bill, your green jumper, this photograph of your granddaughter etc.

COMMON USEFUL ENVIRONMENTAL MODIFICATIONS	KEY INFORMATION TO KNOW ABOUT THE PERSON
<ul style="list-style-type: none"> ■ Ensure glasses and hearing aids available and functioning ■ Dim lights at night time, bright light during the day, ■ Quiet at night, familiar sounds during the day ■ Orientating material in a form the person can read: calendar, clock etc ■ Family or familiar people present ■ Minimise risk of injury (may require a low bed in the lowest position, with cot sides down, bed against the wall, potential hazards such as bedside tables removed). 	<p>Ask the person and their carer</p> <ul style="list-style-type: none"> ■ What they like to be called ■ What may cause distress ■ What may help them settle ■ Are there set routines that help them settle ■ Are there repetitive questions that need specific answers ■ Signs or triggers that indicate the person has a need

MORE INFORMATION AVAILABLE FROM: *Assessment And Management Of People With Behavioural And Psychological Symptoms Of Dementia (BPSD): A Handbook For NSW Health Clinicians Delirium Care Pathways*

LOCAL SUPPORTS WHEN NEEDED BY STAFF MANAGING A PERSON WITH BPSD (To be inserted locally)

Making the most of one to one (1:1) staff time caring for a person with Behavioural and Psychological Symptoms of Dementia

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

- Memory
- Ability to understand or speak language, especially second languages
- Carrying out coordinated motor tasks such as dressing
- Failure to recognise objects or a familiar face
- Planning, organizing tasks, and abstract thinking (e.g. understanding slang)
- Decline in activities of daily living and in social functioning.

“Behavioural and Psychological Symptoms of Dementia” (BPSD) refers to the non-cognitive presentations of dementia, such as agitation, aggression, psychosis, depression and apathy.

1:1 ‘special’ care for a person with BPSD may be utilised for a variety of reasons; almost always to increase the safety of the person and/or those around them. This flyer does not provide instructions on how to provide 1:1 care, but does provide some helpful hints to make the most of such time.

It is essential that anyone providing such care clarify their role and duties with their supervisor

It is easy for a person with dementia and behavioural disturbance to be viewed as ‘a difficult or disruptive patient’, but it is important to see them as a person who is unwell and requiring care. Often the person and those around them see

things quite differently. 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 with BPSD

Through the clinician's eyes

Confuses words

Tries to hit out

Tries to get out of bed

Withdrawn/doesn't join in with others

Convinced someone is stealing things from his room

Resists when staff try to assist him with his shower



Through the person's eyes

People here speak so quickly I need time to think of what I am going to say

I'm afraid; I don't know what is happening to me I don't know the people here

I can't sleep on my own I miss my wife

I'm bored and I miss my garden These people here are not my friends

I hear things at night. Lights are on during the night I can't find my glasses

People here are too busy to help me

Five things you can do to get to know the person and their carer

1. Ask them or someone who knows them

- What they like to be called
- What may cause distress
- What may help them settle
- Whether there are set routines that help them settle
- Whether there are repetitive questions that need specific answers
- Signs or triggers that indicate the person has a need.

2. Become involved: talk to the person and relatives or carers, find out activities you can do with them, make your own observations

3. Tell other staff what helps or causes problems, and document these.

4. Strategies that may help communication

- REMEMBER BODY LANGUAGE IS MOST IMPORTANT
- Minimise background noise and distractions
- Staying calm and still while talking and remain in the person's line of sight
- Using short sentences and simple words
- Talk in a gentle tone
- Allow time for what you say to be understood
- Allow plenty of time for the person to reply
- Clarifying what they have said - repeat or reword
- Ensuring that hearing aids are functioning and turned on or a hearing amplifier is available
- Stick to one idea a time
- Explain all procedures and activities slowly in simple terms
- Break down tasks into smaller steps
- Using personal references where available; e.g. your son Bill, your green jumper, your favourite music, this photograph 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

- Adjusting lighting or music / TV / radio choice or level
- Where available, put personal objects where the person can see them.
- Have family write key words in the person's primary language or use pictures to assist care.

