

Advancing practice in the care of people with dementia

4th Edition

Module 5: Treatment and intervention options



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Module 5: Treatment and Intervention options

Introduction

Although there is currently no cure for dementia, many therapeutic intervention 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 these options, informed by the best available evidence.

Objectives

On completion of this module you will be able to:

- 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 several clinical areas.

Module topics

Assessment

Options for treatment

Pharmacological management of dementia

Other intervention options

Behavioural and psychological symptoms of dementia (BPSD)

Clinical issues

Falls

Pain

Nutrition

Continence

Personal care

Palliation

Summary

References

Suggested reading for this module

Ames, D., Brodaty, H., Chiu, E., Katona, C., Livingstone, G., & Sadavoy, J. (2007). A consensus on defining and measuring treatment benefits in dementia. *International Psychogeriatrics*. Vol 19. Pp 343–344. <https://findanexpert.unimelb.edu.au/scholarlywork/293052-a-consensus-on-defining-and-measuring-treatment-benefits-in-dementia>

Erdal, A. Flo, E. Selbaek, G. Aarsland, D. Bergh, S. Slettebo, D. & Husebo, B. (2017). Associations between pain and depression in nursing home patients at different stages of dementia. *Journal of Affective Disorders*. Vol 218. Pp 8-14. <https://doi.org/10.1016/j.jad.2017.04.038>

Kitching, D. (2015). Depression in dementia. Australian Prescriber. Vol 38(6). Pp 209-211.

<https://www.nps.org.au/australian-prescriber/articles/depression-in-dementia>

Assessment

As with any care recipient, the provision of appropriate care to the person with dementia must be based on comprehensive assessment of the needs of the individual. A comprehensive health assessment includes

“an understanding of the physical, psychological, social, environmental and pathological effects of ageing” (Koch, 2001, p 22).

A comprehensive health assessment can assist with identifying issues, potential risks and care needs related to falls, functional decline, hydration and nutrition, infections, pain and respiratory symptoms (Fetherstonhaugh, Bauer & Winbolt, 2016).

Goal-orientated and strength-based assessment

Traditionally, health 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). Holistic assessment means identifying strengths, and strategies for coping previously. It is important to identify how the person perceives the problems and what care they desire, as well as what they do not want (Koch, 2001).

Options for treatment

The care of people 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 behaviour 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
- Stroke
- Parkinson's disease.

Why is this important?

Holistic care 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 behaviour and psychological symptoms of dementia (BPSD). BPSD is an acronym utilised in clinical practice (Guideline Adaptation Committee, 2016). The term ‘Responsive Behaviours’ is preferred by people living with dementia. It is based on a person-centred approach that seeks find meaning in the behaviour and understand what an unmet need might be (Clifford & Doody, 2017). This is discussed in more detail later in this module.
- 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 some benefit with vascular dementias (VaD) and in Lewy body dementia (LBD).
- 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
- Though ‘Complementary Medicine’ therapy is very common and popular, it is unlikely to be efficacious drug therapy. Physicians should also caution patients about the potential for interactions, and counsel them about the quality and safety of available herbal and nutritional supplements (Kligler, Teets & Quick, 2016).

Acetylcholinesterase inhibitors (AChEIs) and memantine are the only currently available symptomatic medications for cognition and global functioning in people with dementia.

AChEIs target the acetylcholine deficit arising from the loss of neurons seen in people living with dementia. 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. They are considered symptomatic therapies only and are not believed to be neuroprotective or to alter the underlying disease trajectory.

In Australia, within the PBS criteria, AChEIs are recommended for use only in Alzheimer's type disease. They provide symptomatic drug therapy for Alzheimer's dementia, as well as Parkinson's dementia and Dementia with Lewy Bodies (Liu, Cooper, Weintraub & Dahdwal, 2019; Rolinski, Fox, Maidment & McShane, 2012). Despite its modest effect size, treatment with these drugs is clinically relevant and seems to be cost-effective (Hausner & Frolich, 2019). However, expert opinion remains divided about the benefits of cognitive enhancers for other types of dementia. Therefore, a considered and prudent approach to clinical practice and prescribing is required.

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 (Dementia Australia, 2020b).

The Cholinergic hypothesis

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

- The cholinergic system is implicated in the modulation of several behavioural states, including attention, memory and learning
- Degeneration and loss of cholinergic neurons is part of the pathology of Alzheimer's disease
- Experimental cholinergic-rich grafts in the diseased brain have demonstrated some symptomatic relief

(Morelli et al, 2017).

