

Module 4:

Treatment and intervention options



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Module 4: Treatment and Intervention options

Introduction	Although there is currently no cure for dementia, many treatment options are available, including the selective use of pharmaceuticals and strategies aimed at relieving symptoms, enhancing the quality of life of the person with dementia, and minimising the impact of presenting symptoms on the affected person and people around them. This module discusses such treatment options, informed where possible by evidence-based interventions.
Objectives	<p>On successful completion of this module you will be able to:</p> <ul style="list-style-type: none"> ■ Discuss the options for both treatment and care of the person with dementia ■ Critique the role of pharmaceuticals in the care of people with dementia ■ Demonstrate knowledge relating to therapeutic interventions in a number of clinical areas.
Module topics	<p>Assessment</p> <p>Options for treatment</p> <p>Pharmacological management of dementia</p> <p>Other intervention options</p> <p>Behavioural and psychological symptoms of dementia (BPSD)</p> <p>Clinical issues</p> <ul style="list-style-type: none"> ■ Falls ■ Pain ■ Nutrition ■ Continence ■ Personal care ■ Palliation <p>Current controversies and issues</p> <p>Summary</p> <p>Resources</p>
Suggested further reading for this module	<p>Ames, D., Brodaty, H., Chiu, E., Katona, C., Livingstone, G., & Sadavoy, J. (2007). A consensus on defining and measuring treatment benefits in dementia. <i>International Psychogeriatrics</i>, 19, 343–344.</p> <p>Alzheimer's Association (USA) Treatments for Alzheimer's disease (2013) (http://www.alz.org/alzheimers_disease_treatments.asp)</p> <p>Alzheimer's Australia (2013) Treatments for Alzheimer's disease (http://www.fightdementia.org.au/understanding-dementia/how-is-dementia-treated.aspx).</p> <p>Ritchie, C., Ames, D., Masters, C., & Cummings, J. (2007). <i>Therapeutic Strategies in Dementia</i>. Oxford: Clinical Publishing.</p> <p>Scherer, S., Rule, J., Browning, M., Darzins, P., & Gibson, S. Correlations between insomnia, pain and depression in nursing home residents. <i>American Medical Directors Association Annual Scientific Conference</i>, June 2006.</p>

Assessment

As with any patient, the provision of appropriate care to the person with dementia must be based on comprehensive assessment of the needs of the individual. Ebersole and Hess (1998) point out that: "a comprehensive health assessment requires not only physical data, but also an integration of the biologic, psychosocial, and functional aspects of the person" (p.102) and this applies equally to the person with dementia.

Goal-orientated and strength-based assessment

Traditionally, patient assessment has focused on the identification of problems and deficits, and the development of strategies by the treating clinician to address these.

A more appropriate approach is a goal-orientated and strength-based assessment, focusing as much on what the person can do, as on what they cannot. Using this approach, goals are set in consultation with the person and support network, having identified what is important to them, and in keeping with a person-centred approach to care (Kitwood, 1997).

Options for treatment

The management of patients with dementia can be a highly complex and rewarding clinical undertaking. A range of therapeutic options need to be considered, discussed, trialled and evaluated to ensure optimal response. This section covers the options for treatment, the importance of identifying and managing co-morbidities, and the management of the behavioural and psychological manifestations of dementia.

Management of co-morbidities

Older people often have multiple health conditions that require management; for example, treating a person with combined Alzheimer's disease/vascular dementia demands management of dementia, vascular disease and its modifiable risk factors, and all attendant medical conditions to which older people are prone, and which often adversely influence cognitive and behavioural function, and the affected person's ability to cope.

Such conditions include (among others):

- Diabetes mellitus
- Acute infections
- Adverse effects of multiple medications (polypharmacy)
- Chronic conditions such as cardiac, respiratory and renal impairment
- Strokes
- Parkinson's disease.

Why is this important?

Holistic management of the person with dementia demands not only understanding of dementia, but also the impact of dementia on the development of co-morbidities, and effect of managing co-morbid conditions on function and quality of life.

An assumption that a person's cognitive decline is due to progression of dementia may lead to missing treatable co-morbidities. Optimal management of such co-morbid conditions is possible, and extremely important in people with dementia, but it is often complex, and requires a considered approach that involves health professionals, family and carers.

Medical
interventions

Pharmacological management of dementia

All pharmacological treatments bring a risk of side effects and pharmacological treatment should not be considered a substitute for non-pharmacological approaches—these should be considered together. A wide range of medications are available and the major classes focus on:

- Improvement or enhancement of cognition (cognitive “enhancers”)
- Management of the behavioural and psychological symptoms of dementia (BPSD)
- Modification of risk factors.

Why is this important?

- There is definite, but limited, evidence of the capacity of pharmacological therapy to reverse or halt the progression of dementia, most relating to dementia of the Alzheimer type, but with emerging evidence of benefit with vascular dementias
- Symptom management is critical for optimal quality of life and maintenance of independence
- Modifying risk factors early may prevent dementia, and reduce the overall burden of dementia on the community
- Complementary therapy is very common and popular and likely to remain so in the absence of efficacious drug therapies.

Acetylcholinesterase inhibitors (AChEIs) work by preventing the breakdown of acetylcholine in the brain, thereby increasing the level which is important for proper nerve cell function and memory. An increase in acetylcholine can improve nerve cell communication and may stabilise the symptoms of Alzheimer’s disease (Centre for Health Economics, 2012).

AChEIs are recommended for use only in Alzheimer’s disease. However, studies in those with vascular risk factors demonstrated equivalent benefit, suggesting that the distinction between vascular dementia and Alzheimer’s disease may be less critical than is believed (Kumar, Anand, Messina, Hartman, & Veach, 2000). International consensus is lacking in all areas relating to pharmacological intervention, and expert opinion remains divided about the benefits of cognitive enhancers; therefore, a considered and prudent approach to clinical practice and prescribing is required.

The Cholinergic hypothesis

There is often a strong and understandable desire from the person with dementia and their supporters to “try anything” that may modify the disease process, but this is not always supported by research evidence.

It is important to remember that medication neither removes nor replaces the need for non-pharmacological measures.

Cholinergic neurons are essential for memory. Research has shown that:

- Inhibition of cholinergic function with scopolamine results in cognitive loss
- Experimental damage to cholinergic tracts cause cognitive loss
- Cholinergic-rich grafts restore memory functioning (**Francis, Palmer, Snape & Wilcock, 1999**).

As such it should be borne in mind that anticholinergic drugs (e.g., frequently used in the management of urinary incontinence) may in fact aggravate the cognition and behaviour of a person with dementia.

The role of cognitive enhancers in the management of dementia

- Selected people with dementia may be considered for treatment with one of the currently available dementia-specific drugs (see below).
- Medication should only be used once other causes of dementia have been excluded and treated
- Most clinical trials have focused on Alzheimer’s disease (as defined by the researchers) but positive effects have also been shown in vascular and other types of dementia.

Why is this important?

- Both health professionals and patients perceive medication as an important part of therapy and evidence of “something being done”
- Positive effects of the medication may offset the need for additional support or residential placement
- Failure of response to medication does not obviate the use of other approaches
- Dementia-specific medication is currently available
- Cholinesterase inhibitors are the commonest agents used both in Australia and other parts of the world.