More helpful information can be found in the Assessment and Management Of People With Behavioural And Psychological Symptoms Of Dementia (BPSD): A Handbook For NSW Health Clinicians



Behaviour Management, a Guide to Good Practice, Managing Behavioural and Psychological Symptoms of Dementia http://www.dementia.unsw.edu.au/images/dccr/output-files/328-2012_dbmas_bpsd_guidelines_guide.pdf

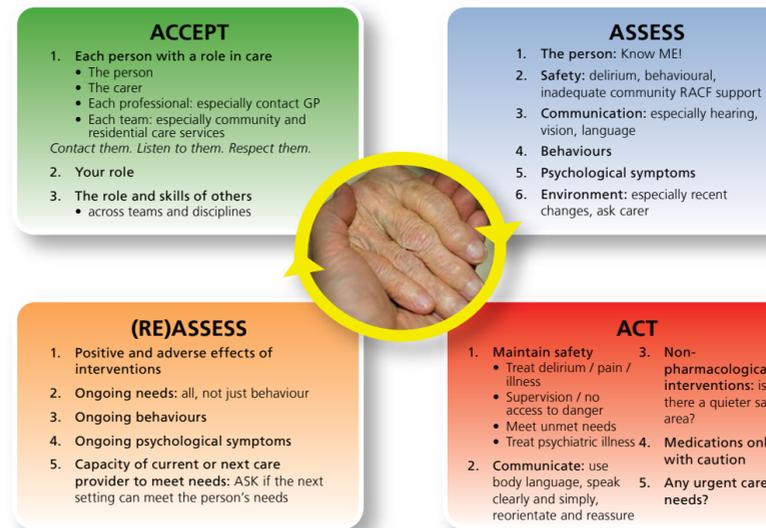
Emergency Department Settings

Assessment and Management of People with Behavioural and Psychological Symptoms of Dementia

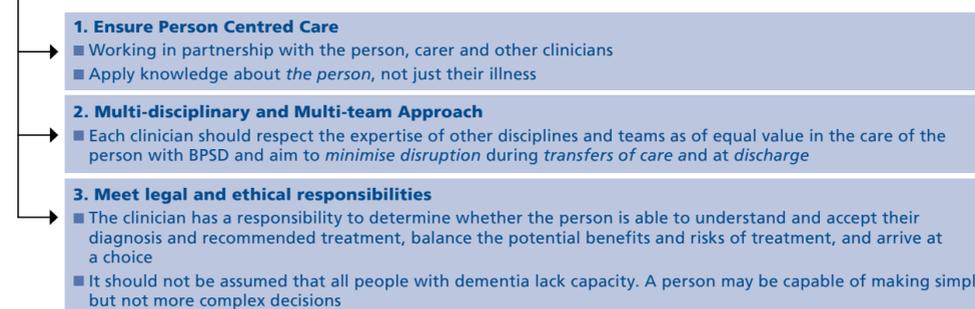
Behavioural and Psychological Symptoms of Dementia (BPSD) refers to the non-cognitive presentations of dementia, such as agitation, aggression, psychosis, depression and apathy. Almost all services will care for people with dementia and disturbed behaviour. In addition to managing the primary reason for presentation, staff need to incorporate the Cycle of Care for BPSD into the treatment plan. The Cycle of Care involves four stages, three care principles and five care priorities.

A person with dementia and behavioural disturbance should not be viewed as 'a difficult or disruptive patient' but a person who is unwell and requires care.