As such it should be borne in mind that anticholinergic drugs (e.g. those frequently used in the management of urinary incontinence) may in fact have a negative impact on the cognition and behaviour of a person with dementia (Veterans Mates, 2014).

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 mixed dementia, as well as Parkinson's dementia and Lewy body 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. Rivastigmine is also available as a transdermal patch and may be more suitable for some patients in reducing the potential for GIT upset and loss of appetite, and poor adherence to therapy.

The AChEIs have been shown to have positive therapeutic effects on both cognitive and behavioural deficits: and, if one in the group “fails” to cause a positive response, then another in the group may be trialled.

The AChEIs’ positive effect are variable in about one-third of people treated, which will be 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. Therapy should be continued over time, particularly where patients are transferred from home to an Aged Care Facility (RACF) (Hogan, 2014).

Ceasing AChEIs, at this time, may promote the recurrence of original cognitive and behavioural deficits symptoms; and, if required, the medication dosage should be reduced slowly over a few weeks (Greiman, Dear & Wilkening, 2019; Hogan, 2014).

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 – a transdermal patch may be more suitable here
- 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

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 or illiteracy. Special dispensation is also possible in Aboriginal and Torres Strait Islanders).

The initial PBS 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 (as of 2013) (NPS Medicinewise, 2012).

How to assess the benefits and add to the benefits

The U.S. Food and Drug Administration (FDA) states medications must be proven to provide a benefit to cognition as well as global overall functioning (Kurz & Lautenschlager, 2017). 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 residential aged care facilities.

Pharmaco-economic modeling 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 (Barnett, Lewis, Blackwell & Taylor, 2014).

- There are several points to consider when evaluating the effect of medication
 - Improvement on global assessment
- Slowing of cognitive deterioration
- Delay in reaching significant clinical end points
- Reduction in behavioural disturbance
- Attainment of individual goals for the person living with dementia and caregivers
- Reduced admission to residential aged care facilities

(Kurz & Lautenschlager, 2017).

Donepezil

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

Donepezil requires a once-daily dosing (5 or 10 mg). The lower dose is often prescribed in the first four weeks of treatment. The medication may be administered at any time of day and is not influenced by food intake (Kurz & Lautenschlager, 2017).

Rivastigmine

Rivastigmine (marketed as Exelon in Australia) is a slowly reversible acetylcholinesterase inhibitor.

Extensive safety studies have demonstrated that rivastigmine is safe, well-tolerated and has little interaction with other classes of drugs.

Rivastigmine requires twice-daily dosing (1.5-3mg), but is available as a skin patch, which is more acceptable to some people with dementia (Kurz & Lautenschlager, 2017).

Galantamine

Galantamine is a competitive reversible acetylcholinesterase inhibitor for which there is evidence of improvement in cognition, global state, neuropsychiatric symptoms and ADL function. The recommended dose is 16-24 mg/day (Kurz & Lautenschlager, 2017).

Memantine

Memantine works quite differently to the AChEIs. It is a non-competitive modulator and works by normalising glutamatergic neurotransmission. It is an N-methyl-D-aspartate (NMDA) receptor antagonist (Kurz & Lautenschlager, 2017). It is approved for use in Australia in people diagnosed with moderate to severe Alzheimer's disease. Eligibility for PBS is based on MMSE scores of between 10/30 and 14/30 (Dementia Australia, 2016).

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. 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.pbs.gov.au/reviews/anti-dementia-drugs-files/submission-11.pdf;jsessionid=jsdcm8w02kwwg69zg019sn91q/>

Further reading

Dementia Australia. (2020). Drug treatments and dementia. <https://www.dementia.org.au/national/about-dementia/how-is-dementia-treated/drug-treatments-and-dementia>

Cessation of cognitive enhancers

The latest evidence suggests the benefits of these drugs are in reaching an optimal therapeutic level and continuing the drug/s for the longer term. Decisions to discontinue should be made on an individual basis (Greiman et al, 2019; Hogan, 2014).

Cessation of cognitive enhancers should be considered and trialed 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 residential 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 for the person with dementia involves a multi-faceted approach to therapeutic interventions. Some of the more common non-pharmacological interventions to improve quality of life are outlined below.