Choline esterase inhibitors (AChEIs)

Three cholinesterase inhibitors are available in Australia: Donepezil, Galantamine and Rivastigmine. Their effects are broadly equivalent, although the mode of administration varies.

These drugs have been shown to have positive therapeutic effects on both cognitive and behavioural deficits.

Prescription of cholinesterase inhibitors in Australia

The available medication has a positive effect of variable duration in about one-third of people treated, which is obvious to both patients and carers and may decrease care needs.

In one-third of people with dementia treated, the progression of the disease may be slowed; in the other third no clinically positive effect may be detectable.

Side effects of cholinesterase inhibitors

- The side effects are rarely life-threatening but may lead to cessation of treatment. Nausea and vomiting are most common and may attenuate with time
- Cardiac arrhythmias, neurological disturbances and hepatotoxicity are the more severe side effects, but are far less frequent, though do require monitoring
- Sometimes side effects occur with one of the cholinesterase inhibitors and not others, and so substitution of one medication for another may be useful.

Prescription of cholinesterase inhibitors in Australia is subject to restrictions. Government subsidy is only available for all three cholinesterase inhibitors in people who meet the following criteria:

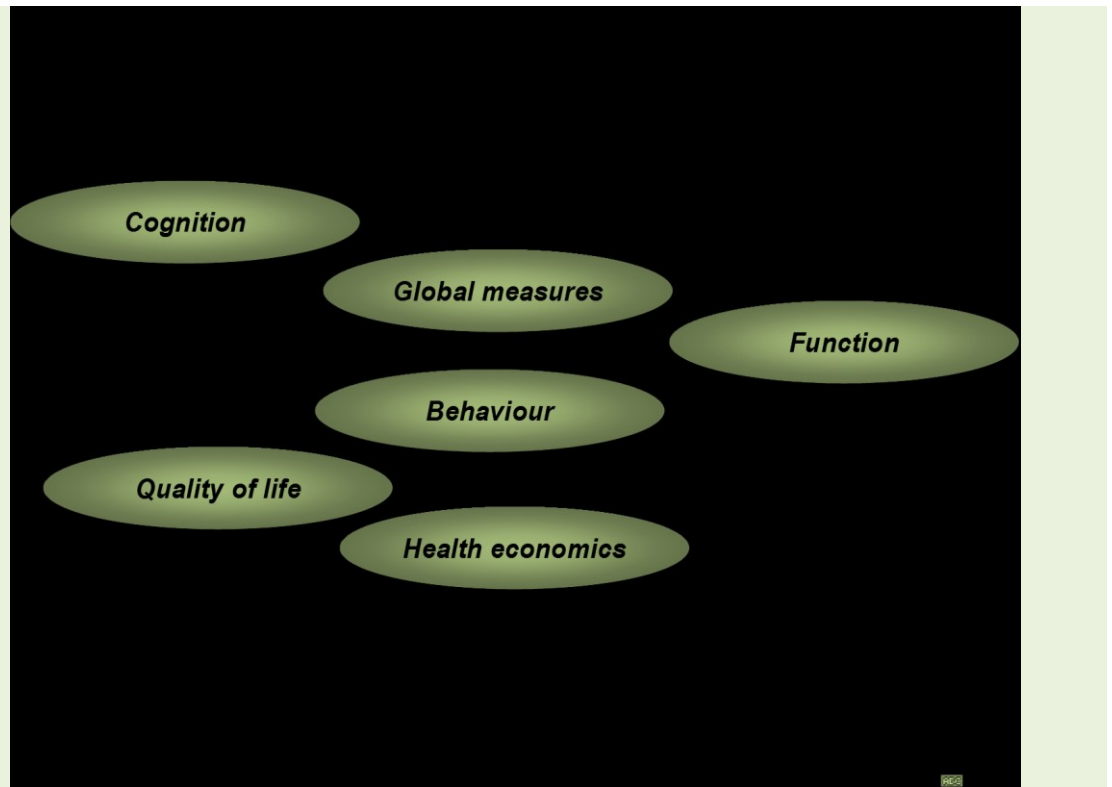
- Diagnosis of Alzheimer's disease confirmed by medical specialist
- MMSE >10/30 (except in people with specific additional factors such as aphasia and illiteracy. Special dispensation is also possible in Aboriginal and Torres Strait Islanders).

The initial prescription authority lasts six months; continuation is contingent on "improvement" as judged by the treating clinician. Improvement in the MMSE of 2 points or ADAS-Cog of 4 points is no longer mandatory.

How to assess the benefits and add to the benefits

The Food and Drug Administration (FDA) Central Nervous System (CNS) Drugs Group suggested that, as cognition is central to the clinical syndrome, an effect on cognition is a minimum requirement. In addition, therapies should demonstrate an effect on global functioning. Secondary measures such as behaviour may be more important for service utilisation and carer assessment, and service purchasers may be particularly concerned with cost-benefits and health economic measures, including utilisation of nursing homes.

Pharmaco-economic modeling using the results of randomised controlled trials (RCT) has been used to match costs of medication to the costs of care for people with moderate dementia, and have shown that the costs of the drug are indeed partially offset by a reduction in the costs of care due to limitation of decline in cognitive functioning, and the delay in deterioration to more costly disease stages and resultant increased costs of care (Neumann et al., 1999).



Donepezil

Donepezil (marketed as Aricept in Australia) is a reversible acetyl cholinesterase inhibitor.

Donepezil requires a once-daily dosing (5 or 10 mg)

Rivastigmine

Rivastigmine (marketed as Exelon in Australia) is a pseudo-irreversible acetyl cholinesterase inhibitor.

Extensive safety studies have demonstrated that rivastigmine is safe, well-tolerated and has little interaction with other classes of drugs (Grossberg et al., 2000).

Rivastigmine requires twice-daily dosing (1.5-3mg), but is available as a skin patch, which is more acceptable to some people with dementia.

Galantamine

Galantamine is a competitive reversible acetyl cholinesterase inhibitor for which there is evidence of improvement in cognition, global state and possibly function (Raskind et al., 2000; Tariot et al., 2000).

Memantine

Memantine works quite differently to the AChEIs. It blocks glutamate and prevents excess calcium entering the brain's nerve cells, thereby restricting cell damage (Centre for Health Economics, 2012). Technically it is an N-methyl-D-aspartate (NMDA) receptor antagonist, which has limited PBS approval for use in Australia in people with MMSE scores of between 10/30 and 14/30.

In 2012 the federal government requested submissions to a review by the Pharmaceutical Benefits Advisory Committee of subsidised anti-dementia drugs including cholinesterase inhibitors and memantine.

Cessation of cognitive enhancers

The terms of reference for the review included: utilisation of these medications; patient-relevant outcomes; safety; efficacy; and cost effectiveness. In a submission by Alzheimer's Australia it was concluded that evidence to date showed the efficacy of these drugs for mild to severe forms of dementia as well as cost benefits to the aged care system using these drugs compared with other healthcare system costs. The submission and other reference material can be downloaded from:

<http://www.fightdementia.org.au/research-publications/pbac-review-into-dementia-treatments.aspx>

The latest evidence suggests the benefits of these drugs are in reaching an optimal therapeutic level and continuing on the drug/s for the longer term.

