



An Australian Government Initiative



Government of Western Australia  
Department of Health  
Osborne Park Hospital

# Dementia: Osborne Park Hospital Guide for Occupational Therapists in Clinical Practice







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# Dementia: Osborne Park Hospital Guide for Occupational Therapists in Clinical Practice

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## Forward

The contemporary challenges of Australia's ageing population, and the corresponding increases in the incidence of dementia, have resulted in the need for health professionals and service providers in a variety of general and speciality areas. It is important that those who provide care to people with dementia have the right knowledge, skills and understanding of dementia to provide quality dementia care.

The Australian Government aims to strengthen the capacity of the health and aged care sectors to provide appropriate evidence-based prevention, early intervention, assessment, treatment and care for people with dementia.

The Australian Government is committed to supporting and building the professionalism and capacity of the dementia care sector through the provision of quality education and training programs. The Dementia Training Study Centres (Training Centres) form an integral component of this commitment. The aim of the Training Centres is to improve the quality of care and support provided to people living with dementia and their families through the development and up skilling of the dementia care workforce and the transfer of knowledge into practice.

The Australian Government provided funding for the development of this resource through the Western Australia Dementia Training Study Centre. Occupational Therapists at Osborne Park Hospital in Western Australia recognised a need to improve their skills, knowledge and resources on evidence based practice in dementia care in the hospital and community settings.



This resource has been developed by clinicians for clinicians with advice and assistance from Consultant Geriatricians to ensure that all information included in this resource accurately reflected current medical guidelines and clinical practice. In addition, Osborne Park Hospital Physiotherapists provided information on mobility and falls to support a cooperative approach to rehabilitation and care.

The information contained in this resource has the potential to support a broad range of clinical settings for Occupational Therapists and other clinicians.

I trust that this resource will be of relevance and importance to your daily practice of dementia care.

**Nicole O'Keefe**  
State Manager  
Western Australia State Office  
Department of Health and Ageing

## Introduction

'Dementia: Osborne Park Hospital Guide for Occupational Therapists in Clinical Practice' (the 'Guide') is the outcome of a twelve-month quality improvement project undertaken by the Occupational Therapy (OT) Department at Osborne Park Hospital (OPH) in Western Australia.

The project was prompted by:

- Osborne Park Hospital's commitment to continual improvement of clinical skills and service
- an increasing number of inpatient and community clients with dementia being referred to Osborne Park Hospital Occupational Therapy Department
- a desire to improve Occupational Therapy practice in dementia care
- a desire to improve the professional resources on evidence based practice in Occupational Therapy and dementia care relevant to the needs at Osborne Park Hospital Occupational Therapy.

The project was supported by a grant from the WA Dementia Training Study Centre, at Curtin University's Centre for Research on Ageing. A part time project officer, an experienced Occupational Therapist, worked with the Osborne Park Hospital Occupational Therapy project team to research and develop this Guide.

The project team used an action-research approach for project management and development. This approach facilitated shared learning, and provided the flexibility the project team needed to accommodate caseload demands. The project officer and the project team, worked cooperatively on the Guide; which is based on evidence based practice.



The Guide commences with an overview of the roles and responsibilities of Occupational Therapists at Osborne Park Hospital. This provides context for the information that follows. The first section of the book provides an overview of dementia including types, symptoms and disease progression. A summary of the dementia assessments used by Occupational Therapists at Osborne Park Hospital is provided, including their reliability and validity. Relevant Australian and international standards and useful evidence based practice resources relevant to Occupational Therapy, are documented.

The majority of the Guide is devoted to identifying common issues or problems associated with dementia, and to outlining evidence based strategies that Occupational Therapists can consider to address these issues. It covers a wide range of activities and functions including home and hospital design, activities of daily living, mobility and falls, communication, wandering, and transport and driving. The final chapter provides information to assist when advising families on community based resources, or residential care options. The Guide provides an extensive evidence based practice resource, which will be invaluable to Occupational Therapists working in our department. We also hope it will be useful for other Occupational Therapists, aged care nurses and allied health clinicians around Australia and further afield.



## Osborne Park Hospital OT Roles and Responsibilities

Osborne Park Hospital is a community general hospital in Perth, Western Australia that provides a range of specialist rehabilitation and aged care services. These include:

- inpatient clinical service (Rehabilitation and Aged Care - Wards 3, 4, 5)
- specialist rehabilitation services including Stroke and Parkinson's Disease
- Rehabilitation and Aged Care Intervention Liaison Service (RAILS)
- Aged Care Assessment Team (ACAT)
- Day Hospital.

Osborne Park Hospital is committed to providing high quality care. Osborne Park Hospital Occupational Therapists work in multidisciplinary teams led by Consultant Geriatricians, using a client centred approach within a medical model. This booklet has specifically been written for Occupational Therapists working at Osborne Park Hospital, however it reflects the multidisciplinary approach to the care of people with dementia and is therefore useful for other clinicians and settings.

A significant number of people seen by Osborne Park Hospital Occupational Therapists have dementia, or dementia related symptoms, either as a primary diagnosis or comorbidity. Occupational Therapists often identify dementia related symptoms during assessments or home visits, which are fed back at team meetings. This usually results in a medical review with the Consultant Geriatrician or their team, or a referral to the Osborne Park Hospital Memory Clinic for opinion and diagnosis.

Osborne Park Hospital Occupational Therapists have many responsibilities and the time available with individuals with dementia, and their families, is often limited. Community based ACAT Occupational Therapists usually have one occasion of service, for approximately 60 – 90 minutes, during the home visit. Occupational Therapists working with inpatients, Day Hospital, or Parkinson's Disease Clinic may have a longer period of contact over a number of appointments.

The Osborne Park Hospital Occupational Therapist role, in relation to assessment and therapy for patients with dementia includes:

- assessment: memory, orientation, concentration, insight, motivation, perception, behaviour, activities of daily living (ADLs), home environment, seating, falls risk, client needs, support systems, and carer needs (including stress and capacity)
- communication: with client and their family, the multidisciplinary team, carers or service providers, documentation (GP letters, patient notes), and ACAT assessments, reports, or referrals
- interventions: home aids and equipment provision, home or environmental modifications or adaptations, provision of specialised seating and cushions, ADL retraining, risk management strategies, work or activity simplification techniques, energy conservation techniques, advice on graded instructions and cueing, behaviour management strategies, stress management and relaxation techniques, upper limb therapy, falls prevention education and training, client and carer education, manual handling training, information provision, cross referrals to other multidisciplinary team members (doctors, nurses, physiotherapist, social worker, speech pathologist, memory clinic), and referral to resource and support agencies.



## Understanding Dementia

### Definition of Dementia

The World Health Organisation defines dementia as: “a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer’s disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.” (World Health Organisation, 2007).

The Alzheimer’s Association of Australia (2010b) defines dementia as a generic term that is used to describe a group of illnesses, which cause a progressive and irreversible decline in a person’s higher cognitive brain functioning. The global deterioration affects the person’s intellectual capacity including memory, learning, orientation, language, comprehension, judgement, rationality, social skills, emotional reactions, and an inability to carry out day-to-day activities.

## **Prevalence and Incidence of Dementia in Australia**

The following data is taken from the report that was commissioned by Alzheimer's Australia to assist with future planning of dementia care (Access Economics, 2009). The full report can be viewed online at Alzheimer's Australia web site [www.alzheimers.org.au](http://www.alzheimers.org.au).

Dementia is the leading cause of disability in Australians aged 65 years or older. It is one of the fastest growing sources of major disease for this group and is responsible for one year in every six years of disability burden. There are currently around 245,000 people living with dementia in Australia and this number is projected to increase fourfold to around 1.13 million people by 2050. Incidence of dementia is estimated to increase from 69,600 new cases in 2009 to 385,200 new cases in 2050. By 2020 there will be approximately 75,000 baby boomers living with dementia. Currently, over 9,600 Australians under the age of 65 have younger onset dementia. In 2009, the majority of people with dementia speak English at home (211,000), compared to the Culturally and Linguistically Diverse (CALD) population (35,000). People with dementia speaking English at home is expected to increase 4.8 times, to 1.01 million by 2050, with those speaking a CALD language at home increasing 3.4 times, to about 120,000 by 2050.

In 2009 there was an estimated 21,800 people living with dementia in Western Australia; projected to increase 5.7 fold to 125,300 by 2050. There were approximately 6,200 new cases of dementia in Western Australia in 2009, and this is projected to increase 6.9 fold to 42,800 by 2050.

By the 2060s spending on dementia is set to outstrip that of any other health condition. It is projected to be \$83 billion, and will represent around 11% of the entire health and residential aged care sector spending. Dementia care is predicted to become the third greatest source of health and residential aged care spending by 2040. Dementia is a major determining factor in precipitating entry to residential care. At least 60% of people in high care facilities, and 30% of people in low care facilities, have a diagnosis of dementia, while many more are cognitively impaired (90% high care; 54% low care).

## Types of Dementia

Dementia syndrome is linked to a large number of underlying brain pathologies, classified into several different subtypes of dementia. This section is intended to give a brief overview of each subtype. The boundaries between these subtypes are indistinct and mixed forms may be the norm. Further information is available from the Alzheimer's Association at [www.alzheimers.org.au](http://www.alzheimers.org.au), Alzheimer's Disease International at [www.alz.co.uk](http://www.alz.co.uk), or The Frontotemporal Dementia Research Group at [www.ftdrg.org](http://www.ftdrg.org).