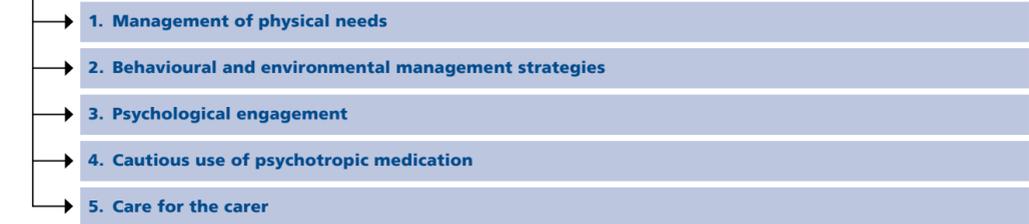
Complete the Cycle of Care



Principles of Care



Care Priorities



KEY CLINICIAN TASKS

Accept those who may be involved Agree on the roles of each	Assess	Act	Reassess
Person Relatives/carers Medical officer Psychologist Dietitian Nurses Social worker Physiotherapist Occupational therapist Aged Care Assessment Team (ACAT) Aboriginal mental health workers Aboriginal Health Workers Multicultural workers Diversional therapist Other care providers	Ongoing assessment of: <ul style="list-style-type: none"> physical health psychological health cognition behaviour function unmet needs mobility and falls risk social needs carer needs capacity of discharge supports to meet needs 	Ensure immediate safety. Obtain consent for treatments. Establish rapport with the person and carer. Communicate respectfully develop a treatment plan. Meet unmet needs: <ul style="list-style-type: none"> physical health discomfort pain loneliness boredom. Use non-pharmacological interventions. Start discharge planning early with the person, carer and community providers. Assist family/carers to understand the person's needs. Only use psychotropic medication if essential for immediate safety and/or the above interventions have failed.	Reassess regularly. Expect behaviour to fluctuate, not be perfect. Continue to monitor physical health. Monitor for drug side effects. Adapt treatment plan according to response. Ensure discharge supports can continue management.

KEY COMMUNICATION POINTS

Body language and the tone of your voice provide most communication.

The actual words used are less important, so that a warm smile, laughter or touch, where appropriate, may be more effective than conversation.

Non-verbal actions	Verbal actions
<ul style="list-style-type: none"> Minimise background noise Stay calm and still while talking, in the person's line of sight Use a portable hearing amplifier if no hearing aids available Ensure hearing aids are functioning and turned on Break down tasks into smaller steps Communicate at eye level Use simple, calm hand gestures and facial expressions Allow plenty of time for the person to reply 	<ul style="list-style-type: none"> Talk in a gentle tone Use short sentences and simple words Explain all procedures and activities slowly in simple terms Allow time for what you say to be understood Clarify what they have said - repeat or reword Use personal references where available, e.g. your son Bill, your green jumper, this photograph of your granddaughter etc.

COMMON USEFUL ENVIRONMENTAL MODIFICATIONS	KEY INFORMATION TO KNOW ABOUT THE PERSON
<ul style="list-style-type: none"> Ensure glasses and hearing aids available and functioning Dim lights at night time, bright light during the day, Quiet at night, familiar sounds during the day Orientating material in a form the person can read: calendar, clock etc Family or familiar people present Minimise risk of injury (may require a low bed in the lowest position, with cot sides down, bed against the wall, potential hazards such as bedside tables removed). 	Ask the person and their carer <ul style="list-style-type: none"> What they like to be called What may cause distress What may help them settle Are there set routines that help them settle Are there repetitive questions that need specific answers Signs or triggers that indicate the person has a need

MORE INFORMATION AVAILABLE FROM: Assessment And Management Of People With Behavioural And Psychological Symptoms Of Dementia (BPSD): A Handbook For NSW Health Clinicians [Delirium Care Pathways](#)

LOCAL SUPPORTS WHEN NEEDED BY STAFF MANAGING A PERSON WITH BPSD (To be inserted locally)

Making the most of time with a person with dementia and disturbed behaviour or emotions (BPSD)

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

- Memory
- Ability to understand or speak language, especially 'second' languages
- Carrying out coordinated tasks such as dressing
- Failure to recognise objects or a familiar face
- Planning and organising tasks, and abstract thinking (such as understanding slang)
- Decline in activities of daily living and in social functioning.

BPSD means "Behavioural and Psychological Symptoms of Dementia". These symptoms refer to other problems that may occur in a person with dementia, such as agitation, aggression, psychosis, depression and apathy.

It is easy for a person with dementia and behavioural disturbance to be viewed as 'a difficult or disruptive patient', but staff know it is important to see them as a **person** who is unwell and requiring care. Often the person and those around them see things quite differently. Your knowledge about the person may help staff try to both understand the person's experience, and help describe this to others involved in their care.

If you are visiting a person with dementia and BPSD, it can be useful to check if the staff need to know anything about the person, or whether the staff need to tell you anything that you can do to help the person.