(Small & Bullock, 2011).

Cessation of cognitive enhancers should be considered and trialled when:

- **Continuation of futile therapy is inappropriate**
- **Dementia** has become advanced, often indicated by the patient requiring substantial assistance with personal care and necessitating high level care.

Why is this important?

- Emotive and traumatic time for patient and carer
- Often sceptical that treatment is being withdrawn because of lack of efficacy; may consider decision is financially driven by government etc.
- External sign of loss of hope and need to face the reality of decline and death.

Other intervention options

Psychosocial interventions

The complex nature of care to the person with dementia involves a multi-faceted approach to therapeutic interventions. Some of the more common non-pharmacological interventions to improve the quality of life of this group are outlined below.

Music

The World Federation of Music Therapy defines music therapy as “the use of music and/or its musical elements (sound, rhythm, melody and harmony) by a qualified music therapist, with a client or group, in a process designed to facilitate and promote communication, relationships, learning, mobilisation, expression, organisation and other relevant therapeutic objectives in order to meet physical, emotional, mental, social and cognitive needs.”

The purpose of music therapy is to optimise the abilities of the person with dementia so as to improve quality of life (Vink, Birks, Bruinsma & Scholten, 2003). These authors describe how music therapy differs from

listening to music as a recreational activity and identify the skills required by the therapist.

These skills include goal setting and identification of appropriate activities for the individual.

The National Ageing Research Institute (NARI) is currently conducting several studies relating to the role of music in the treatment of people with dementia. Initial results from two of the studies show that:

- Music may have beneficial effects on the cognitive and social capabilities of dementia patients. Many case studies have found that the capacity to understand music is retained even when language abilities have been lost. However, NARI has shown objective evidence by using a novel measure of vascular flow together with an EEG coherence measure of cortical brain function, whereby behavioural changes associated with music are partnered by improved blood flow and a clear pattern of ordered brain activity in patients with Alzheimer's disease.
- "Brain functions underlying the very early perceptual and attentional processes involved in a cognitive task are responsive to music. This may indicate that even in moderate to late stage dementia there is a preserved potential for neuroplastic changes to occur. This warrants further investigation." (Barber et al., 2007–2011).

See the NARI Website at

http://www.mednwh.unimelb.edu.au/nari_research/nari_research_dementia-ct.html

Reality orientation
(also known as reality therapy)

Reality orientation aims to familiarise the person with dementia with their surroundings and situation (Patton, 2006). Patton describes several methods of implementation of reality orientation including through every interaction and intermittent cuing. Reality orientation usually involves verbal prompting, reminding, explaining and repetition of information and or visual cues such as orientation boards and signs. Reality orientation is seen as a useful therapeutic technique for some people with dementia but more research into the efficacy of the method is required. Generally a validation approach is seen as more appropriate.

Validation therapy

Feil (1993) described validation as a therapy that facilitates communication with older people with dementia. Validation essentially involves acceptance of the other person's reality (Feil, 1993). A Cochrane review in 2007 links this form of therapy to a person-centred philosophy of care (Neal & Barton-Wright, 2003) in that it accepts the person with dementia as a unique individual. See Module 6 for more information on person-centred care.

Recreation therapy

Buettner and Kolanowski (2003) describe the purpose of recreation therapy as being:

to provide recreation resources and opportunities to improve health and well-being.

These authors go on to say that:

therapeutic recreation is provided by professionals who are trained and certified, registered, or licensed to provide therapeutic recreation. Therapeutic recreation interventions show great promise as management strategies for dementia-related behaviours.

Formal recreation therapy is guided by assessment of the individual and the development of individualised and appropriate activities.

Further information can be found at the website of the American Therapeutic Recreation Association (ATRA): <http://www.atra-online.com/>

Reminiscence therapy

In a Cochrane systematic review Woods, Spector, Jones, Orrell and Davies (2005) describe reminiscence therapy as the use of familiar objects, photographs or music from the past to prompt discussion of a person's past life and experiences. Woods et al. report anecdotal evidence of the benefits reminiscence brings to both people with dementia and their carers but found only limited research evidence to support this. The limited research they identified did indicate that mood, cognition and function did improve and that carers reported lower levels of strain following reminiscence therapy.

Simulated family presence

Where it is not possible for a family member to be with the person with dementia, audiotapes of the family member's voice can be made and replayed to the individual. The aim of this is to reassure the person and to reduce anxiety. Bayles et al. (2006) indicated this has been found to be effective.

Multi-sensory environments (Snoezelen Rooms)

Commonly referred to by the registered trademark name of Snoezelen rooms, multi-sensory environments aim to provide multi-sensorial stimulation within a calm and safe environment (Hope & Waterman, 2004). It involves stimulation of the senses through a combination of light, touch, music and aromatherapy. Multi-sensory stimulation was developed as a therapy for children with intellectual disabilities and is now frequently used in the care of older people, particularly those with dementia (Cox, Burns & Savage, 2004). There is, however, only limited evidence as to the benefits of this approach. In a literature review Burns, Cox and Plant (2000) concluded that multi-sensory stimulation should only be seen as a leisure activity until well-designed research is undertaken to evaluate its therapeutic impact.

Simple strategies to help in coping with memory loss

A Cochrane Systematic Review (revised in 2008) did not find any evidence that Snoezelen was of value as an intervention therapy for people with dementia. The authors stated that there is a “need for more reliable and sound research-based evidence to inform and justify the use of Snoezelen in dementia care” (Chung, & Lai, 2002, 2008). Further, more recent research on the benefits of Snoezelen to manage dementia-related behaviour in one Australian state found that multi-sensory therapies had been adopted in many residential aged care services in Victoria but there was “little evidence to support their use in clinical practice” (Bauer et al., 2012).

Often called ‘Memory Centres’, some simple strategies can be put in place in the home to assist people with early stage dementia to compensate for memory impairment:

- Asking the person to repeat what you have said to them promotes registration of the information
- Memory centres can be set up in the home and involve using visual cues: clocks, signs which display the day and date, even glass doors to cupboards which allow contents to be seen
- Use of lists – encouraging the person to write things down
- Use of diary and calendar

Developing regular routines and habits can reduce the need to remember. For example, if keys are always placed in the same spot habit will minimise the risk of them being lost.

Behavioural and psychological symptoms of dementia (BPSD)

Behaviours such as aggression, wandering, restlessness, agitation, shadowing, sexual dis-inhibition, hoarding, anxiety, delusions and depressed mood are recognised as behavioural and psychological symptoms of dementia (BPSD; International Psychiatric Association, 2008). This section focuses on the management of these symptoms of dementia.

BPSD

- BPSD is common and affects up to 90% of people with dementia
- BPSD has a wide range of manifestation including sleep disturbances through to acute psychosis
- Awareness of the underlying pathological process will assist in understanding of BPSD; for example, frontal lobe damage resulting in loss of planning and emotional personality (See Module 1 for more information on the impact of pathology on behaviours)
- BPSD requires an early, considered and co-ordinated response that includes a range of measures including risk minimisation

Why is this important?