Music

The World Federation of Music Therapy (2017) defines music therapy as:

“the professional use of music and its elements as an intervention in medical, educational, and everyday environments with individuals, groups, families, or communities who seek to optimize their quality of life and improve their physical, social, communicative, emotional, intellectual, and spiritual health and wellbeing.”

Music therapy has been demonstrated to be an effective intervention that supports wellbeing and quality of life for people living with dementia (Grady & Beach, 2020; Matthews, 2015). It is an intervention that can improve communication and relationships between the person living with dementia and their caregivers. Thus, it can assist with improving the psychological impact of being a carer for a person living with dementia (Raglio et al, 2016). Music therapy can also be used as an intervention to alleviate agitation in people living with dementia. Multiple studies have demonstrated the usefulness of calming or relaxing music in reducing agitation in people living with dementia (Gerdner & Remington, 2017). Gerdner (2010) has developed a guideline for the use of music in this context.

Reality orientation (also known as reality therapy)

Reality orientation aims to familiarise the person with dementia with their surroundings and situation. It is based on the premise that regular reminders can improve function in people with impaired orientation. Randomised controlled trials have been unable to demonstrate positive evidence of efficacy regarding neuropsychiatric symptoms (Livingston & Cooper, 2017).

Reality orientation can be achieved using notice boards, calendars, clocks, or by environmental modification to indicate celebrations and festivities, e.g. Melbourne Cup (Chiu, Chen, Chen & Huang, 2018).

A meta-analysis by Chiu et al. (2018) found that reality orientation can provide moderate improvement in cognitive function, however, this analysis was unable to demonstrate significant improvements in behavioural or depressive symptoms.

Validation therapy

This type of therapy recognises the uniqueness of the individual and seeks to resolve conflict by validating feelings, rather than focusing on facts. A large randomised controlled trial failed to demonstrate benefit regarding neuropsychiatric symptoms (Livingston & Cooper, 2017).

A smaller study in Germany found validation therapy was a useful intervention for assisting people living with dementia transition to long-term care as it allowed people with dementia to express their strong feelings and cope better with emotional distress (Erdmann & Schnepf, 2016).

Diversional and recreational therapy

Leisure and recreation allow individuals opportunities for purposeful engagement and give a sense of autonomy.

Recreation therapy uses meaningful, goal directed interventions to involve people in activities that improve multiple aspects of the person's life; this includes psychological, physical, emotional, and social well-being (Mitchell & Van Puymbroeck, 2019).

It is described as:

"a definition of 'health' which includes not only the absence of 'illness', but extends to enhancement of physical, cognitive, emotional, social and leisure development so individuals may participate fully and independently in chosen life pursuits."
(American Therapeutic Recreation Association, 2020).

This therapy is provided by a qualified professional and uses individual recreational modalities that may include activities such as therapeutic conversation or gardening.

Formal recreation therapy is guided by assessment of the individual and the development of individualised and appropriate activities that are designed to support, challenge and enhance the wellbeing of people who encounter obstacles to participation in their preferred leisure and recreational pursuits (Diversional and Recreation Therapy Australia, 2020).

Reminiscence therapy

This is a psychosocial intervention that seeks to stimulate autobiographical memory and increase subjective well-being. There is no 'gold standard' or agreed definition. This means there are several methods utilised in practice (Kirk, Rasmussen, Overgaard & Berntsen, 2019).

Therapy may be individualised using strategies such as life story books. Group therapy utilises memory triggers such as music, photographs, and other objects relevant to group participant's earlier years. There is some evidence this therapy has positive effects on quality of life, cognition, communication and mood (Kirk et al, 2019; Lok, Bademli & Selcuk-Tosun, 2018).

Simulated presence therapy

This is a psychosocial intervention that utilises video or audio recordings of family members to play to the person living with dementia when it is not possible for the family member to be present. The intention is to be reassuring and thus reduce anxiety and distress. It is based on the observation that residents in residential aged care facilities with more frequent family visits are less agitated and more experience greater life satisfaction. A study in 1995 reported increased verbalisation and smiling, along with reduced episodes of aggression and social isolation (Abraham et al, 2016).

Multi-sensory environments

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. It involves stimulation of the senses through a combination of light, touch, music and aromatherapy. There is evidence of short-term benefits in relieving agitation but little evidence the benefit is sustained over a longer period (Bauer et al, 2015; Livingston & Cooper, 2017).