**Table 1: Characteristics of Dementia Subtypes**

| Dementia Subtype         | Early Characteristic Symptoms  | Neuropathology  | Proportion of Dementia Cases |
|--------------------------|--|---|------------------------------|
| Alzheimer's disease (AD) | <ul style="list-style-type: none"> <li>▪ gradual onset</li> <li>▪ early symptoms subtle</li> <li>▪ impaired memory, word finding difficulties, apathy, and increased time to complete ADL's</li> <li>▪ emotional unpredictability, depression, deterioration in social skills, wandering, and aggression.</li> </ul> | <ul style="list-style-type: none"> <li>▪ cortical amyloid plaques and neurofibrillary tangles</li> <li>▪ mainly affects the hippocampus located in temporal lobe</li> <li>▪ cholinergic deficits, including reduced transmission of the neurotransmitter acetylcholine, involved in learning, memory, and attention (Salama, 2008)</li> </ul> | 50 %                         |
| Vascular dementia (VaD)  | <ul style="list-style-type: none"> <li>▪ sudden onset, stepwise progression</li> <li>▪ clinical deficits determined by the size, location, and type of damage</li> <li>▪ similar to AD, but memory less affected, and mood fluctuations more prominent</li> <li>▪ executive functions affected.</li> </ul>           | <ul style="list-style-type: none"> <li>▪ cerebrovascular disease</li> <li>▪ ischaemic or haemorrhagic infarcts</li> <li>▪ single infarcts in critical regions, or more diffuse multi-infarct disease.</li> </ul>  | 20 %                         |

| Dementia Subtype                | Early Characteristic Symptoms   | Neuropathology   | Proportion of Dementia Cases |
|---------------------------------|---|--|------------------------------|
| Dementia with Lewy Bodies (DLB) | <ul style="list-style-type: none"> <li>▪ slow progression</li> <li>▪ marked fluctuation in cognitive ability</li> <li>▪ Visual hallucinations</li> <li>▪ parkinsonism (tremor, rigidity)</li> <li>▪ rapid progression</li> <li>▪ frontal lobe and visuospatial impairments</li> </ul>   | <ul style="list-style-type: none"> <li>▪ cortical Lewy bodies (alpha-synuclein)</li> <li>▪ deficit in dopaminergic and cholinergic neural transmission (Salama, 2008)</li> </ul> | 15 %                         |
| Frontotemporal dementia (FTD)   | <ul style="list-style-type: none"> <li>▪ personality changes</li> <li>▪ mood changes/apathy</li> <li>▪ disinhibition</li> <li>▪ language difficulties</li> <li>▪ earlier onset (as young as 30-40 years of age)</li> </ul>  | <ul style="list-style-type: none"> <li>▪ no single pathology</li> <li>▪ damage limited to frontal and temporal lobes</li> </ul>  | 5 %                          |
| Parkinson's Disease (PD)        | <ul style="list-style-type: none"> <li>▪ PD is progressive disorder characterised by tremors, slowness of movement (bradykinesia), speech impediments, and difficulty initiating movement</li> <li>▪ later stages of the disease and with increasing age, 50 % of people may develop some degree of cognitive decline</li> <li>▪ can be difficult to distinguish DLB from PD</li> </ul> | <ul style="list-style-type: none"> <li>▪ central nervous system, which results in the loss of the neurotransmitter dopamine</li> </ul>   | 3-4%                         |

| Dementia Subtype                                     | Early Characteristic Symptoms   | Neuropathology  | Proportion of Dementia Cases   |
|--|---|---|--|
| Alcohol related dementia                             | <ul style="list-style-type: none"> <li>related to poor nutrition, and excessive consumption of alcohol, causing a thiamine deficiency (Korsakoff's syndrome), and may also include direct effects of alcohol</li> <li>affects memory, learning, and other mental functions</li> </ul> | <ul style="list-style-type: none"> <li>damage to the medial thalamus and possibly to the mammillary bodies of the hypothalamus, as well as generalised cerebral atrophy</li> </ul>                                      | under diagnosed  |
| AIDS related dementia or AIDS Dementia Complex (ADC) | <ul style="list-style-type: none"> <li>Complicated syndrome</li> <li>symptoms include poor concentration, poor memory, slowed mental processing, difficulty with recall, unsteady gait, poor coordination, and depression</li> </ul>  | <ul style="list-style-type: none"> <li>HIV can indirectly affect nerve cells. Immune cells that are present in the brain act as HIV reservoirs, and are the primary source of indirect damage to nerve cells</li> </ul> | uncommon in early stages of the illness, in the later stages for the population not taking anti-HIV medication 7%. |
| Down syndrome and AD                                 | <ul style="list-style-type: none"> <li>genetic disorder</li> <li>impaired memory, thinking, and behaviour</li> </ul>  | <ul style="list-style-type: none"> <li>abnormal amyloid breakdown, with similar pathology to Alzheimer's Disease</li> </ul>   | 100% of people with down syndrome, who have died, have changes in the brain associated with AD                     |

| Dementia Subtype                | Early Characteristic Symptoms   | Neuropathology   | Proportion of Dementia Cases                |
|---------------------------------|---|--|---|
| Creutzfeldt-Jacob disease (CJD) | <ul style="list-style-type: none"> <li>▪ a degenerative neurological disorder that is incurable and invariably fatal</li> <li>▪ the first symptom of CJD is rapidly progressive dementia, leading to memory loss, personality changes, and hallucinations.</li> <li>▪ accompanied by physical problems such as speech impairment, myoclonus ataxia, changes in gait, rigid posture, and seizures</li> </ul>   | <ul style="list-style-type: none"> <li>▪ swelling and loss of nerve cells</li> <li>▪ increase in the size and number of brain cells (astrocytes)</li> <li>▪ abnormal prion protein deposits between nerve cells</li> </ul> |   |
| Huntington's disease (HD)       | <ul style="list-style-type: none"> <li>▪ an inherited degenerative brain disease that affects both the mind and body.</li> <li>▪ usually appears between the ages of 30-50</li> <li>▪ Characteristics include intellectual decline, irregular involuntary movements of limbs, and facial muscles</li> <li>▪ other symptoms include personality changes, memory disturbance, slurred speech, impaired judgement, and psychiatric problems</li> </ul> | <ul style="list-style-type: none"> <li>▪ central nervous system</li> <li>▪ damage mainly occurs in the neostriatum (comprised of the caudate nucleus and putamen)</li> </ul>   | Dementia occurs in the majority of HD cases |

(Adapted from tables by Alzheimer's Australia website and Access Economics, 2009)

## Symptoms of Dementia

**Table 2: Symptoms of Dementia**

| Function                               | Challenges   |
|--|--|
| Memory / registration                  | Remembering where they are going<br>Remembering what they are doing e.g., leaving stove on<br>Remembering what to do next<br>Mixing up time                                    |
| Loss of insight                        | Inability to plan and make decisions<br>Inability to reason or learn new ideas   |
| Learning                               | Revert to old patterns<br>Use old patterns to solve new problems<br>Mastering new skills, knowledge  |
| Orientation                            | Inappropriate actions for time and place<br>Become lost<br>Way finding   |
| Language                               | Communicating needs, interests, desires using words<br>Developing language difficulties e.g., anomia, dysphasia, paraphrasia, aphasia- receptive/expressive                    |
| Comprehension<br>(reading and writing) | Difficulty understanding what is said or written   |
| Abstract thinking                      | Understanding relationships between 'things' e.g., up/down, under/over, next to<br>Interpret language, jokes in concrete terms e.g., 'hop up'<br>Inability to reason           |
| Calculation and denomination           | Difficulty judging distance<br>Managing money  |
| Judgement                              | Inability to plan and make decisions<br>Foresee consequences<br>Identifying and/or correcting mistakes<br>Consider safety of self/others<br>Assessing relative success/failure |

| Function                      | Challenges  |
|-------------------------------|---|
| Decision making               | <ul style="list-style-type: none"> <li>Difficulty choosing between options</li> <li>Where to go</li> <li>What to do next</li> </ul>   |
| Concentration                 | <ul style="list-style-type: none"> <li>Easily distracted by other people, noises, movement, objects, etc.</li> <li>Staying focussed on a task until successful completion</li> <li>Inability to filter information – becomes distracted easily</li> </ul>   |
| Motivation                    | <ul style="list-style-type: none"> <li>Desire to act</li> <li>Seeing the purpose of an action</li> <li>Changing the actions once it started</li> </ul>  |
| Behavioural/Emotional Control | <ul style="list-style-type: none"> <li>Making sense of the world</li> <li>May be afraid to move</li> <li>Reaction to frustration and fear</li> <li>Misinterpret the intentions of others</li> <li>Depression</li> <li>Easily overwhelmed</li> <li>Anxiety</li> <li>Pain perception</li> <li>Agitation</li> <li>Aggression</li> <li>Wandering</li> <li>Intolerance to stress</li> <li>Sundowning</li> <li>Hallucinations</li> <li>Disinhibited behaviours</li> </ul> |
| Social behaviour              | <ul style="list-style-type: none"> <li>Misinterpret the actions of others</li> <li>Waiting</li> <li>Misinterpret environmental cues</li> </ul>  |

| Function                             | Challenges   |
|--------------------------------------|--|
| Perception/Spatial awareness/ Gnosis | <p>Difficulty interpreting figure ground which can lead to falls e.g., missing a chair</p> <p>Difficulty recognising object and/or function</p> <p>Misinterpretation of changes in texture/colour of decor</p> <p>Sensitive/insensitive to touch, taste, smell, hearing , vision</p> <p>Difficulty with construction/drawing</p> <p>Difficulty reading/interpreting maps</p> |
| Patterns of movement                 | <p>Difficulty adapting to changes in position</p> <p>Difficulty carrying out learnt patterns of movement</p> <p>Difficulty learning new tasks</p> <p>Difficulty adapting learnt patterns to new situations</p>   |
| Ideomotor Apraxia                    | <p>Inability to translate an idea into motion. There is no loss of the ability to perform the action automatically, such as tying shoelaces, but the action cannot be performed on request (Mosby, 2002)</p>   |
| Ideational Apraxia                   | <p>A condition where the conceptual concept is lost. There is no loss of motor movement but the person is unable to formulate a plan of movement and does not know the proper use of an object because of lack of perception of its purpose (Mosby, 2002)</p>  |

Adapted from the WADTSC Long definition of Dementia handout (Freegard, 2008) and Hierarchic Dementia Scale (Cole and Dastoor, 1996)

## Progression of Dementia

The symptoms of dementia can vary widely with different diseases and different people. This section is intended to give a general and brief overview of the stages /progression of dementia. Further information is available from the Alzheimer's Association at [www.alzheimers.org.au](http://www.alzheimers.org.au), from Alzheimer's Disease International at [www.alz.co.uk](http://www.alz.co.uk)

The Department of Health and Ageing publication 'Dementia- The Caring Experience', (2006) or from the Palliative Care Dementia Interface: Enhancing Community Capacity publication 'Dementia information for carers, families and friends of people with severe and end stage dementia' (2007).