- BPSD significantly impacts on a person's functional status and the burden on carers
- It often requires involvement of psychiatric services, which can be confronting to the person with dementia and carers
- Specialty services are limited and proactive planning and management is required
- Significant legal and safety issues may need to be considered, especially where BPSD cannot be adequately modified
- Future decisions about client care require a definitive clinical opinion about whether BPSD can be modified and also the prognosis

BPSD impact upon:

- Prognosis – reduces prognosis
- Functional ability – functional ability is reduced often as a result of management – for example, drugs, restraint
- Carer burden – increases the workload and burden on informal carers
- Admission to residential care – BPSD causes earlier institutionalisation
- Nursing Home staff – BPSD are one of the greatest causes of concern for care staff
- Hospital length of stay – increases length of stay.

(Brodaty, Draper & Low, 2003; Pearson, Teri, Reifler, & Raskind, 1989; Brodaty, 1996; Rodney, 2000; Moore, Zhu, & Clipp, 2001; Herrmann & Black, 2000)

The language of BPSD

In the experience of many of the authors of this module, both professional and family carers are sensitive regarding the terminology surrounding BPSD. Phrases used include 'problem behaviours' (Cassidy et al., 2001), and 'challenging behaviours' (Innes & Jacques, 1998), both of which seem to apportion blame and a sense of control to the person exhibiting the behaviour. They are therefore inappropriate terms. More recently, the concept of behaviours being an expression of a need such as hunger, thirst, boredom or untreated pain is gaining popularity (Algase et al., 1996; Allen, 1999; Gruber-Baldini et al., 2004) has given rise to the term 'unmet needs behaviour'. Personal experience in using 'unmet needs behaviour' has identified that clinicians can respond negatively to this terminology as it is taken as a criticism of the care they are providing. That is, they are not meeting the needs of the person with dementia. For this reason this module supports the concept of behaviours as communication: the person with dementia is exhibiting the behaviour in order to communicate with those around them.

BPSD is often only seen as an issue if it is repetitive and creates a problem to staff, family or other patients/residents. It is therefore overt behaviours such as aggression, screaming, restlessness, agitation, sexual dis-inhibition, constant questioning, shadowing and wandering that cause concern amongst clinicians. It must be remembered that less obvious behaviours such as withdrawal, ruminating, hoarding, hallucinations, and anxiety can also be an expression of need and an attempt to communicate.

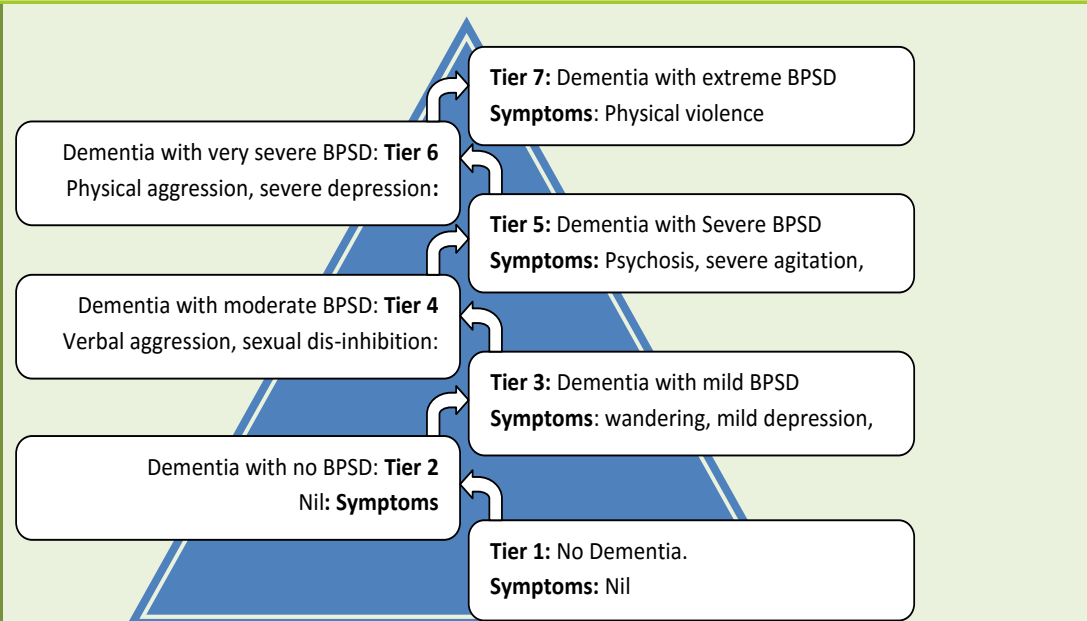
Principles for responding to BPSD

There are two management routes of BPSD. The first and recommended approach is non-pharmacological in nature—the psychosocial interventions as described at the beginning of this module and used to help reduced the frequency and severity of the behaviour.

The way in which we as health professionals interpret a person's behaviour will influence the way in which we respond to it. If you take a neuropathology approach that interprets the behaviour as a direct result of brain dysfunction then your primary management response will be pharmacological in nature. If, however, you take a psychosocial approach you are more likely to interpret the behaviour in relation to the interplay of cognitive impairment.

Principles for addressing behaviours

BPSD can emerge at any stage of the disease and present with varying levels of frequency and severity. The Brodaty, Draper and Low (2003) seven tiered model of service delivery is useful for describing BPSD symptoms, severity and recommended service delivery response. The following diagram is an adaptation of the model showing severity and symptom examples only.



Activity

It is recommended that you view this model in its entirety. For this activity read the article: Brodaty, H.; Draper, B.; Low, L-F. (2003). Behavioural and Psychological Symptoms of Dementia: a seven-tiered model of service delivery. *Medical Journal of Australia*, 178(5), 231-234. The article is available on open access:

<https://www.mja.com.au/journal/2003/178/5/behavioural-and-psychological-symptoms-dementia-seven-tiered-model-service>

Assessment of BPSD

Identifying factors behind the behaviour change is the guiding principle to addressing behaviours. The process by which this is achieved is through a detailed assessment of the person, including detailed information from family and carers about the behaviour. The key assessment aspects recommended by the Dementia Behaviour Advisory Service (DBMAS) include:

- Establish the level of risk that the behaviour presents to the person and to others
- Provide a clear description of the behaviour, including the frequency, severity and triggers
- Gather information about the person: their characteristics, life history, diagnosis and support needs
- Gather information about the carer: characteristics, communication approach, relationship factors and stress threshold
- Critically review the care environment: physical, social, cultural, emotional and spiritual
- Rule out medical causes.

This may seem daunting; however, we are able to draw on a number of behaviour assessment and management approaches that have been developed in Australia.

Behaviour Management. A Guide to Good Practice. Managing behavioural and psychological symptoms of dementia. (Burns, K., Jayasinha, R., Tsang, R., Brodaty, H. 2012).

DBMAS use this comprehensive bio psychosocial approach to the assessment and management of BPSD facilitated by experienced and knowledgeable practitioners or Dementia Specialists as defined by the nursing competency standards (NSW/ACT DTSC) and career pathways in dementia care (Vic/Tas DTSC). A copy of the Guide is available on the DCRC website

<http://www.dementiaresearch.org.au/newsletters/jul12/111-bpsd>

Team concept mapping (Aberdeen, S.)