A study in Victoria found there were barriers to effective implementation of Snoezelen:

- A failure to perform a comprehensive assessment of the person's needs prior to implementation
- Sensory interventions being delivered by staff with limited training in the intervention
- A lack of formal evaluation of the interventions undertaken
- appeared the multi-sensory interventions were more recreational rather than a specific individualised intervention for a person living with dementia who is experiencing symptoms of BPSD

(Bauer et al, 2015).

Simple strategies to help in coping with memory loss

There are some simple strategies that can be put in place in the home to assist people with early stage dementia to compensate for memory impairment. Ensure you ask the person what strategies they are already using and try to draw on strategies that may have been used previously as they will be familiar. A wide range of strategies will be more helpful. Strategies are usually based on focussing attention, adding meaning to the information to be remembered, or reducing the amount of information needed to be remembered (Unkenstein, 2017).

- Change conversational questions – e.g. ask “Did you enjoy the show on TV last night?” rather than “What show did you watch on TV last night?”
- Asking the person to repeat what you have said to them promotes registration of the information
- Utilise reminders from family (telephone or notes). Make sure they are specific; e.g. “Back in 5 minutes” is not helpful. “Mary will be here at 1pm” is better
- Memory centres can be set up in the home and involve using visual cues: clock, noticeboard, notepad etc.
- Consider utilising a dosette box for medications – or contact the local pharmacist for a dose administration aid that provides individualised medication in a plastic ‘bubble’ pack with tablets already sorted for times and date. These are usually presented as a weekly pack
- Clocks that display the day and date, some include additional information such as the weather
- Use basic alarms such as the oven timer as a reminder of a task
- Install a telephone that can store frequently used contacts – consider obtaining a ‘smart’ phone or tablet
- Ensure devices such as kettles and irons have the capacity to automatically shut off

- Consider changing lights to sensor controlled if appropriate
- Consider installing glass doors to cupboards which allow contents to be seen
- Use of lists – encouraging the person to write things down as reminders. Notebooks, noticeboards and sticky notes are all useful. Keep a pen or a pencil close by
- Use of diary and calendar
- Storage of objects in designated places
- Developing regular routines and habits can reduce the need to remember. For example, if keys are always placed in the same place this will minimise the risk of them being lost
- Consider using a ‘Communication Book’ for family and carers to write messages. The person living with dementia can be encouraged to check this book to see if they have had the carer or family member visit that day
- Avoid unnecessary furniture rearranging. The person living with dementia will manage better in a familiar environment. If changes are required, introduce them slowly and explain why.

Clinical issues: treatment and management

Dementia is a major cause of disability and dependence, especially among older people. People with dementia are likely to have more than one health condition. In Australia, people with dementia who are hospitalised have an average of another eight health conditions. 70% of these hospitalisations were classified as being of the highest clinical complexity, this is in comparison with 16% of hospitalisations with no diagnosis of dementia. Type 2 Diabetes Mellitus is the most common co-morbid condition, followed by urinary incontinence. The average length of stay for a person living with dementia is 13 days. Most hospitalisations were related to acute care. Almost half of these hospitalisations resulted in the person being discharged back home to their normal place of residence (Australian Institute of Health & Welfare, 2019).

Health professionals need to consider multiple clinical issues for the person living with dementia. Some clinical issues are discussed in the following paragraphs, please note this list is not inclusive of all potential clinical issues.

Pain

Pain is a common problem for older people. Unfortunately, it remains under-recognised and under-treated. Dementia or cognitive impairment is one of the biggest barriers to pain assessment and treatment (Podder, 2019). This is because cognitive impairment can compromise the ability of the older person to self-report pain (Horgas, Laframboise-Otto, & Yoon, 2020).

The Australian Pain Society defines pain as:

“a distressing experience associated with actual or potential tissue damage with sensory, emotional, cognitive and social components” (Goucke, 2018, p19).

Self-report of pain has long been the ‘Gold Standard’ means of identifying pain (Horgas et al, 2020). However, it is important to recognise that a person with cognitive impairment may be experiencing pain even though they cannot communicate this verbally.

Access to pain relief was recognised as a human right in the Declaration of Montreal in 2010 (International Association for the Study of Pain (IASP), 2010). Any person in pain requires treatment (Merskey & Bogdut, 1994).

Unrelieved pain is known to cause many complications. These include depression, social withdrawal, sleep disturbances, impaired mobility, decreased engagement in activities, and reduced quality of life. Unrelieved pain is also likely to exacerbate falls risks, cognitive decline, deconditioning, malnutrition, and gait disturbances (Horgas et al, 2020).