### Early Stage

The early stage is often overlooked or viewed as the normal ageing process as the early signs of dementia are very subtle and vague and may not be immediately obvious. Often this stage is only apparent in hindsight.

The person may:

- have significant memory loss – particularly for things that have just happened
- have difficulty learning and retaining new information
- have problems talking properly (language problems)
- repeat the same questions and stories or lose the thread of their conversation
- lose valuables, keys, wallet or blame others for “stealing” lost items
- not know the time of day or the day of the week
- confusion
- have difficulty remembering the names of friends, family, home address
- become lost in once-familiar places (spatial awareness)
- difficulty handling complex tasks
- show poor judgment and make poor decisions (reasoning)
- become inactive and unmotivated
- show mood changes, depression or anxiety
- react unusually angrily or aggressively on occasion
- show a loss of interest in hobbies and activities
- withdraw socially

- be unwilling to try new things
- be unable to adapt to change
- be slower to grasp complex ideas and take longer with routine jobs
- become more self-centered and less concerned with others and their feelings
- be more irritable or upset if they fail at something
- have difficulty handling money.

### **Moderate Stage**

At this stage the problems are more apparent and disabling. The person will experience difficulty with day to day living and can no longer live alone without problems and poses numerous safety concerns.

The person may:

- be more forgetful of recent events. Memory for the distant past generally seems better, but some details may be forgotten or confused
- be confused regarding time and place
- become lost if away from familiar surroundings
- forget names of family or friends, or confuse one family member with another
- have difficulties with normal ADL's
- have difficulty with cooking, cleaning and shopping
- safety hazards such as forget saucepans and kettles on the stove
- may leave gas unlit
- wander around streets, perhaps at night, sometimes becoming lost
- behave inappropriately, for example going outdoors in nightwear
- have hallucinations and see or hear things that are not there
- become very repetitive
- be neglectful of hygiene or eating and would benefit from assistance with these areas
- become angry, upset or distressed through frustration
- have increased difficulty with speech
- become dependent on their family or caregivers
- experience disturbed sleep patterns
- have communication difficulties.

### **Advanced Stage**

At this third and final stage, the person is severely dependent and requires total care.

The person may:

- be unable to remember occurrences for even a few minutes, for instance forgetting that they have just had a meal (or that they haven't)
- have difficulty understanding what is going on around them
- lose their ability to understand or use speech
- have bladder and bowel incontinence
- experience recurrent infections
- show no recognition of friends and family
- need help with eating, washing, bathing, toileting and dressing
- have difficulty swallowing/eating which may lead to malnutrition
- fail to recognise everyday objects
- be disturbed at night
- be restless, perhaps looking for a long-dead relative
- be aggressive, especially when feeling threatened or closed in
- display inappropriate behaviour in public
- have uncontrolled movements
- have difficulty walking, eventually perhaps becoming confined to a wheelchair
- immobility will become permanent, and in the final weeks or months the person will be bedridden.

## **Delirium and Dementia**

Delirium needs to be ruled out before a clinical diagnosis of dementia is determined. Risk factors for delirium include age, dementia, severe illness, alcohol abuse, depression, reduced ADL's, male gender, abnormal sodium levels, hearing impairment and visual impairment (Weber, Cloverdale, and Kunik, 2004). Accurate identification of delirium is critical as there is some concern that the risk of permanent brain damage increases the longer the condition goes untreated. Delirium often accompanies physical illness in older adults e.g., surgery, urinary tract infection, pneumonia, cerebrovascular disease, congestive heart failure, fever, dehydration and hypoglycaemia. Delirium develops over a short period of time (hours to days), involves a disturbance in consciousness along with cognitive difficulties and the clinical manifestations can fluctuate throughout the day. Activity levels may be increased or decreased, restlessness may occur, the persons sleep wake cycles may be reversed, they may experience rapid fluctuations in their emotional state and their speech can be rapid, rambling or incoherent (Flood and Buckwalter, 2009).

Delirium superimposed on dementia is less likely to be recognised and treated than is delirium without dementia. A person with dementia is 4-5 times more likely to experience delirium than the general population. Delirium and dementia usually increase the risk of longer hospital admission, further decline in cognitive and physical functioning, re-hospitalisation, placement in an aged care facility or death (Fick and Mion, 2007).

## **Mental Health and Dementia**

Dementia, delirium and depression are the three most prevalent psychiatric disorders in older people (Pountney, 2007). Alcohol and substance abuse/misuse are under diagnosed in the older population (Flood and Buckwalter, 2009). The numerous behavioural symptoms and problems associated with dementia have been discussed earlier in this chapter. Often clinicians focus their diagnostic assessments on impairment in memory and other cognitive functions, and loss of independent living skills. For carers, it is the behavioural and psychological symptoms linked to dementia, typically occurring later in the course of the disease that are most relevant and have most impact on their quality of life. Behavioural and psychological symptoms are an important cause of strain on carers, and a common reason for institutionalisation as the family's coping reserves become exhausted (Alzheimers Australia, 2010a). It is important to refer to appropriate community and mental health services to assist families/carers with appropriately dealing with the issues.

## Assessments Utilised in Dementia Care

The following table has been included to provide a concise overview of suitable assessments to screen for cognitive impairment or to determine a person's functional level. Please refer to the assessment manuals or web pages listed in text for further details or discuss with your senior for further guidance regarding suitability and implementation. Consider the differing amounts of time taken to complete each of the cognitive assessments.

**Table 3: Assessments Utilised in Dementia Care**

| Assessments used by OT's                        | When are they used  | Score and cut offs   | Reliability and Validity   |
|---|---|--|--|
| Mini Mental State Examination (MMSE) (Folstein) | <ul style="list-style-type: none"> <li>most widely utilised screening tool.</li> <li>mandatory at OPH and other facilities in WA</li> </ul> | <ul style="list-style-type: none"> <li>26-30 (Cognitive impairment may still be present - especially in Fronto-temporal dementia and PD) - may require further assessment.</li> <li>20-25 mild cognitive impairment</li> <li>10-19 moderate cognitive impairment</li> <li>0-9 severe cognitive impairment (Molloy, 2000)</li> <li>a score of 23 or less in an individual with more than 8 years education indicates cognitive impairment (Folstein, Folstein, McHugh, and Fanjiang, 2001)</li> </ul> | <ul style="list-style-type: none"> <li>reliable and valid</li> <li>performance can be affected by age, education and literacy levels, cultural background i.e. English as a second language</li> <li><a href="http://www.minimental.com">www.minimental.com</a></li> </ul> |
| Rowland Universal Dementia Scale (RUDAS)        | <ul style="list-style-type: none"> <li>screening tool</li> <li>english as second language or low levels of education/literacy</li> </ul>    | <ul style="list-style-type: none"> <li>23 is cut off indicating cognitive impairment</li> </ul>  | <ul style="list-style-type: none"> <li>excellent inter-rater and test retest reliability and validity</li> </ul>   |

| Assessments used by OT's | When are they used   | Score and cut offs   | Reliability and Validity  |
|--------------------------|--|--|---|
| COGNISTAT                | <ul style="list-style-type: none"> <li>▪ screening tool</li> <li>▪ borderline MMSE/ RUDAS score</li> <li>▪ identifying basic strengths and weaknesses so that further tests (if necessary) can be selected</li> </ul>  | <ul style="list-style-type: none"> <li>▪ the examiner tallies the points earned in each section, and plots them on the cognitive status profile. Numerical scores are described to fall within the normal or impaired range. The impaired range is broken down into mild, moderate and severe</li> <li>▪ normative data exist for adolescents, and adults in three age groups: 60–64, 65–74 and 75–84</li> </ul> | <ul style="list-style-type: none"> <li>▪ high level of reliability and validity</li> <li>▪ training is required prior to administering assessment</li> </ul>                  |
| Clock drawing test       | <ul style="list-style-type: none"> <li>▪ simple screening tool</li> <li>▪ used with people who have executive cognitive dysfunction and a normal MMSE</li> <li>▪ measures a range of cognitive functions including visuospatial construction which is a skill known to be impaired in the early stages of dementia (Schramm et al., 2002)</li> <li>▪ used by ACAT</li> </ul> | <ul style="list-style-type: none"> <li>▪ a normal clock suggests that a number of functions are intact and contributes to the weight of evidence that the patient may, for example, be able to continue independently. Alternatively, a grossly abnormal clock, is an important indicator of potential problems warranting further investigation or resource (Braunberger, 2001)</li> </ul>                      | <ul style="list-style-type: none"> <li>▪ good reliability</li> <li>▪ more sensitive in identifying cognitive impairment than the MMSE (Flood and Buckwalter, 2009)</li> </ul> |