Not be to confused with dementia care mapping, the Aberdeen model of concept mapping (Aberdeen et al., 2010) was developed to manage BPSD in residential aged care. A spider map is used which places the person and their wellbeing as the central concept to thinking rather than focussing on the behaviour to be resolved. A skilled and knowledgeable facilitator guides the care team to draw on their personal knowledge of the person; critically review and reflect on care practices, learn to look for pattern recognition and problem solve. The concept map has many benefits. It offers a person-centred assessment, a team problem-solving approach as well as improved team communication and learning within a case conference format.

ReBOC. Reducing Behaviours of Concern. A hands-on guide. A resource to assist those caring for people living with dementia. A copy of the guide is available on the DBMAS website:

http://dbmas.org.au/Want_to_know_more_/Resources1.aspx

The Loddon Mallee Regional Dementia Management Strategy (2001) utilises the ABC approach (Antecedent >Behaviour>Consequence) to find the connection between behaviours. The strategy is inclusive of community health, ambulance and emergency department, acute hospital and residential care. It provides the templates for ABC assessment and management strategies for 10 different behaviours. Within the Antecedents you are also directed to assess the environment, physical status of the person with dementia and their psychological factors. This model can be easily accessed through the dementia management strategy website

<http://www.dementiamanagementstrategy.com>

An overview of the international dementia behaviour assessment and treatment models can be found in James, I. A. (2011). *Understanding Behaviour in Dementia that Challenges. A Guide to Assessment and Treatment*. Jessica Kingsley Publishers: London.

Knowing about the person is at the centre of any response to BPSD and requires health professionals to gather information about the person.

Assessing BPSD using Team Concept Mapping

Residential care environments do this consistently using some form of life history document. It may not be feasible to gather this amount or depth of information in the acute care sector but brief, 'key points' regarding likes, dislikes, can be gathered and documented on a simple template.

Team concept mapping is an evidence-based approach which is gaining popularity as a BPSD assessment and problem solving tool in Victoria. This section will provide you with a brief overview of the five main steps of a team concept map.

Step 1: Initiate

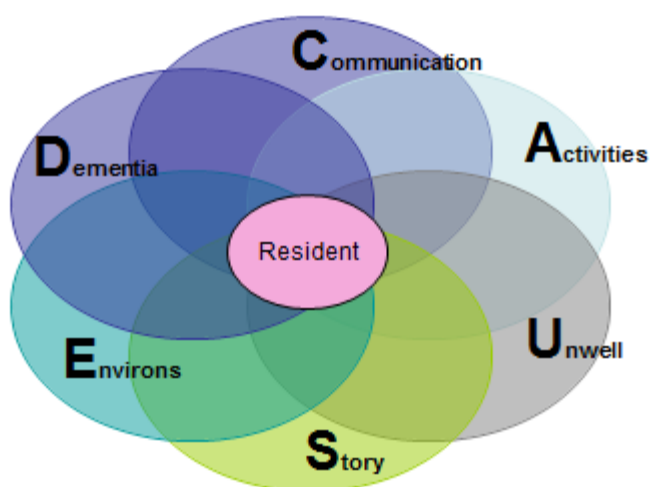
The need for a concept map for a person with dementia is triggered by:

- A concern about behaviour and/or care
- The need for a case conference
- A new care plan or care plan evaluation

The facilitator and/or manager organise the mapping session and involve staff, GP, family and others who may be relevant to the person's care. The care documentation is reviewed by the facilitator and any additional helpful information is collected (e.g., pain assessment, behaviour charting) in readiness for the mapping session.

Step 2: Implement

During the mapping session, the facilitator draws on the care documentation and wealth of knowledge held by the participants about the person with dementia. The facilitator uses the CAUSE D mnemonic adapted by Dr Sue Aberdeen from the Alzheimer's Australia Dementia Care Essentials to guide the gathering of information. Using a white board and coloured marker pens the facilitators starts developing the 'map' using the following CAUSE D assessment guide.



Communication

The person's communication and comprehension abilities are explored.

- Can they understand what's expected of them?
- What are their communication abilities?
- Can they communicate their needs?

How skilled are the staff and family in adapting their communication style to the person's needs?

Activities

The person's activity and occupation needs, abilities and access to an individualised activity program are reviewed to reduce the risks of boredom, over-stimulation, or inappropriate due to complexity.

Unwell

Do any recent changes in symptoms or behaviour indicate change to health status/delirium? This includes a review of:

- Health/ physiological (e.g., delirium, medical condition; pain, elimination)
- Psychological (e.g., fear, anxiety, depression, grief and loss)
- Hunger, thirst, hot/cold, tired, bored
- Medications
- Sleep

Story

How does the person's story influence how they experience dementia and how their needs are met?

- Cultural/social (e.g., background, language, habits, rituals)
- Personal history (e.g., education, experiences such as war, abuse)
- Personal preferences, values and beliefs
- Family details and relationships
- Job and leisure interests

Environment

Consideration of the environment and its impact on the person includes:

- The physical environment
- The care environment
- Social environment

Dementia

Exploring the impact of dementia on the person's cognitive functioning, such as memory, insight, judgement, planning and organisation to name but a few. Knowledge of the disease process and of the impact of damage to particular areas of the brain can lead to a greater understanding of the behaviour being displayed. The DVD 'Understanding the Brain' produced by Alzheimer's Australia provides an excellent description of the link between the pathology in the brain and the deficits manifested by the individual. It is therefore essential to be aware of the type and extent of dementia the person has.

Step 3: Evaluate and Review Care

The facilitator will help the group to explore ideas and construct the map by identifying

- Patterns of behaviour
- Behaviour triggers
- The relationships between concepts that may also be contributing to the behaviour
- Identify how the remaining strengths of the person with dementia can be supported.

The resulting outcomes enable the team to agree on the care interventions and incorporate these into the care plan.

Step 4: Act on Outcomes

The agreed care interventions are communicated across the care team, family and others involved in the person's care and support. Relevant assessments are re-instigated to support evaluation of the new approaches to care. The person's responses to the revised approach to care are monitored, documented and communicated as appropriate

Step 5: Evaluate Results

Pharmacological management of BPSD

Pharmacological management is the second line approach and indicated when behaviours are causing severe distress or harm. Antidepressants, antipsychotics and analgesic medications can be effective when "behaviours stem from co-morbid mood disorders, anxiety, psychosis or pain". There is concern that there has been too much reliance on antipsychotic drugs for the first line management of BPSD (Alzheimer's Australia position statement, 2012).

Prescribing of an antipsychotic drug should always be made with the end in mind. Targeting the right drug therapy to the right symptom is an early consideration. Aggression, agitation and psychotic symptoms such as delusions and hallucinations respond best; whereas symptoms such as apathy, wandering, vocalisation, socially inappropriate voiding or undressing will not respond (National Prescribing Service [NPS] 2007).

The preferred response to BPSD therefore is psychosocial rather than pharmacological. The advantages of this approach are:

- It recognises rather than masks the underlying needs being communicated by the behaviour
- Fewer limitations than pharmacological management; that is, side effects, drug interactions
- Practical and relatively in-expensive
- Enhances carer attitudes towards care recipients with BPSD compared to pharmacological approach.