Multiple studies have been conducted on the prevalence of pain. Detailed research reveals prevalence rates of pain in residential care of between 83-93%. 40% of residents in residential aged care facilities are unable to report pain due to a major cognitive or communicative disability (Goucke, 2018).

Health professionals need to be aware that they will be providing care for people experiencing pain who will report in different ways, choose not to report, or will have difficulty in reporting. Known barriers in addition to dementia include hearing and vision, dysphasia, dysarthria, and cultural and linguistic diversity. Another barrier is that older people are known to have attitudes and beliefs about pain that include accepting it as a normal part of ageing or thinking it can't be treated (Goucke, 2018).

Guidelines on pain assessment are available in Australia via the PMG Kit for Aged Care. These guidelines specify that pain assessment is an ongoing process that should occur:

- On admission
- In the event of a significant change in condition
- Any time pain is suspected and
- At least every three months

(Edith Cowen University, 2007).

Pain assessment for people with cognitive impairment is difficult. There may be several factors causing uncertainty about what is happening to the person, especially if they are unable to communicate verbally. Other aspects that may be impacting on the person are factors such as depression, fatigue, or agitation (Abbey et al, 2004). Assessments must be carefully conducted in order to ascertain what is happening.

Falls

Falls and the subsequent injuries are a serious problem for older people. Tripping, slipping, or stumbling are common reasons for a fall. Negative outcomes to a fall include immobilisation, loss of independence and autonomy, depression, and death (Victorian State Government, 2017). People living with dementia are at even higher risk for falls, some studies suggest the increased incidence may be as much as eight to ten times higher for people who are cognitively impaired (Casey, Caulley & Phelan, 2020). One retrospective study found people with dementia with symptoms of wandering or agitation were more likely to have a fall in the future (Marin, 2018). Half of all falls in people with dementia result in injury such as a fractured hip (Miller, 2020).

There is no validated falls risk screening tool for people living with dementia (Casey et al, 2020). It is recommended to utilise standard falls risk screening tools with careful consideration of the additional risk factors for this population. Falls risk should be assessed at the initial encounter and repeated whenever the person's condition changes. This is even more important for a person living with dementia who may experience more fluctuations in condition due to the dementia and other co-morbidities (Miller, 2020).

Falls risk factors related to people with dementia include:

- History of a recent fall
- Bladder and/or bowel incontinence
- An episode of an acute illness
- Depression
- Impaired judgement
- Lack of insight regarding mobility limitations
- Visual or hearing impairment
- Ambulatory impairment
- Neuromuscular rigidity
- Difficulty in using assistive mobility devices
- Impaired balance or gait
- Slow reflexes
- Behaviours such as wandering, restless pacing, resistance to care
- Anxiety
- Agitation
- Sleep disturbances

(Miller, 2020).

Strategies to reduce falls risk:

- Exercise programs such as strength training, Tai Chi, or balance training have demonstrated good results in reducing the incidence of falls
- Vitamin D supplementation may be recommended
- Refer to physiotherapist and/or occupational therapist for suitable mobility aids
- Address visual impairments – encourage use of appropriate lens corrective devices
- Address environmental hazards in the home
- Refer to podiatrist for management of foot pain and recommended footwear
- Consider medication review related to medications known to increase falls risk

(Casey et al, 2020).

Assessment of environmental hazards in the home includes:

- Floor surfaces, use of rugs etc.
- Lighting levels
- Placement of furniture
- Clutter
- Chair heights
- Availability of grab bars in bathroom

- Toilet seat height
- Stairs without handrails

(Casey et al, 2020; Victorian State Government. 2017).

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 reduce the incidence of falls. Poor outcomes related to physical restraint include:

- Increased confusion
- Increased anxiety and agitation
- Increased risk of fall-related injuries
- Negative emotional responses including fear, anger, resistance, and humiliation

(Miller, 2020).

It must be remembered that in Australia, both physical and chemical restraint are subject to Commonwealth legislation minimising use of restraint as detailed in the Quality of Care Principles (2014). Restraint in an aged care setting must only be used as a last resort (Australian Government Department of Health, 2020).