| Assessments used by OT's                      | When are they used   | Score and cut offs   | Reliability and Validity   |
|---|--|--|--|
| Hierarchic Dementia Scale (HDS)               | <ul style="list-style-type: none"> <li>▪ to determine a baseline and monitor a person's cognitive function.</li> <li>▪ to assist with the formulation of care plans.</li> </ul>  | <ul style="list-style-type: none"> <li>▪ consists of 20 subscales each worth a maximum of 10, therefore the maximum obtainable score is 200.</li> <li>▪ 160-190 mild dementia</li> <li>▪ 159-42 moderate dementia</li> <li>▪ 40-0 severe dementia</li> </ul>   | <ul style="list-style-type: none"> <li>▪ sensitive to change over time</li> <li>▪ high inter rater reliability, test-retest reliability, concurrent validity and internal consistency (Cole and Dastoor, 1996)</li> </ul>  |
| Assessment of Motor And Process Skills (AMPS) | <ul style="list-style-type: none"> <li>▪ an occupational therapy specific standardised assessment.</li> <li>▪ an observational assessment that is used to measure the quality of a person's occupational performance objectively.</li> <li>▪ can be used with all persons without regard for their diagnosis or reasons for clients' disability.</li> <li>▪ useful for assisting with determining return to independent living and guardianship hearings.</li> </ul> | <ul style="list-style-type: none"> <li>▪ AMPS is designed to allow the person evaluated to choose what ADL task he or she will perform for the evaluation based on (a) the familiarity and relevance of the task to the clients daily life needs, (b) the degree of challenge that the tasks offer the client.</li> <li>▪ 16 ADL motor and 20 ADL process skill items</li> <li>▪ the person being assessed chooses two familiar, and life-relevant ADL tasks to complete.</li> <li>▪ administration of AMPS requires no special equipment and can be administered in any task relevant setting within 30-40minutes.</li> </ul> | <ul style="list-style-type: none"> <li>▪ fully standardized, internationally and cross-culturally on 46,886 subjects</li> <li>▪ valid reliable and sensitive assessment tool.</li> <li>▪ intense training required prior to administering assessment.</li> <li>▪ to be an AMPS assessor AMPS training and rater calibration workshop must be completed and passed. This is a 5 day training workshop and includes theoretical and practical components including rater calibrations of 10 live observations.</li> <li>▪ some staff at OPH are trained</li> </ul> |

| Assessments used by OT's              | When are they used  | Score and cut offs  | Reliability and Validity   |
|---------------------------------------|---|---|--|
| Modified Barthel Index (MBI)          | <ul style="list-style-type: none"> <li>measure dependence in ADLs</li> <li>currently completed on admission and discharge to wards at OPH (if appropriate)</li> </ul>                     | <ul style="list-style-type: none"> <li>measures a person's performance in 10 ADLs with a maximum score is 100.</li> <li>lower score the higher the level of dependence</li> </ul> | <ul style="list-style-type: none"> <li>good reliability and validity</li> <li>high inter-rater reliability</li> </ul>                        |
| Functional Independence Measure (FIM) | <ul style="list-style-type: none"> <li>assesses physical and cognitive disability and focuses on the burden of care (Turner-Stokes, Nyein, Turner-Stokes, and Gatehouse, 1999)</li> </ul> | <ul style="list-style-type: none"> <li>18 items scored 1-7 for level of independence. Scores can range from 18 to 126 with higher scores indicating more independence</li> </ul>  | <ul style="list-style-type: none"> <li>good reliability and validity</li> <li>requires training prior to administering assessment</li> </ul> |

| Assessments used by other professions    | When are they used  | Score and cut offs  | Reliability and Validity   |
|--|---|---|--|
| IQ code (Jorm, 2004)                     | <ul style="list-style-type: none"> <li>▪ screening tool</li> <li>▪ useful for individuals who are unable to undergo cognitive testing due to acute illness, lack of cooperation or for screening in populations with low levels of education/literacy and language proficiency</li> </ul> | <ul style="list-style-type: none"> <li>▪ score from 1-5</li> <li>▪ community samples cut off range is 3.3-3.6</li> <li>▪ inpatient samples the cut off range is 3.4-4.0</li> <li>▪ scores above these cut offs indicates some cognitive decline has occurred</li> </ul> | <ul style="list-style-type: none"> <li>▪ highly reliable</li> <li>▪ validity can be affected by age, education, rapport with subject</li> </ul>                                    |
| Cambridge Cognitive Examination (CAMCOG) | <ul style="list-style-type: none"> <li>▪ standardised assessment used to measure the extent of dementia and to assess the level of cognitive impairment</li> </ul>  | <ul style="list-style-type: none"> <li>▪ total score ranges from 0-107</li> <li>▪ scores lower than 80 are considered indicative of dementia</li> </ul>   | <ul style="list-style-type: none"> <li>▪ reliable and validity however no studies have examined the reliability and validity of the assessment with clients with stroke</li> </ul> |



## Occupational Therapy and Dementia Care: Standards, Guidelines, and Evidence Based Practice

From the outset, the Osborne Park Hospital OT project team wanted this booklet to be evidence based. The aim was to develop a clinical guideline for Osborne Park Hospital OT practitioners who are working in hospital and community settings. The first task of the project team was to identify relevant standards and guidelines on dementia care. Throughout the project, the project team sought evidence based information to underpin the booklet, so it would be a useful clinical guide for OT's working with clients with dementia.

### Standards and Guidelines

The National Health and Medical Research Council (NHMRC) states that Standards and Guidelines are sets of non-mandatory rules, principles, and recommendations for procedures or practices in a particular field (2007). Clinical practice guidelines are defined as 'systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances'(Field and Lohr, 1990).

The Clinical Guidelines for Stroke Management developed by the National Stroke Foundation is an example of a NHMRC approved guideline. These have proven to be an excellent resource for OT's working in stroke management. The project team contacted the NHMRC to identify if there was a similar guideline for dementia management, and were advised that they are "not aware of any specific Australian dementia guidelines in development or in circulation at the moment, although they understand the revised Guidelines for a Palliative Approach in Residential Aged Care is due for completion in 2012 will have a dementia component" (Duggan, 2011).

Whilst the team did not identify a NHMRC clinical guideline on dementia care, it did locate a number of relevant Australian and International standards. A database search conducted using the WA Health Department's online resources identified the following protocols:

- Management of patients with dementia. A national clinical guideline. Edinburgh. Scottish Intercollegiate Guidelines Network (Scotland) (2006)
- Dementia: The NICE-SCIE guideline on supporting people with dementia and their carers in health and social care (National Clinical Practice Guideline Number 42). The British Psychological Society and The Royal College of Psychiatrists (2007).
- Dementia Guidelines for Early Detection, Diagnosis and Management of Dementia. The American Geriatrics Society (2010).
- Guidelines for the Care of Patients with dementia in General Practice The Royal Australian College of General Practitioners (2003).
- Clinical Practice Guidelines and Care Pathways for People with Dementia Living in the Community. Queensland University of Technology (2008)
- Nonpharmacologic and pharmacologic therapy for mild to moderate dementia (Hogan et al., 2009).

The team also identified the following Australian guidelines for residential care:

- Quality Dementia Care Practice in Residential Aged Care Facilities for All Staff. Alzheimer's Australia (2007a).
- Quality Dementia Care Standards: A Guide to Practice for Managers in Residential Aged Care Facilities. Alzheimer's Australia (2007b).

## Review of Guidelines

The Osborne Park Hospital OT project team reviewed the above guidelines with the aim of identifying standards, guidelines, or recommendations relevant to OT practice with inpatients, or in the community.

Titles and abstracts identified from the searches were checked by two reviewers. If it was clear that the study did not refer to a clinical protocol for dementia management relevant to OT practice, it was excluded. If it was not clear from the abstract and title, then the full text was obtained for reviewer assessment. Whilst this review does not discuss the medical and pharmacological management of dementia, it acknowledges that medical assessment for the purposes of early detection, diagnosis, and pharmacological management is integral to the successful management of the individual with dementia.

The project team identified the following key recommendations relating to OT practice from the guidelines when working with people with dementia or their families:

### Assessment of Dementia

- Referral to Geriatrician, Geriatric Psychiatrist, Neurologist or other medical professional may be necessary (Abbey, et al., 2008)
- A clinical history should be supplemented by an informant where possible (Waldemar et al., 2007).

Recommended assessment techniques include:

- brief cognitive assessment instruments that focus on limited aspects of cognitive function e.g., Clock Drawing Test, Time and Change Test (may be considered when screening for dementia) (The American Geriatrics Society, 2010)
- neuropsychiatric batteries (particularly those that focus on memory function) (i.e., Neuropsychologic Battery, Mattis Rating Scale, Halifax Mental Status Scale, and Fuld Object Memory Test), (The American Geriatrics Society, 2010)
- interview techniques (i.e., Blessed Roth Scale, Clinical Dementia Rating, Informant Questionnaire on Cognitive Decline in the Elderly) (The American Geriatrics Society, 2010).

### **Coordination of Services**

- provide information on services available and how agencies cooperate (Abbey, et al., 2008; The British Psychological Society and The Royal College of Psychiatrists, 2007)
- Home and Community Care (HACC)
- Community Aged Care Package (CACP)
- The National Respite for Carers Program (NRCP)
- Extended Aged Care at Home (EACH)
- Extended Aged Care at Home-Dementia (EACH-D)
- Dementia Behaviour Management Advisory Services (DBMAS)
- The National Dementia Support Program (NDSP)
- hospital care
- low and high care residential facilities
- ensure a continuum of care (diagnosis to palliative phase) (Abbey, et al., 2008).