BPSD that may respond to medication

- Anxiety
- Depressive symptoms
- Manic-like symptoms
- Persistent and distressing hallucinations/delusions
- Persistent and severe verbal and physical aggression

BPSD that will not respond to medication

- Wandering
- Socially inappropriate urination/ defaecation
- Socially inappropriate dressing/undressing
- Repetitive activities (perseveration) or vocalisation
- Hiding/hoarding
- Eating inedibles

Some key considerations when initiating antipsychotic drug therapy:

- Research has found that BPSD symptoms generally resolve within three months without pharmacological interventions. (NPS, 2007)
- Are the behaviours intermittent, situation-specific (e.g., emerging on care interventions) or goal-directed (e.g., trying to leave the premises)? (NPS 2013)
- Have non-pharmacological approaches been trialled first?
- There is an increased risk of death, stroke and falls (MHRA, 2005). Do the benefits of this antipsychotic outweigh the risks? (NPS, 2013)
- The aim of pharmacological treatment is to utilise the lowest dose for shortest duration
- They should only be used for a finite amount of time. Once the antipsychotic is prescribed, monitor to ensure side effects are tolerated and review its effectiveness at least three-monthly

Use a BPSD assessment measure to monitor BPSD symptoms. A selection of recommended tools can be found on the Dementia Outcomes Measurement Suite (DOMS) <http://www.dementia-assessment.com.au>

Activity

Is the use of pharmacological interventions in your work place first or second line approaches?

The National Prescribing Service has developed a number of health professional publications and tools to assist health professionals to review antipsychotic use in residential aged care facilities. Explore their website <http://www.nps.org.au>

Clinician behaviour as trigger

Aged care antipsychotic review checklist

http://agedcare.nps.org.au/_data/assets/pdf_file/0009/228645/NPS-Aged-Care-Antipsychotic-Review-Checklist.pdf

Drug Use Evaluation (DUE): Antipsychotic use for behavioural and psychological symptoms of dementia

<http://www.nps.org.au/health-professionals/professional-development/due-programs>

It is important to note that clinicians' approach and behaviour impacts on the person with whom they are interacting. Be cognisant that you may inadvertently be the trigger. Healthcare facility work routines and care delivery systems can also trigger unmet need behaviours.

Remember it is much easier to change our own behaviour than it is to alter the person with dementia's behaviour. We can also control and change our responses to the person exhibiting BPSD and to the behaviour itself.

Some very simple behaviour and communication strategies that can minimise the risk of behavioural symptoms presenting include:

- Maintain person's personal space
- Sit down – standing over a person can be perceived as intimidating and threatening. Being at the same height reduces this threat
- Stand shoulders sideways – again, standing directly face-to-face can appear threatening whereas standing with your shoulder facing the person and turning your head towards them is much less intimidating
- Move slowly – do not rush movements as any sense of urgency or perceived sudden movement can invoke fear
- Voice tone should be calm
- Closed questions should be used wherever possible as the person may more easily be able to respond, allowing them a sense of control
- Give limited choices as again this enables the person with dementia to make choices within the limitations of their impairment
- Short, one-step instructions are more easily understood and followed and cause less frustration and anxiety
- Allow the person time to consider, reply and respond to your question or instructions
- Generally it is better not to contradict, argue, or attempt to reason with the person with dementia. It is extremely difficult and often unproductive to try to convince someone with dementia that they are incorrect

- Never talk over the patient as though they were not present. It is very easy for clinicians to fall into the trap of excluding the person with dementia from their conversation with each other or with the person's family members. This can cause fear and frustration and trigger behavioural symptoms, such as aggression
- As with the statement above it is very easy in care situations for two or more clinicians to ask questions or give instructions to the person with dementia at the same time. This only promotes confusion and frustration. It is therefore important that only one person speaks at a time.

(The above information is based on expert opinion)

Strategies to minimise BPSD

A person-centred approach to care delivery together with flexible routines can mean that care is delivered at times that better suit the person with dementia

Activity

Imagine what your response might be if staff wake you from deep sleep and insist that you go immediately into the shower:

- Think about minimising as far as possible movement such as changing rooms or beds around the ward/ facility – bed changes or between departments in a hospital
- Think about minimising/prioritising interventions – consider whether an intervention is absolutely vital and prioritise accordingly. For example, if a person with dementia will only accept taking two tablets, which tablets should they be?
- The use of holistic therapies such as aromatherapy and massage is a growing area in the care of people with dementia generally and in relation to RCS. It is explored later in this module
- Promotion of an appropriate environment including minimising noise and minimising glare (Johnson, Wilson, O'Donnell, Martinelli, & McAuliffe, 2005) More information regarding creating an appropriate environment can be found in *Module 8: Creating dementia friendly environments*.

(Unless otherwise stated the above information is based on expert opinion)

Cultural considerations for BPSD assessment and management

Although assessing and addressing the behavioural and psychological symptoms of dementia (BPSD) remain constant, there are particular issues to consider with people from culturally and linguistically diverse (CALD) and Aboriginal and Torres Strait Islander (ATSI) populations.

Considerations include:

- English may not be the first language of the person with dementia
- There may be cultural differences in communication styles; either verbal or non-verbal communication
- The person's current or past lifestyle and habits may be very different from that commonly found in a westernised society
- People from CALD and ATSI populations may have a complex past life history
- People from CALD and ATSI may have lived in home environments away from that typical of westernised culture
- There is still a stigma associated with dementia within cultural groups, with negative words used to describe dementia
- Dementia is not well-understood. Many cultural groups still regard memory loss as a normal part of ageing
- Access to dementia education and services will vary according on how well-established the CALD community is and their geographical location.

People with dementia from different cultural groups are at risk of poorer health outcomes, health services for dementia are underutilised and they tend to access services later at a more severe state of dementia, or when they reach crisis point.

Difficulties for clinicians include:

- Lack of cross-cultural assessment tools
- Assessment takes more time
- Communication barriers; interpreters need to be trained in how to work with people who have dementia
- The need to consider experiences of war, trauma, migration, family separation and disappearance of relatives.

There is increasing awareness that the dementia prevalence rate for remote and rural Indigenous people is 4-5 times higher than the rest of the population. In Aboriginal and/or Torres Strait Islander cultures there are wide variances in the way dementia is defined and understood. Dementia is perceived as “bad spirit” or “sick spirit” and there are no dreaming stories for memory loss which reflects as a punishment for those who have dementia. Elders with dementia may be able to draw on their autobiographical memory to maintain their story-telling role, but the community will ignore dementia symptoms out of respect for the elder.

More information relating to approaching BPSD in ATSI populations is obtained in “Aboriginal and Torres Strait Islander Cultural Considerations for Best Practice Guidelines for Behaviour Management Frontier Services (2008).” Northern Territory Dementia Behaviour Management Service

BPSD Resources

Aboriginal and Torres Strait Islander Cultural Considerations for Best Practice Guidelines for Behaviour Management Frontier Services. (2008).

Northern Territory Dementia Behaviour Management Service

Behaviour Management - a guide to good practice. Managing Behavioural and Psychological Symptoms of Dementia. (2012).

Dementia Collaborative Research Centre - Assessment and Better Care. Available as a free download from the Dementia Collaborative research Centre

http://www.dementiaresearch.org.au/images/dcrc/output-files/328-2012_dbmas_bpsd_guidelines_guide.pdf

Aboriginal and Torres Strait Islander Cultural Considerations for Best Practice Guidelines for Behaviour Management Frontier Services. (2008).