More detailed information regarding assessment and management of falls risks in older people is detailed in the Victorian Government Standardised Care Process for Falls (2017): <https://www2.health.vic.gov.au/Api/downloadmedia/%7BD336FB2A-20BD-4E0B-ADAB-FF590E524C43%7D>

Nutrition

Optimal nutrition is essential for people living with dementia. It is important to consume adequate amounts of food and fluid as well as preserve dignity and personhood with the social interaction and rituals often associated with meals. This means it is important to recognise diminished ability to manage meals as early as possible. Early detection allows multiple strategies to be implemented to promote function and prevent malnutrition (Martin, 2019).

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
- Assess oral health.

Undernutrition and clinically significant weight loss occur in nearly 50% of people living with dementia. This can result in:

- Reduced muscle mass and function
- Reduced bone mass
- A decline in immune function
- Slower wound healing
- Further cognitive decline

These issues will all contribute to adverse events, increases in hospital presentations, and mortality (Brooke & Ojo, 2015).

Changes in the ability to eat and drink may be due to several issues:

- Diminished executive planning
- Changes in taste
- Reduced ability to concentrate
- Lack of recognition of food and hunger
- Agnosia (sensory processing difficulties)
- Dyspraxia
- BPSDs

(Brooke & Ojo. 2015).

Common manifestations in the ability to eat and drink independently are:

- Reduced ability to use cutlery
- Reduced ability to cut up food
- Reduced ability to identify food items
- The plate slides around the table
- Reduced ability to identify or use cups/glasses
- Increased frequency of spills
- Episodes of staring at food/table without eating
- Episodes of falling asleep during mealtimes

(Martin, 2019).

Later changes include:

- Diminished swallowing ability
- Reduced ability to eat and drink independently

(Brooke & Ojo, 2015).

A person-centred approach to enabling nutrition and hydration for a person living with dementia utilises these principles:

- Provide choices and preferences
- Support independence
- Demonstrate respect
- Promote social interactions

(Martin, 2019).

Interventions need to be based on these principles:

- Cueing and encouraging
- Modifying tableware and table settings
- Adapting food or providing supportive assistance

(Martin, 2019).

Specific interventions that have been proven to assist are:

- Setting the table – laying tablecloths, placemats and cutlery
- Using crockery with contrasting colours
- Good lighting

- Background music
- Tempting food aromas e.g. baking bread
- Presenting food in an appealing and appetising manner
- Tables of four people
- Implement grazing menus (useful for people who have wandering behaviours)
- Staggered mealtimes
- Provision of energy dense foods
- Provision of texture modified foods if required
- Provision of finger foods
- Offering one course or item of food at a time
- Providing additional snacks

(Brooke & Ojo, 2015; Murphy, Holmes & Brooks, 2017).

The research also supports the provision of nutritional supplements to people with dementia who are experiencing changes in the ability to eat and drink. These supplements can assist with reducing the adverse outcomes of malnutrition (Nguyen, 2019).

Dysphagia

Dysphagia may become apparent as the person with dementia progresses to more advanced stages. It is essential that a referral is made to a Speech Pathologist for an accurate assessment of swallowing function and recommendations for management (Joanna Briggs Institute, 2020).

Artificial feeding in advanced dementia

The recommended procedure to assist with eating and drinking for a person with dysphagia includes:

- Ensure the person is sitting upright when eating or drinking
- Perform oral hygiene pre and post meals
- Encourage the person to lower their chin when swallowing – this assists the mechanism of swallowing
- Provide equipment such as adapted cups, non-slip mats, modified utensils
- If assisting with feeding – use a small spoon such as a teaspoon
- Provide texture modified foods – as identified by the Speech Pathologist
- Provide moderately thickened drinks – as identified by the Speech Pathologist
- Feed one spoon or sip at a time
- Always ensure the previous mouthful has been swallowed before offering more
- Check food temperature before serving
- Allow time for meals – do not rush
- Reduce external distractions, e.g. television
- Document intake

(Joanna Briggs Institute, 2020; Sivapuram, 2020).

In the later stages of dementia, the risk of malnutrition increases as the person becomes totally dependent on carers to assist with eating. 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.

Nutritional support such as enteral feeding has not been proven to reduce aspiration pneumonia, prolong life, improve nutritional status, or improve quality of life (Schwartz, 2018).

International guidelines support the use of enteral nutrition in people living with dementia for short periods of time to assist in recovery from an acute condition. However, they do not support long term use, especially in end-stage dementia.