### **Supporting the person with dementia**

Maintenance of function:

- assessment of the patient's ability to manage personal care and other ADL's (e.g., using the telephone, shopping and banking) are essential (The Royal Australian College of General Practitioners, 2003)
- care plans should address ADL's and aim to improve function and maximise independence (The British Psychological Society and The Royal College of Psychiatrists, 2007)
- urinary incontinence should be managed through scheduled toileting, prompted voiding and behaviour management techniques (The American Geriatrics Society, 2010)
- functional independence is improved by graded assistance, practice, and positive reinforcement (The American Geriatrics Society, 2010; The British Psychological Society and The Royal College of Psychiatrists, 2007)
- an OT home visit and arrangement of relevant home modifications should be completed to improve function and independence (Abbey, et al., 2008; The British Psychological Society and The Royal College of Psychiatrists, 2007).

#### Falls Prevention:

- clients with dementia have an increased risk of falls (especially those with prior falls, epilepsy, multiple medications, wandering, and delirium) (Abbey, et al., 2008)
- OT assessment, intervention and environmental modification to reduce the risk of falls (Abbey, et al., 2008).

#### Legal Issues:

- decision making capacity should be regularly assessed (Abbey, et al., 2008). A diagnosis of dementia is not synonymous with incapacity (Waldemar, et al., 2007)
- provide information on Enduring Power of Attorney, Advance Health Directives and Guardianship (Abbey, et al., 2008; The Royal Australian College of General Practitioners, 2003)
- financial competency needs to be considered (The Royal Australian College of General Practitioners, 2003).

#### Driving:

- driving ability may be impaired. The person with dementia (and their family and carer) should be advised of (a) how their condition affects driving and (b) the mandatory reporting of their diagnosis to the Department of Transport (Abbey, et al., 2008; The Royal Australian College of General Practitioners, 2003; Waldemar, et al., 2007)
- a persons capacity to drive can be formally assessed by Driver Assessment services (Abbey, et al., 2008; The Royal Australian College of General Practitioners, 2003).

#### Non-pharmacological Interventions:

- non-pharmacological interventions include a variety of activities, techniques or therapies. Available evidence is limited as to the efficacy of these interventions (Abbey, et al., 2008)
- there is fair evidence to suggest that recreational activities and cognitive stimulation should be introduced as part of a 'healthy lifestyle' to enhance quality of life and well-being (Hogan, et al., 2009; Scottish Intercollegiate Guidelines Network, 2006; The British Psychological Society and The Royal College of Psychiatrists, 2007).

There is some evidence that the following have a positive effect:

- reminiscence therapy improved cognition in some studies (Abbey, et al., 2008)
- exercise training improved fitness, physical and cognitive function and behaviours (Abbey, et al., 2008)
- behaviour management reduced aggression and depression (Abbey, et al., 2008)
- music therapy reduced behaviours of concern (Abbey, et al., 2008).

### **Supporting the Carer**

Education:

- short and long term education programs should be offered to carers to increase knowledge and satisfaction (Abbey, et al., 2008; The American Geriatrics Society, 2010)
- intense education may delay long-term placement (The American Geriatrics Society, 2010).

Support groups:

- family should be provided with information on support groups (The British Psychological Society and The Royal College of Psychiatrists, 2007)
- support groups may delay long-term placement (The American Geriatrics Society, 2010).

Respite care:

- referral to respite or centre based care may delay long-term placement (Abbey, et al., 2008).

Financial assistance:

- many carers are eligible for the Carer Payment or Carer Allowance through Centrelink (Abbey, et al., 2008).

Impact of caring on the carer-client relationship:

- the client with dementia may have decreased/increased sexual interest (hyper-sexuality is usually associated with frontal lobe dementia) (Abbey, et al., 2008)
- partners may find their role changing from a sexual partner to a non-sexual carer role (Abbey, et al., 2008)
- health professionals ability to be open in discussion about sexual issues is helpful (Abbey, et al., 2008).

Abuse:

- people with dementia are at increased risk of abuse (emotional, financial, physical and sexual abuse or neglect) (Abbey, et al., 2008; The Royal Australian College of General Practitioners, 2003)
- the individual with dementia can also be an abuser (The Royal Australian College of General Practitioners, 2003).

## Evidence Based Practice

Evidence Based Practice (EBP) is using best research evidence available along with clinical expertise and patient values to inform decisions regarding clinical practice (Sackett, Richardson, Rosenberg, and Haynes, 2000).

The Osborne Park Hospital OT team conducted a literature review to identify EBP articles or books specifically focusing on OT clinical practice for people with dementia living in the community or in a hospital setting. No evidence was obtained that focus on one specific intervention when it comes to OT for people with dementia

Two OT home visiting programs for people living at home with dementia were sourced which had been studied as randomised control trials (RCT's), one in the United States (Gitlin and Corcoran, 2005) and one in Netherlands (M. Graff, 2008; M. J. L. Graff et al., 2007). The results of both these programs indicated that OT intervention for patients with dementia living at home had been effective. These programs are not able to be replicated by Osborne Park Hospital OT as they are labour intensive and involve up to 8 home visits over a 12 month period. This level of service is not within the scope of the Osborne Park Hospital OT service. We included and referenced relevant information from these two studies in this booklet.

Osborne Park Hospital OT purchased Laura Gitlin's excellent book, Occupational Therapy and Dementia Care. The Home Environmental Skill-building Program for Individuals and Families from the American Occupational Therapy Association website, and recommends this to OT's interested in further information.

The Osborne Park Hospital OT project team also sought and included expert opinion from our Consultant Geriatricians and other reputable sources in the booklet, including:

- the Alzheimer's Australia web page <http://www.alzheimers.org.au/>
- the 'Living with Dementia, how the environment, technology and you can help' web page <http://www.dementiatechnology.org.au/>
- Helpful Handbook for Memory Loss (Independent Living Centre and Alzheimer's Australia, 2007)
- Promoting mobility for people with dementia. A problem solving approach (Oddy, 2003).
- ANZSGM (Australian / NZ Society of Geriatric Medicine) Position Statements – which are updated regularly.
- Occupational Therapy Toolkit. (Hall, 2011). Osborne Park Hospital OT department has a copy.
- WADTSC webpage <http://cra.curtin.edu.au/wadtsc/>
- Baptist Community Services - NSW and ACT web page <http://www.bcs.org.au/AgeCare/DementiaCare.aspx>
- Alzheimer's Disease International's web site <http://www.alz.co.uk/>



## Evidence Based Practice: Occupational Therapy Strategies

The majority of people living with dementia live at home and wish to do so for as long as possible. Remaining at home can be assisted through the use of therapeutic interventions including carer education, home modifications and linkage to appropriate community services. Any decision to change the environment or use technology should follow a person centred approach. Focusing on a person's strengths and abilities will have a positive impact on their self esteem, daily life and acceptance of the suggested interventions.

Every person with dementia is an individual and as such will present with a unique clinical picture. All clinicians working with people with dementia should be mindful that the person is not only experiencing the symptoms of dementia but also the normal physical signs of ageing such as reduced vision, strength, hearing loss and poor mobility. The following approaches to managing dementia will not work for all scenarios. Included in this booklet, are strategies to inform clients, care providers or family members about suitable options/alternatives that may assist the person to remain living independently for as long as possible or to assist with reducing the level of stress experienced by the carer/family member. A section specifically looking at hospital environments has also been included as a reference for those Occupational Therapists working on the wards at Osborne Park Hospital.

Involving the person with dementia in the decision making process and where possible testing the item with them beforehand can increase the acceptance of using the item/modification. Ongoing evaluation should be adopted to ensure that any technology or strategy utilised remains appropriate.

Many of the interventions recommended in the next section are sourced from the two EBP OT programs previously discussed in chapter four (Gitlin and Corcoran, 2005; M. J. L. Graff, et al., 2007) as well as The Alzheimer's Australia web page <http://www.alzheimers.org.au/> and the Living with Dementia, how the environment, technology and you can help, web page <http://www.dementiatechnology.org.au/>. Other sources are referenced in text.

## **Home Environment**

It is widely recognised that a building and the environment can have a significant impact on a person with dementia. The environment can be supportive or it can hasten a person's deterioration (O'Sullivan, 2008). People with dementia need to see their environment clearly in order to understand directions and be able to use landmarks to help with way finding (Pollock, 2008). People with dementia may misinterpret aspects of their environment such as reflections off shiny floors appearing slippery or wet, seeing shadows as objects, seeing objects as shadows, or being unable to distinguish small objects or detail on large objects (Victorian Government Health Information, 2010). These misinterpretations may lead to increased risk of falling, increased dependency on others and lowered life expectancy (Pollock, 2008). Features such as seating, flooring and wall coverings, lighting and handrails often pose barriers to people living with dementia. Excess noise, glare or sensory overload may result in agitation or frequent problem behaviours. Environmental design has a major impact on wellbeing, problem behaviours such as wandering or agitation, activity levels, independence and nutrition (Briggs, 2004).

### **Use of colour**

Older adults experience difficulty with distinguishing colours. Ageing causes colours to be seen through a yellowing film, it is thought that yellow is the last colour perception to be lost by people with dementia. Colour depth and brightness appear different under different light. Visual cues can be utilised to aid orientation and maximise a person's function. It is best to use colours from different spectrums. There is a higher incidence of cataracts in older persons, which can also change colour and perception of the environment.