Relating to the person with BPSD

Through the visitor's eyes

Confuses words

Tries to hit out

Tries to get out of bed

Withdrawn/doesn't join in with others

Convinced someone is stealing things from his room

Resists when staff try to assist him with his shower



Through the person's eyes

People here speak so quickly
I need time to think of what I am going to say

I'm afraid; I don't know what is happening to me
I don't know the people here

I can't sleep on my own
I miss my wife

I'm bored and I miss my garden
These people here are not my friends

I hear things at night. Lights are on during the night
I can't find my glasses

People here are too busy to help me

Five things you can do to make the most of time with the person

1. Use what you know about the person.

This might include:

- What they like to be called
- What may cause distress
- What may help them settle
- Whether there are any set routines that help them settle
- Whether there are repetitive questions that need specific answers
- Signs or triggers that indicate the person has a need.

2. Become involved: talk to the person and staff, find out activities you can do with them, make your own observations about what helps.

3. Don't be afraid to ask staff questions, or tell them if you know things that help, or upset, the person.

4. Use these tips to help communication:

- REMEMBER BODY LANGUAGE IS MOST IMPORTANT
- Minimise background noise and distractions
- Stay calm and still while talking and remain in the person's line of sight
- Use short sentences and simple words
- Talk in a gentle tone
- Talk slowly and give the person plenty of time to reply
- Check what they have said - repeat back to them if you are unsure
- Ensure that hearing aids are functioning and turned on: stick to one idea a time
- Explain activities slowly 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. Some changes you might be able to make include:

- Adjusting lighting or music / TV / radio choice or level
- Where available, put personal objects where the person can see them
- Write key words in the person's primary language or use pictures to assist care
- Minimise risk of injury, e.g. ask staff if the person needs help to prevent falls.



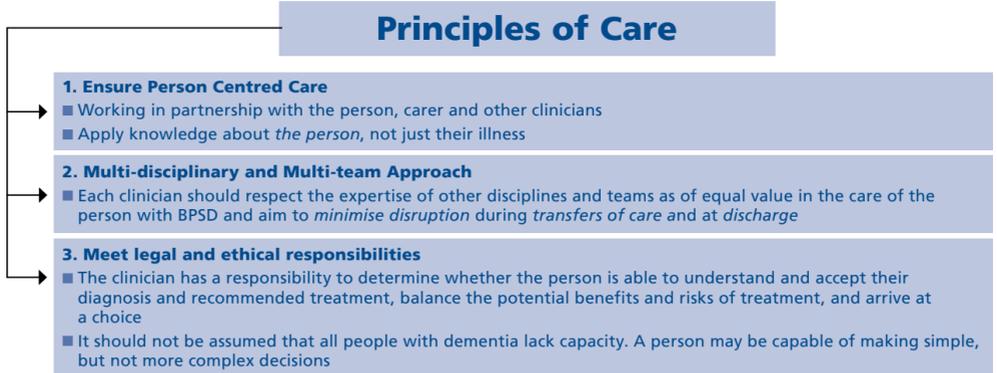
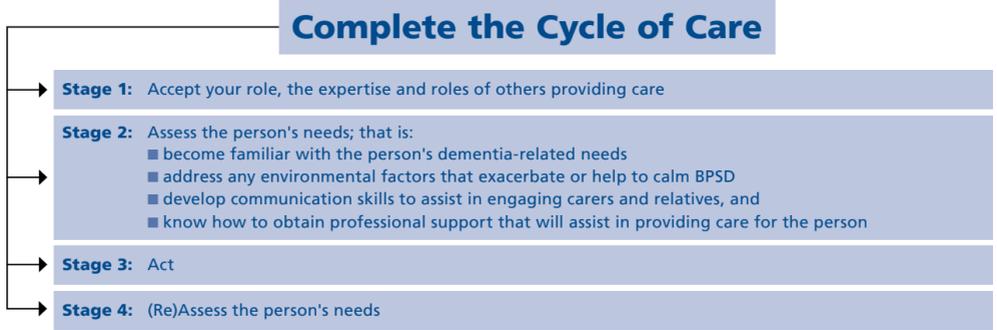
More useful information about dementia can be found at the Alzheimer Australia website: <http://www.fightdementia.org.au/>

Inpatient Ward Settings

Assessment and Management of People with Behavioural and Psychological Symptoms of Dementia

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MORE INFORMATION AVAILABLE FROM: Assessment And Management Of People With Behavioural And Psychological Symptoms Of Dementia (BPSD): A Handbook For NSW Health Clinicians *Delirium Care Pathways*
LOCAL SUPPORTS WHEN NEEDED BY STAFF MANAGING A PERSON WITH BPSD (To be inserted locally)