Decisions regarding the use of enteral nutrition are unique to each person. It is important to discuss options with the person with dementia and their families at earlier stages to facilitate decision making and encourage documentation in an Advanced Care Directive (Brooke & Ojo, 2015; Koh, 2020). The provision of enteral feeding can be ethically challenging – the health professional needs to consider the universal principles of autonomy, beneficence, non-maleficence, and justice (Schwartz, 2018).

If the decision is made not to initiate enteral feeding then oral food and fluid must be provided (Murray, Mulkerrin & O’Keefe, 2019).

Health professionals, families and care partners can experience complex emotional and ethical concerns when faced with this situation. Accurate information about the options needs to be provided.

Discussion points between the health professional and the family/caregiver include:

- Lack of evidence regarding efficacy of enteral feeding in people with advanced dementia
- Evidence of complications associated with enteral feeding
- The decision to decline enteral feeding does not mean nutritional needs will be ignored
- The option of ‘comfort’ feeding should be offered
- Comfort food is defined as any food the person will accept, eat, and tolerate
- The person living with advanced dementia will continue to receive oral hygiene and all other care required

(Miller, 2020).

Contenance

Incontinence is a stigmatised condition; it impacts on identity and can cause feelings of shame and humiliation. Episodes of incontinence can trigger distressed behaviour for the person living with dementia. The person may be attempting to maintain autonomy and privacy, or to communicate an unmet need. Difficulties in maintaining continence may increase as the dementia becomes more advanced. This means it becomes more difficult for the person to self-manage. Common responses include denial, resistance to care, disengagement, and attempts to conceal the problem. Caregivers and health professionals need to be able to approach the person living with dementia who is experiencing episodes of incontinence with empathy and respect (Ostaszkiwicz, 2017).

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 several reversible causes of incontinence and these must be investigated prior to accepting the incontinence as being associated with the dementia.

Issues contributing to the development of incontinence for people living with dementia include:

- Unfamiliar environments – difficulty in locating toilet facilities
- Delayed or ineffective assistance with toileting needs
- Urinary tract infections
- Medical conditions – e.g. urinary retention, prostatic hypertrophy
- Adverse medication effects – e.g. diuretics, narcotics, anticholinergics
- Incontinence aids that impede the person's ability to toilet independently
- Functional limitations that prevent the person from toileting independently

(Miller, 2020).

Strategies to support continence in people living with dementia include:

- Observe and document patterns of bladder and bowel elimination – do not expect the person to self-report
- Observe for, and respond to signs the person is ready to go to the toilet
- Develop a care plan addressing continence needs – e.g. two hourly toileting schedules
- Encourage fluids
- Monitor for signs of constipation; treat constipation when it occurs
- Provide toileting cues and assistance at appropriate intervals
- Ensure bathrooms are clearly sign-posted, keep the passage clear. Consider a night light
- Arrange for clothing to be provided that is easier to remove when toileting - e.g. elastic waists or Velcro fastenings
- Arrange a medical consultation to assess for conditions related to incontinence – e.g. urinary tract infection, enlarged prostate etc.
- Arrange a referral to a continence nurse advisor or a continence physiotherapist
- Use continence aids as recommended
- Ensure the person is cared for in a dignified and respectful manner if there are episodes of incontinence – avoid responding in a manner that could be perceived as judgemental or patronising

*(Continence Foundation of Australia, 2020; Miller, 2020)*Pharmacological management of incontinence

There are limitations in the role of anticholinergic drugs in the management of urinary incontinence in people with advanced dementia. They may be contra-indicated in people taking 'cognitive enhancers' (Veterans Mates, 2014).

Medication for incontinence needs to be assessed on an individual basis by the person's doctor who can make a judgement of benefits versus risks (Continence Foundation of Australia, 2020).

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. This is often the time when informal carers seek support from external services.

Personal care needs to be provided from a perspective of person-centred care. Care is delivered according to these principles:

- Recognise remaining abilities while addressing both cognitive and functional decline
- Treat the person with respect and dignity in all activities
- Accommodate individual abilities as well as likes and dislikes
- Provide assistance in a manner that supports independence

(Miller, 2020).