#### Tips for colour:

- remove bold/busy patterns on wallpaper, curtains or floor covering. Patterns in carpet can be interpreted as holes, steps etc.
- contrasting colours for walls and doorways to highlight boundaries of each room
- colour contrast between furniture and floor
- colour contrast between chair seats and table tops
- colour contrast between counters, sinks and floors
- use matte paint instead of gloss to reduce glare
- colour can be used to highlight or disguise key locations around the home.

#### Signage

Signage can be used to emphasise what is important.

#### Tips for signage:

- big
- bold
- contrasting
- symbols and words
- culturally and age appropriate
- eye level e.g., on a door
- don't laminate or use gloss paint as these mediums increase glare and reduces a person's ability to read the sign. Low glare laminate is available from some office supply stores.

## Lighting

As we age our ability to focus quickly and adapt to changes in light conditions diminishes. People aged 80 to 85 require three to five times more light than people in their twenties (Burton, 2010). Low light levels or glare may make it more difficult for a person with dementia to identify contrast and judge depth accurately. The person may only see part of an object or not see the object at all. Poor lighting can increase a person's risk of falls and may also lead to changes in behaviour.

Possible problems or concerns:

- bruises or abrasions from walking into furniture or fixtures
- difficulty finding their way around or locating items
- disorientation from glare
- distress or agitation from reflections and movement in windows.

Tips for lighting:

- use as much natural daylight as possible
- sheer curtains on windows blocks daytime glare and night time reflections but allows light in
- vertical and horizontal blinds allow small slits of light in and this can be disorientating or distracting
- create sitting areas close to windows
- reduce window obstructions
- encourage people to go outside
- aim for uniform lighting throughout transition areas to help eliminate shadows
- leave lights on during day in places where there isn't sufficient day light
- increase lighting where people need it
- avoid using clear light bulbs or light fittings with a shade as they reflect glare and create shadows
- change the globes to ones that most resemble daylight. The Victorian Health Department (2010) recommends globes with a colour rendering index of 100 or 3000-3500 degrees Kelvin
- use wall mounted lighting to brighten hallways/corridors

- use table or floor lamps to illuminate seating spaces
- use automatic lighting where possible
- use night lights (small lights that plug into the power point and come on at night and turn off during the day) to illuminate passageway or the route to toilet
- a sensor light adaptor or movement activated nightlight are useful for illuminating path to toilet area
- an automated light switch works on a timer or infrared movement detector. It must be installed by a licensed electrician
- bed sensor lamp is a system where a sensor is placed on the bed and when the person gets up from bed the light automatically turns on. It can be programmed to stay on for a set amount of time.
- automated home system: the lighting in the bathroom or toilet can be operated manually or be programmed for night time use to come on at 30% brightness automatically once movement is detected in the bedroom
- smart wiring allows for the lights, sensors and other equipment in the home to be monitored, controlled and programmed to suit the user. This could include sending messages to a remote location, perhaps a call centre or family member, turning lights on when movement is sensed during the night, or providing lights and blind control for security purposes when the resident is not home.

#### Electrical safety tips:

- clearly identifiable light switches (use contrast or labels)
- electrical cord clips or tubing to keep them safe, tidy and disguised
- safety switches/circuit breakers to prevent electrocution
- replace long electrical cords on appliances with coiled or retractable ones.

## Entrances and Exits

- mailbox: no junk mail sticker, lockable
- remove large bushes and shrubbery from front and rear entrances that block the view of the home
- provide high hue and value contrast at the edges of stairs and level changes so they are easy for people to see which may minimise falls
- pathways, stairs and ramps: level, sheltered, clearly lit, non-slip, contrasting edges, visible both day and night
- handrails
- disguising exits with door murals, handle covers
- secure fencing with a gate
- security screens on doors and windows
- secure handrails, broken steps and loose carpeting in and around the home
- securing the home with emergency access e.g., automatic gates, key safe, security door chain with capacity for key access for use in an emergency
- movement activated sensor lights at main entrances
- remote locking capacity
- place bright stickers on glass doors below eye level to minimise chance of person walking into them
- have all the locks keyed alike to operate with one master key and get duplicates made for family and trusted neighbours
- key holders or key safes e.g., 'Storakey' <http://www.ilcaustralia.org/home/search4.asp?state=TAS&page=8&MC=32&MinC=15> with pin number codes can be installed in a discreet place outside the house so that trusted service providers and neighbours can gain access to the house in an emergency if the person cannot find their key to open the door
- keyless door locks (biometric door lock): a door lock that unlocks after reading your finger print after it has been programmed into the device
- video intercom system which allows the person to view visitors and then determine if they should let them in. If the individual is unable to get to the door, entry can be enabled via the push of a button.

## Flooring

- avoid heavily patterned floor coverings as they can create confusion and agitation. People experiencing difficulties with depth perception will find highly patterned floor coverings difficult to walk on and may experience a loss of independence, fear of falling or confusion
- choose flooring for wet areas with a high coefficient of friction (COF) ideally above 80 (Calkins, 2001)
- waxed surfaces such as highly polished vinyl creates excess glare and may look to be slippery which could result in people becoming fearful of falling
- changes in flooring materials can also look like steps, or changes in depth
- do not take floor coverings up the walls as this creates a problem with determining where the floor ends and the wall begins.

## Noise

Hearing loss is the third most common chronic illness amongst the elderly.

- eliminate intercoms as hearing voices that are unattached to people can be frightening and cause agitation
- reduce distractions by lowering volume on radios or televisions
- use sound absorbing decorating materials such as carpets and drapes.

## Temperature

- install insulation in the ceiling or wall cavities
- fitting shutters or awnings to windows that are exposed to summer sun
- fitting heavy curtains to reduce heat lost in winter and heat gained in summer
- closing off parts of the home that are susceptible to extremes
- ceiling heater/extractor fans for bathroom
- split system air conditioning
- oil filled column heaters.

### **Lounge and Living Area**

- have a set place for regularly used items
- minimise clutter
- a square, rather than round, table provides added cues for seating and eating space
- plastic guards on corners of tables or furniture to prevent injury
- labeled photos or memorabilia can provide memory triggers that reinforce the persons sense of identity and provide pleasure
- reduce glare on the TV or computer screen by placing these items in an area that gets the least amount of glare, install net curtains, move light sources that are contributing to glare if possible
- hearing amplifier
- power point safety covers or electrical cord clips
- select fire retardant materials for window coverings
- simplified and universal remote controls.

### **Stairways**

- paint or glue a narrow contrasting strip on the edge of each step
- paint the wall of the stairwell a contrasting colour from the steps
- illuminate stairs at all times
- install handrails
- secure loose floor coverings, broken steps or loose railings
- keep stairways free of objects and clutter
- utilise safety gates where applicable.

### **Garages and sheds**

- pathways should be: level, sheltered, clearly lit, non-slip, contrasting edges, visible both day and night
- minimise clutter
- remove flammable or potentially dangerous items
- remove external locks to ensure the person cannot accidentally lock themselves in
- hinges to allow removal of doors in an emergency
- install lockable cabinets or use padlocks to deny access to dangerous items
- use a sound and movement monitor to allow supervision from a distance.

### **Storage**

- space bag to store non-seasonal clothing or items in a airtight seal
- leave all toxic substances in their original container and lock them away to eliminate the possibility of ingestion
- lockable cabinets/drawers or alarm/bells on cabinets and drawers to alert carer that they are being opened
- utilise clear labels/signs
- medication systems (see section on medication management)
- safe storage of documents/lock up safe
- use Mag locks (discreet magnetic locks) on cupboards or drawers. Mag locks will work on wood, plastic, laminated or ceramic tiled surfaces.

## **Bathroom**

- prescribe any suitable aids or appliances to assist with bathing e.g., shower chair, grab rails, long handled aids
- install window coverings to eliminate glare in bathroom or passageways leading to bathroom
- ensure there is adequate lighting over the sink and bench tops
- use safety gates on stairs where indicated and paint narrow strip at edge of each step
- paint door of bathroom a bright eye catching colour
- modify doorways for increased accessibility
- remove or change lock on bathroom door
- remove shower screens where practicable and replace with shower curtain
- install screens or curtains to hide distracting items from view
- install bells or alarms on doors, cabinets and drawers to alert carers when they are being opened.

## **Kitchen and Dining Area**

- modify doorways for increased accessibility
- install or change lock on kitchen door
- install locks on kitchen cupboards e.g., Mag locks
- install a shut off switch on electric or gas lines
- adjust height of chairs or tables to provide optimal seating
- install a screen or curtain to hide distracting items
- install bells or alarms on doors, cabinets and drawers to alert carers when they are being opened
- store regularly used items between shoulder and hip height, making items easier to see and reach
- install a barn door. Having a half door enables the person to still look into the kitchen but acts as a barrier to wandering into kitchen
- signs on cupboards
- remove cupboard doors or replace with transparent doors to allow ease of viewing contents
- shallow depth fridges can assist with easily viewing and reaching contents which may lead to reduced incidence of food being hidden and spoiling.

## Seating

- chairs with arm rests that are flat, broad and extend from the back of the chair past the front of the chair
- chairs with an opening in the front (lower section) to allow people to put their heels under the chair to assist with the transfer out of the chair
- avoid chairs or sofas with upholstery to the floor as this increases the risk of falls
- use chairs that have a flexed back to allow some motion and good lumbar support
- avoid casters as they increase the risk of falls
- to aid people who have visual impairment or perceptual difficulties to locate a chair, utilise a chair that is a plain colour and contrasts with the flooring and walls
- select coverings that are continence proof, provide good colour contrast with the floor and are comfortable.