Dementia Behaviour Management Service

A free service providing advice and support to carers and health professionals regarding management of behavioural symptoms of dementia www.dbmas.org.au or 1800 699 799

Dementia Dynamics Toolkit <http://www.dementiodynamics.com.au/>

Dementia Outcomes Measurement Suite can be accessed via the Dementia assessment website

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

National Dementia Helpline

A 24-hour telephone information and support service available across Australia.

1800 100 500

The brain and behaviour. DVD available from Alzheimer's Australia Victoria <http://www.fightdementia.org.au/victoria.aspx>

Falls

Clinical issues

It is now accepted that multi-faceted falls prevention programs can reduce falls in older people; however, many of the widely used interventions are not easily implemented in people with dementia (Hill, Smith, LoGiudice, & Winbolt, 2003).

General falls risk factors such as the environment: lighting, clutter, slippery floors; and intrinsic factors such as: vision/hearing impairment; medication-related; medical conditions; functional impairment; poor footwear, poor nutritional status; incontinence and a history of falls apply equally to people with dementia. The risks posed by these factors are compounded by impaired cognition as people with dementia may not have sufficient insight to appreciate that they may fall, or have the ability to use mobility aids.

Minimising falls risk in this group centres on modification of the environment and reducing intrinsic factors wherever possible. Assessing falls risk includes identifying, and, where possible, addressing the risk factors affecting the individual. Falls risk screening should be conducted and individualised falls prevention plans should be used.

Physical restraint is often seen as an option to prevent falls in people with dementia but there is evidence that physical restraint in this group increases the risk of injury and does not in fact reduce falls (Hill et al., 2003). See Module 5: *Social and lifestyle considerations* for more information on issues surrounding physical restraint.

Alternative strategies include falls alarms (chair and bed), supervision and injury minimisation strategies.

The Victorian Quality Council *falls prevention guidelines*

<http://www.health.vic.gov.au/qualitycouncil/downloads/falls/guidelines.pdf>

Pain

It is well-documented that pain is under-assessed and under-reported in people with dementia. Indeed, there still exists a common belief that people with dementia do not experience pain (Cohen-Mansfield, 2006; Nygaard & Jarland, 2005). Pain in people with dementia can manifest as disturbed sleep or behaviour symptoms such as aggression and agitation (Cohen-Mansfield, Billig, Lipson, & Rosentha 1990). In the absence of ability to communicate pain the onus is on carers of people with moderate to severe dementia to assess the presence and severity of pain using objective criteria. Objective pain assessment scales such the Aged Care Pain Chart or the Abbey pain scale should be used.

Pain should be appropriately assessed and managed, including non-pharmacological interventions and/or adequate use of analgesia; both regular regime and as required dosage.

Nutrition

The nutritional status of the person with dementia may be compromised due to the symptoms of dementia. Factors impacting on altered nutrition include:

- Impaired cognition leads to an inability to prepare meals, forgetting to eat, forgetting how to chew or swallow or being unable to recognise the food placed in front of them
- Diminished appetite
- Ill-fitting dentures
- Reduced variety of food and inappropriate foods
- Reduced calorie intake
- Lack of physical activity
- Being embarrassed by eating difficulties
- Behavioural and psychological symptoms of dementia such as wandering, restlessness and agitation. (*Alzheimer's Australia, 2011*)

Commonly there is a loss of interest in food but in some cases the person may experience extreme hunger and craving for sweets.

If concerns are raised as to the nutritional status of someone with dementia it is important to:

- Exclude other medical causes—acute illness, depression
- Review medications as these may be affecting appetite or causing nausea
- Check oral health.

Suggested strategies to promote good dietary intake include:

- Use of finger food
- Provide healthy snacks
- Keep fluids visible throughout the day
- Small frequent meals
- Uncomplicated table settings
- Unpatterned crockery
- Serve one dish at a time
- Keep the environment calm and quiet at mealtimes.

In the community families/carers can try to prompt the person with dementia to eat by using an alarm clock or by telephoning them to remind them. Home-delivered meals or pre-cooked meals delivered by family/carers are an option.

The above information is taken from Alzheimer's Australia Services and Support on nutrition available at:

<http://www.alzheimers.org.au/services/nutrition.aspx>

Artificial feeding in advanced dementia

In the later stages of dementia the risk of malnutrition increases as the person becomes totally dependent on carers to assist with eating. As dementia progresses it is inevitable there will be a time at which the person may not be taking any solid food; modifying the texture of the food or adding liquid food supplements may need to be considered. Ultimately, the person may not take any oral food or fluids. Health professionals along with the family are often faced with having to decide whether enteral feeding is appropriate.

Brockett (1999) summarises the debate regarding artificial feeding in stating:

About 10% of elderly residents in chronic care facilities are tube-fed. Yet there is persuasive evidence that common beliefs about tube-feeding cannot be supported: tube-feeding is not similar to spoon-feeding, it is not necessarily indicated in patients with aspiration pneumonia, swallowing evaluations are not very helpful in selecting patients for tube-feeding, and when artificial nutrition and hydration are withheld or withdrawn patients do not have a painful death. So why are patients tube-fed? (p. 120)

Yet the decision regarding tube-feeding of people with severe dementia remains emotive and difficult for both health professionals and family members.

Fear of 'starving the patient to death' and inflicting pain and suffering are said to guide decision-making; Yarborough (1989) suggests that emotion rather than fact often drives decision-making. There is little evidence indicating that withholding artificial feeding causes discomfort, and it has been suggested that discomfort is minimised by the endogenous analgesic mechanisms within the body (Post, 2001).

It is therefore suggested that the most appropriate strategy is to continue to offer oral food and fluids and to promote comfort through a palliative approach. See section on advanced care planning in Module 5: *Social and lifestyle considerations* for information relating to end-of-life decision-making.

Continence

Maintaining continence necessitates the cognitive ability to recognise the need to void or defecate, to remember how to respond to the sensation and to be able to locate the toilet. As cognition declines people with dementia are more susceptible to both urinary and faecal incontinence. As in any person, there are a number of reversible causes of incontinence and these must be investigated prior to accepting the incontinence as being associated with the dementia.

If no other direct cause for the incontinence is found, behaviour interventions can be employed to promote continence. Behaviour interventions include timed toileting, habit retraining and prompted voiding.

Timed toileting involves regular toileting according to a pre-determined schedule. Studies indicate that timed toileting in the community setting can reduce the incidence of urinary incontinence, particularly in people with moderate dementia and who are able to follow instructions. Timed toileting is, however, extremely labour-intensive (Jirovec & Templin, 2001; Colling, Owen, McCreedy, & Newman; 2003).

Habit retraining is similar to timed toileting and the schedule is then adjusted to fit the person's voiding pattern. Habit retraining requires cooperation and a degree of understanding so it is often not the intervention of choice in people with dementia.

Prompted voiding involves prompting the person to go to the toilet 2-3 hourly. Prompted voiding, when implemented following staff training, has been shown to be moderately successful in reducing urinary incontinence in residential aged care settings. A prompted voiding program developed in Wisconsin showed a 29.7% reduction in urinary incontinence through staff training, detailed patient assessment and development of 'stepped' patient goals (Dixon, 2002; Stone et al., 2002).