Personal care is by its very nature an intimate action. People living with dementia may experience feelings of embarrassment or humiliation when helped. They may refuse to bathe or change clothing. There are several strategies to consider:

- Provide reassurance and be patient
- Provide privacy
- Choose the best time of day for the person, provide hygiene options they are used to and prefer
- Break down tasks into simple steps
- Encourage the person to be as independent in personal care as possible
- Provide items in a sequential manner
- Be sensitive to fear of water – be flexible with bathing/showering arrangements
- Consider using a hairdresser for hair washing
- Tactfully substitute clean clothing for soiled
- Encourage oral care, assist as required. Maintain regular dental check-ups
- Consider providing a manicure for fingernails. Consult with a podiatrist for toenails

(Dementia Australia, 2017a).

Further advice and resources to support caregivers and health professionals are available in the earlier section on BPSDs if there are ongoing challenges with the provision of personal care.

Sleep

Sleep disturbances become more common in older people. This is further exacerbated when the person also has cognitive impairment (Chu, 2017; Podder, 2019b). Conversely, sleep disturbances are known to impact cognitive function (Vaou, Lin, Branson & Auerbach, 2018). The Sleep Health Foundation (2011) estimates that as many as 50% of people living

with dementia experience sleep difficulties. Sleep patterns may change – the person may experience more sleepiness during the day followed by lighter and less restful sleep at night. Some forms of dementia are known to disrupt the body clock (Miller, 2020; Sleep Health Foundation, 2011). Sleep disturbances are a notable early symptom of Dementia with Lewy Bodies. People diagnosed with this form of dementia need a referral to a neurologist for sleep management, especially as they may have atypical reactions to medications (Miller, 2020).

It is important to consider other reasons contributing to sleep disturbances. Do not assume the sleep disturbance is solely attributable to dementia. Coexisting conditions that need to be assessed for include:

- Pain
- Anxiety
- Delirium
- Depression
- Sleep apnoea
- Medical morbidities
- Restless legs syndrome
- Medication side effects

(Miller, 2020).

Pharmacological interventions for sleep management are a last resort. Non-pharmacological interventions to optimize sleep hygiene should be tried first. These include:

- Maintenance of a regular daily schedule that reflects the person's preferences
- Consideration of taking a warm bath in the afternoon or early evening
- Encouragement of physical activity during the day
- Alleviation of pain, anxiety, distress, and any other sources of discomfort
- Encouragement of exposure to sunlight or full-spectrum lighting during the day
- Avoidance of food, fluids and medications with caffeine or stimulants after 1pm; e.g. coffee, chocolate, refined carbohydrates, cold/flu preparations
- Encouragement of food and fluids that promote sleep in the evening; e.g. warm milk, chamomile tea
- Use of soothing music in the background
- Maintenance of a comfortable temperature and environment in the bedroom
- Control of light and noise at nighttime
- Avoidance of stimulating activities when the person wakes during the night; e.g. no television or distracting conversations
- Use of relaxation strategies; e.g. deep breathing, meditation, massage, a rocking chair

(Miller, 2020).

Other strategies such as the use of melatonin has not been proven (Sleep Health Foundation, 2011; Vaou et al, 2018).

The Sleep Health Foundation (2011) advises daytime naps can be helpful. However, they should be of short duration and encouraged earlier in the day.

Palliation

The World Health Organisation (2020, para 1) defines palliative care as:

“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.”

Dementia is progressive and life shortening. A palliative approach acknowledges the terminal nature of the disease. It allows people living with dementia and their caregivers an understanding of treatment options. The goal is more likely to be to preserve function and quality of life as long as possible, rather than seek what is so far an unavailable cure. A palliative approach also assists health professionals to recognise when it is appropriate to institute end of life care such as pain relief. The other advantage of this approach is that it encourages people living with dementia to consider appropriate advanced care planning earlier (Hughes & van der Steen, 2017).

The course of dementia is difficult to predict and people living with dementia develop quite complex needs as the disease advances. Excellent communication with caregivers is essential as they may have to take on the role of proxy decision maker as well as caregiver (van der Steen et al, 2017). Complex symptoms will require specialist intervention delivered within an interdisciplinary coordinated framework (Sampson et al, 2018).

The most common end-of-life symptoms in dementia are pain, agitation and shortness of breath (Hendriks, Smallbrugge, Hertogh & van der Steen, 2014). Pain and agitation are also common in advanced dementia. It is difficult to predict impending death (Samson et al, 2018).

Good practice in end-of-life care for people living with dementia is based on these four principles:

- Leadership and management of care
- Integration of clinical expertise
- Continuity of care
- Use of relevant guidelines and pathways

(Lee, Bamford, Exley, & Robinson, 2015).

ACTIVITY

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.

Summary

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

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