Useful resources:

- Independent Living Centre [www.ilc.com.au](http://www.ilc.com.au)
- [www.dementiatechnology.org.au](http://www.dementiatechnology.org.au) home checklist, DVD, website virtual tours, posters and help sheets or phone 1300 275 227
- assistance with home modifications is available from the Home Maintenance and Modifications program (HMM) via HACC
- checklist 'Living with Dementia. How the Environment, Technology and You Can Help' available at <http://www.dementiatechnology.org.au/Checklists.aspx>
- Dementia friendly environments [www.health.vic.gov.au/dementia/index.htm](http://www.health.vic.gov.au/dementia/index.htm)
- age friendly home fact sheets available at <http://www.bcs.org.au/AgeCare/AgeFriendlyHome.aspx>
- Dementia Service Development Centre, University of Stirling, Stirling Scotland [www.dementia.stir.ac.uk](http://www.dementia.stir.ac.uk)
- Belgia Cantous Association. Tools for the future: how dementia friendly is your building. Dementia Services Development Centre. [www.cantous.be/pub6.htm](http://www.cantous.be/pub6.htm)
- The National Dementia helpline 1800 100 500
- Alzheimer's Australia [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Alzheimer's Australia The environment help sheet <http://www.alzheimers.org.au/common/files/NAT/20100920-Nat-Helpsheet-Building-environment-and-dementia.pdf>
- Alzheimer's Australia Furnishings and decor help sheet <http://www.alzheimers.org.au/common/files/NAT/20100920-Nat-Helpsheet-FurnishingsDecor-environment-and-dementia.pdf>
- Alzheimer's Australia Living room help sheet <http://www.alzheimers.org.au/common/files/NAT/20100920-Nat-Helpsheet-LivingRoom-environment-and-dementia.pdf>
- Alzheimer's Australia Utilities help sheet <http://www.alzheimers.org.au/common/files/NAT/20100920-Nat-Helpsheet-Utilities-environment-and-dementia.pdf>
- Alzheimer's Australia Outside help sheet <http://www.alzheimers.org.au/common/files/NAT/20100920-Nat-Helpsheet-Outside-environment-and-dementia.pdf>
- Alzheimer's Australia New housing and renovations help sheet <http://www.alzheimers.org.au/common/files/NAT/20100920-Nat-Helpsheet-New-housing-and-renovations-environment-and-dementia.pdf>

## Hospital Environment

Hospital environments can create confusion, fear and anxiety and these feelings are likely to result in inappropriate reactions or responses. Some of the effects caused by being admitted to hospital are:

- changes to routines
- unfamiliar people and surroundings
- lack of signs or cues which may result in disorientation
- over stimulation: changes in levels of noise, lighting and smell or presence of pain or discomfort
- under stimulation: being left alone or without companionship, lack of activity
- change in level of independence secondary to unfamiliar environment or staff 'taking over' tasks that the person had previously completed.

The hospital environment should (where possible and practicable) provide the following for people with dementia:

- safety: controlled exit, hot water controls, safety switches, minimise clutter
- quality care in small groups
- have good visual access
- minimise unnecessary stimulation
- highlight helpful stimuli e.g., toilet doors, patients own room
- provide planned walking in a safe environment
- be familiar: that is use recognisable furnishings and decor
- opportunities for both privacy and interaction with visitors.

**Table 4: Hospital Environment Adaptations Checklist**

|                 | <b>Issue</b>  | <b>Suggestions</b>   |
|-----------------|---|--|
| safety          | <ul style="list-style-type: none"> <li>▪ mobility</li> <li>▪ falls risk</li> </ul>                                    | <ul style="list-style-type: none"> <li>▪ place items within reach</li> <li>▪ remove clutter</li> <li>▪ correct bed height to aid transfers</li> <li>▪ temperature controlled taps</li> <li>▪ non-slip flooring</li> <li>▪ grab rails (colour contrast to walls)</li> <li>▪ sensor lights for accessing bathroom at night</li> <li>▪ minimise changes to flooring colour, texture or pattern</li> </ul> |
| signage         | <ul style="list-style-type: none"> <li>▪ lack of recognition</li> <li>▪ way finding</li> <li>▪ orientation</li> </ul> | <ul style="list-style-type: none"> <li>▪ signage on toilet and bathroom areas (words or pictures)</li> <li>▪ bold signs at eye level</li> <li>▪ large clocks, calendars, pictures</li> <li>▪ regular prompts or cueing</li> </ul>  |
| colour          | <ul style="list-style-type: none"> <li>▪ reduced sensitivity to visual contrast</li> </ul>                            | <ul style="list-style-type: none"> <li>▪ colour contrast is essential for doors, frames or door handles to assist detection.</li> <li>▪ high contrast colours for plates, cups, tableware</li> <li>▪ disguise doors, cupboards etc., that may be causing confusion, by painting them a matching colour to the wall, to assist door to blend in.</li> </ul>   |
| light and shade | <ul style="list-style-type: none"> <li>▪ misreading glare/shadows</li> </ul>  | <ul style="list-style-type: none"> <li>▪ avoid shiny floor surfaces</li> <li>▪ adequate even lighting throughout the day may require leaving lights on</li> <li>▪ allow time for eyes to adjust when moving from light to darker areas or vice versa</li> </ul>  |
| noise           | <ul style="list-style-type: none"> <li>▪ over stimulation</li> </ul>  | <ul style="list-style-type: none"> <li>▪ remove or reduce unnecessary background noises</li> <li>▪ choose best ward position</li> </ul>  |
| thermal         | <ul style="list-style-type: none"> <li>▪ reduced temperature awareness</li> </ul>                                     | <ul style="list-style-type: none"> <li>▪ temperature controlled taps</li> <li>▪ ensure patients are adequately clothed</li> </ul>  |

|                       | Issue   | Suggestions   |
|-----------------------|---|---|
| bed/ward position     | <ul style="list-style-type: none"> <li>disorientation</li> </ul>                                | <ul style="list-style-type: none"> <li>avoid transferring rooms/wards where possible</li> <li>close access to toilets, bathrooms, dining room</li> <li>visual access by staff</li> </ul>  |
| familiar objects/view | <ul style="list-style-type: none"> <li>lack of familiarity</li> </ul>                           | <ul style="list-style-type: none"> <li>encourage relatives to bring in photos, personal items</li> <li>pictures of natural views or gardens/natural environments</li> </ul>   |
| provision for walking | <ul style="list-style-type: none"> <li>agitation</li> <li>boredom</li> <li>wandering</li> </ul> | <ul style="list-style-type: none"> <li>if wandering is problematic try to admit patient to a dementia specific ward (if available)</li> <li>access to safe outdoor and social spaces</li> <li>assist with walking as required</li> </ul>  |
| social interaction    | <ul style="list-style-type: none"> <li>loneliness</li> <li>boredom</li> </ul>                   | <ul style="list-style-type: none"> <li>use a patient profile. have family or staff from care facility provide information about the person's past, their likes and dislikes etc.</li> <li>encourage visitors and interaction</li> <li>reminisce: talk about familiar topics</li> <li>use a memory box/book</li> <li>engage person in daily routine</li> <li>if using one to one supervision, encourage activity e.g., reading, walking, knitting</li> </ul> |

Adapted from Alzheimer's Australia WA Effective Dementia Training Resource Kit (Nichols and Graham, 2008)

Useful resources:

- Alzheimer's Australia Going to hospital help sheet [http://www.alzheimers.org.au/common/files/NAT/20050700\\_Nat\\_HS\\_2.10GoingToHospital.pdf](http://www.alzheimers.org.au/common/files/NAT/20050700_Nat_HS_2.10GoingToHospital.pdf).

## Assistive Technology

Assistive technology is any item or object that enables a person to complete a task that they would otherwise be unable to do. Independence in task completion impacts positively on a person's sense of self worth, self esteem and self reliance. Assistive technology should not replace human contact. When considering assistive technology interventions a simple approach should be utilised and only changing what needs to be changed. Caution should be utilised as every person's reaction to technology will be individual and in some cases it may have a negative impact. Involving the person with dementia in the decision making process and trialling of items will lead to greater acceptance and use of the technology solutions. Professional assessment/advice from an OT is recommended prior to purchasing products.

Areas where technology can be beneficial for people with dementia and their carer's are:

- sleep disturbances
- safe use of home appliances
- locating misplaced items
- medication management
- orientation
- safe walking/wandering, way finding
- summoning assistance in an emergency.

Examples of some of the technology currently available:

- electronic assistive technology: automated door openers, alarms, computers, smart stove tops, smart wirings
- mobile phones: features will vary on each phone but can include one touch dialing, call blocking, larger buttons and screen, calendar with reminders, GPS tracking
- computers: larger keys or keyboard; touch screen rather than mouse or keyboard; screen enlarger or magnifier, speech and voice recognition programs; screen readers that read all screen contents; software programs that use speech synthesisers for auditory feedback about what is being typed; use databases with photos, songs, video clips
- voice over protocol (VOIP) works on most internet connected computers and allows the computer user to talk to, hear and see family or friends using the computer or web camera
- Telecare is a type of assistive technology that is used to provide support from a distance. Telecare is provided via a number of organisations in Australia. Each have their own range of services and costs involved
- universal or simple remote for TV/DVD.

Useful resources:

- [www.dementiatechnology.org.au](http://www.dementiatechnology.org.au) home checklist, DVD, website virtual tours, posters and help sheets or phone 1300 275 227
- Independent Living Centre [www.ilc.com.au](http://www.ilc.com.au)
- The National Dementia helpline 1800 100 500
- Alzheimer's Australia [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Alzheimer's Australia safety issues help sheet [http://www.alzheimers.org.au/common/files/NAT/20050700\\_Nat\\_HS\\_2.3SafetyIssues.pdf](http://www.alzheimers.org.au/common/files/NAT/20050700_Nat_HS_2.3SafetyIssues.pdf)
- Alzheimer's Australia WA has an assistive technology display room. Appointments are necessary 9388 2800.