Pharmacological management

There are limited data as to the role of anticholinergic drugs in the management of urinary incontinence in people with advanced dementia. They can be contra-indicated in people taking 'cognitive enhancers'.

Treatment of asymptomatic bacteruria is not supported in the literature.

Suggested strategies to address incontinence include:

- Medical assessment to exclude and treat reversible causes
- Conduct a continence assessment and determine the person's usual pattern
- Prompt the person to go to the toilet, or, if not able to respond to prompting, take them to the toilet regularly based on the information gained from the continence assessment
- Encourage fluid intake to minimise risk of urinary tract infection and constipation. Recommend avoidance of caffeinated drinks as these can contribute to urge incontinence
- Observe for physical cues of a need to go to the toilet. For example, restlessness, agitation, flushed face
- Recommend clothing which allows ease of undressing and dressing
- Make the toilet more recognisable; an example might be leaving the door open, leaving the light on at night, use of signs (pictures and words)
- Use of appropriate continence aids. Information regarding types of aids and availability of financial assistance for aids can be obtained from The National Continence Helpline - 1800 33 00 66.

(Alzheimer's Australia, 2005; DoHA, 2003)

A simple screening tool is provided in Thomas, Nay, Moor, Fonda and Hawthorne (2006), which may aid assessment, referral and management of incontinence.

Thomas, S., Nay, R., Moor, K., Fonda, D., & Hawthorne, G. (2006). *Continence Outcomes Measurement Suite*. Canberra: Commonwealth of Australia.

More information regarding continence management issues can be obtained from:

The Continence Foundation

<http://www.continence.org.au>

Alzheimer's Australia Services and Support for families and carers: Continence

<http://www.alzheimers.org.au/services/continence.aspx>

Royal Australian College of General Practitioners. Medical care of older persons in residential aged care facilities (the silver book).

<http://www.racgp.org.au/your-practice/guidelines/silverbook/>

Department of Health and Ageing Fact sheet: dementia and urinary incontinence.

<http://www.myagedcare.gov.au/caring-someone-particular-need/caring-someone-dementia>

Personal care

The ability to perform normal activities of daily living including hygiene and dressing diminishes as dementia progresses. In advanced dementia the person with dementia becomes totally dependent on carers to meet these needs. The need to perform personal care tasks is a source of carer burden and is often the time at which informal carers seek support from external services.

Evidence exists that cognitive enhancers can increase the ability of the person with dementia to manage their own personal care needs. The onus, however, often remains with both informal and professional carers to meet the personal care needs of the person with moderate and severe dementia. This can be made easier by maintaining the person's normal habits and routines wherever possible.

Personal care is by its very nature an intimate action and carers are often faced with what is termed 'resistance to care'. The person with dementia may become angry and aggressive when carers attempt to undress them or take them into the shower or bath. This places great strain on all concerned.

The Dementia Behaviour Management Advisory Service can provide advice and guidance on meeting the needs of someone who is resistive to personal care interventions: www.dbmas.org.au

Grealy, McMullen and Grealy (2006) provide numerous simple strategies to minimise resistiveness and/or resulting injuries:

Grealy, J., McMullen, H., & Grealy, J. (2005). *Dementia care: a practical photographic guide*. Oxford; Malden, MA: Blackwell.

Sleep

Alteration to sleep and sleep patterns frequently occur in people with dementia and are often the cause of great distress and burden to carers (Walther, Mahlberg, Eichmann, & Kunz, 2006). As well as altered sleep patterns and timing, the quality of sleep may be affected due to changes in the structure of sleep (Petit et al., 2004).

Sleep disturbances include:

- Early wakening
- Night-time wandering and restlessness
- Reversed day-night cycle
- Disorientation to time.

Changes in sleep patterns may be a symptom of the dementia but it is important to exclude, and, if necessary, treat underlying causes such as acute illness, co-existing morbidities (e.g., cardiac failure, diabetes) pain, depression or sleep apnoea.

Many drugs, especially benzodiazepines, can reduce stage four sleep and increase confusion. They are therefore best avoided.

Suggested non-pharmacological strategies to promote sleep include:

- Medical assessment to exclude reversible causes or to review management of co-existing morbidities
- Medication review, particularly review of diuretic regimes

- Environmental assessment focusing on room temperature and lighting. A person with dementia may wake and become disorientated in a darkened room or shadows may cause confusion and fear
- Limit caffeinated drinks
- Encourage exercise – physical and mental.

(Alzheimer's Australia, 2005)

Eeles et al. (2006) summarised the available evidence in relation to interventions aimed at promoting sleep and concluded that:

- Increasing activity during the daytime can improve sleep
- Increasing exposure to light can assist, but there is little clear evidence that bright light therapy alone promotes sleep
- The evidence for use of lavender in aromatherapy shows no clear results
- The evidence for administering exogenous melatonin to compensate for the decrease in melatonin production common in dementia is equivocal
- Acetylcholinesterase inhibitor has the potential to improve sleep structure. There is clear evidence of it promoting Rapid Eye Movement sleep and may actually cause nightmares
- Strategies to promote sleep require an approach that is individualised to the needs of the person.

More information regarding promoting sleep in people with dementia can be obtained from:

<http://www.alzheimers.org.au/services/sleeping.aspx>

Palliation

The World Health Organization (WHO, 2008) definition of palliative care:

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patient's illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*

Dementia is a progressive and ultimately terminal condition. Palliation as a treatment and philosophical approach is therefore an important clinical and social issue to be addressed. The principles of palliation to optimise quality of life and limit disability are entirely compatible with advancing dementia. Clarification around end-of-life decisions is best undertaken early to include the individual in planning their future care. In advanced dementia individuals usually have limited ability to participate, which can increase the care burden on staff and families. Treatment of acute severe medical conditions (e.g., lobar pneumonia) needs to occur in the context of an individual's underlying disease, having regard wherever possible to their previously stated wishes. Conversely, the label of dementia itself should not be a bar to appropriate medical and care interventions, nor be a fast track into palliative care.

Refusal of oral intake is often seen in advanced dementia and needs to be viewed in the context of the disease state.

See sections on end-of-life decision-making and guardianship in Module 5: *Social and lifestyle considerations* for information on end-of-life decision-making.

Activity

More information regarding a palliative care approach can be obtained from

Guidelines for a Palliative Approach in Residential Aged Care.

Department of Health and Ageing, 2006.

<http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-workf-guide.htm>

Consider the trajectory of Alzheimer's dementia and write a summary of what treatment and interventions you might choose for yourself if you were living with dementia.

Current controversies and issues

When is a palliative approach appropriate?

- Who decides and when is such a decision made in the absence of an appropriately empowered person or in the presence of advanced care directives?
 - Use of enteral feeding in advanced dementia
 - Use of restraint – both mechanical and chemical in BPSD, delirium and advanced dementia
 - Use of cognitive enhancers including their withdrawal in moderate to advanced dementia or in the setting of admission to residential care
- Management of chronic co-morbidities (e.g., hyperlipidaemia) in advancing dementia.

Summary

This module has provided information on intervention and treatment options once dementia has been diagnosed and an overview of strategies to address a number of common clinical issues that might arise in the care of people with dementia.

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