## Mobility and Falls

Falls in older people can occur for a wide variety of reasons. According to Hernandez, Coelho, Gobbi and Stella (2009) people with cognitive decline are three times more likely to fall, than elderly people without cognitive issues.

Benefits of maintaining mobility:

- maintain strength and endurance
- improved balance
- maintain joint mobility
- cardiovascular health
- facilitation of continence
- maintain independence
- sense of self and control.

Possible warning signs that a person is falling or having near misses:

- bruises or abrasions
- furniture walks i.e. grabs into fixtures and fittings to secure self when mobilising
- difficulty with transferring
- difficulty managing steps
- difficulty dualtasking – refer to ‘stops walking when talking’ article by beauchet et al.

Possible problems or concerns that may affect mobility:

- any condition associated with ageing such as pain from arthritis, osteoporosis, shortness of breath or lack of energy resulting from heart and lung conditions, pain and discomfort from circulatory diseases and problems associated with deteriorating eyesight
- different types of dementia are more prone to falls e.g., lewy body dementia
- as dementia advances the persons level of function will deteriorate and the person will be more prone to falling, this needs to be closely monitored and strategies implemented as required
- poor lighting

- uneven flooring
- inappropriate footwear or clothing e.g., trousers that drag, shoes that are too big
- inactivity resulting in weaker muscles and joint stiffness
- incorrect use of medication or side effects from some medications e.g., sedation
- urinary incontinence
- poor nutrition
- difficulty judging depth perception and distance which can lead to falls or missing seated surfaces
- difficulty with concentration and judgement
- reduced strength and flexibility
- poor balance. may fall when reaching above chest height to obtain items
- sensory deficits
- agnosia: no longer recognising objects or their function
- difficulty understanding or following instructions
- slowed response rate to instructions
- difficulty expressing needs
- grasping at items or people
- resistiveness to transferring or mobilising
- leaning backwards
- dizziness when turning their head or moving from sit to stand
- forgets to use walking aids. According to Oddy (2003) people with dementia can learn new skills like using a walking aid with wheels (if deemed appropriate by a PT) which reduces the amount of assistance required to mobilise. The person may not remember to use the aid or how to position it correctly so they will require supervision with mobility.
- forgets how to walk
- forget that they need assistance and fall
- fear of falling, using stairs or walking up/down a sloped surface
- distress or fear at changing position
- poor motivation: may “lose the will to move” (Oddy, 2003 pg7)
- incorrect furniture height or depth.

Tips to assist with mobilising and falls prevention:

- a medical review to determine any medical cause that is impacting on the person's mobility
- multidisciplinary review to assess risk of falls / falls clinic
- referral to a physiotherapist may be indicated if the person has poor balance, unsafe transfers, is unsteady when mobilising, furniture walking, low endurance or if the care giver is experiencing physical strain from assisting the person to transfer and mobilise
- for community clients, consideration of the person's capacity to remember instructions and learn new skills should be given prior to referral to a physiotherapist. In some cases the person with dementia has reached a stage where they need standby assistance or a wheelchair to be safe. In these scenarios carer training is required not client intervention.
- referral to a podiatrist
- referral to a falls clinic if deemed appropriate by the medical team
- fall prevention packs are available in the Osborne Park Hospital OT department
- if an inpatient, utilise the falls risk chart and document any falls or near misses
- encourage daily physical activity and make movement enjoyable e.g., use music, incorporate a favourite past time, completing household chores etc.
- ensure furniture that the person transfers from is a suitable height, has a firm base, where possible use chairs with arm rests
- ensure suitable footwear is worn. Pamphlets are available from Osborne Park Hospital OT department regarding footwear
- minimise clutter by arranging furniture simply and leave it in the same place
- keep the floor free from hazards such as rugs or items that can be walked into or tripped upon
- strategically place sturdy furniture for use when mobilising
- eliminate glare from all areas where the person is transferring or mobilising

- allow time for the care recipient's eyes to adjust to changes in light when moving from one area to another. Ensure there is a safe place to sit or stand while their eyes adjust
- cordon off wet areas as signs stating 'wet floor' are ineffective for people with dementia
- secure handrails, broken steps and loose carpeting in key rooms, access ways and stairwells
- seal carpet edges
- furniture guards (to cap sharp edges)
- consider installing safety film on glass areas up to one metre to prevent lacerations, including shower screens that are not safety glass. This needs to be installed by a licensed installer.
- enough circulation space to move about and access the area freely with a walking stick, frame, wheelchair if used
- pain relief prior to movement
- if the care recipient needs to concentrate when walking or transferring do not talk to them while they are moving around. According to Hornbrook et al. (1994), one third of all falls occur because the person who fell was not paying sufficient attention while moving around. (Dual Tasking).
- allow time for person to respond to requests. Make one request at a time
- utilise one word commands when directing transfers or ambulation e.g., turn, sit, stand
- if the care recipient is unwell or not at their best, provide extra assistance and avoid situations where falls may occur e.g., bathtub, stairways, outdoors
- when rising to stand, direct the person's attention along a vertical line or to a place above their head to encourage back extension
- don't allow any person to pull on you to stand. Manual handling training may be required to teach safe transfer and handling techniques. The carer may also benefit from back protection or strengthening techniques.
- if the person becomes immobile due to fear try enticing them with a goal such as 'let's go and look at the photos on the wall'

- provide positive reinforcement when the person displays safe behaviours e.g., holding the grab rail
- personal emergency response alarms: helpful for people in early stages of dementia
- chair or bed occupancy sensors. These can work as a standalone or be linked to a call centre
- hip protectors - These may reduce the rate of hip fractures for people in residential care. Refer to Cochrane review by Gillespie WJ etc al.
- pictorial cues
- verbal cues e.g., 'nose over toes'
- auditory cues e.g., pat back of the chair while requesting person sits in the chair
- visual cues: demonstrate movement
- use gestures to indicate direction
- automated or Smart home systems can be used to operate lights, heating and security. A person's movement around their home can be monitored for any unusual changes. These systems can be linked to a call centre or family carers.
- Telecare is a home based call centre system that monitors a person's blood pressure, blood sugar levels or other health measures and sends the information to a call centre or GP via a set top box, where it can be reviewed and actioned if required
- Safe2walk.com.au utilises a device adapted by Alzheimer's Australia for people with dementia. It is a low cost service.

Useful resources:

- Independent Living Centre [www.ilc.com.au](http://www.ilc.com.au)
- [www.dementiatechnology.org.au](http://www.dementiatechnology.org.au) home checklist, DVD, website virtual tours, posters and help sheets
- The National Dementia helpline 1800 100 500
- Alzheimer's Australia at [www.alzheimers.org.au](http://www.alzheimers.org.au)
- referral to a physiotherapist
- Safe2walk service [www.safe2walk.com.au](http://www.safe2walk.com.au)
- Alzheimer's Australia Safer walking for people with Dementia help sheet <http://www.alzheimers.org.au/common/files/NAT/20100920-Nat-UpdateSheet16-Safer-walking-for-people-with-dementia.pdf>
- Alzheimer's Australia Keep on moving physical exercise and dementia help sheet <http://www.alzheimers.org.au/common/files/NAT/20100920-Nat-UpdateSheet9-Keep-on-moving-physical-exercise-and-dementia.pdf>
- Promoting mobility for people with dementia. A problem solving approach. Rosemary Oddy 2003.

## Activities of Daily Living

### Bathing and Personal Hygiene

Personal care is often a sensitive issue for people with dementia. Tasks associated with hygiene were once completed independently and privately. As dementia progresses the person may require physical assistance with the tasks resulting in a lack of privacy and autonomy. By focusing on the person rather than the task the person with dementia may be more willing to accept assistance. Identifying potential triggers and interpreting what the person is trying to communicate can assist in making personal care activities positive experiences. Being prepared and familiar with the person's usual routine and normal level of involvement will also assist in positive hygiene experiences.

Possible problems or concerns:

- difficulty with manipulating taps
- forget to turn off taps
- change in sense of perception of hot and cold
- unable to regulate water temperature risk of scolds
- fear of water
- fear of drowning particularly if water is being poured over their head
- fear of falls
- discomfort due to temperature of bathroom usually too cold or feeling of claustrophobia
- access to potentially dangerous items e.g., razors, mouth wash, electrical items
- resistance due to lack of privacy if assistance required
- person may not be used to showering daily
- overwhelmed by complexity of the task (undressing, showering, drying, dressing etc.)
- feeling powerless or out of control
- difficulty shaving, combing hair, applying makeup
- build up of ear wax
- poor oral hygiene, forgetting to brush teeth, forgetting how to use toothbrush etc.
- forget or have difficulty cutting fingernails and toenails.

Possible solutions:

- tap turners or have a plumber install lever taps
- tap cap secured to tap to prevent its use
- set the temperature of the hot water heater to not exceed 50 degree Celsius
- temperature regulated plugs
- automatic taps that turn off if user forgets
- pressure sensitive sink plug or magi-plug: a plug that has a valve which is activated by pressure
- flood detectors: can be placed just above the floor level on the wall in areas that have sinks. If the unit detects water overflow it activates an alarm within the house and contacts a call centre
- thermostatic mixing or shut off valves: these devices need to be installed by a licensed plumber
- separate hair washing from bathing
- visit a hairdresser or arrange for a hairdresser to visit at home
- put a few drops of blue food colouring in the water to strengthen its visual impact
- utilise rinse or water free personal hygiene products
- floor tiles which contrast with wall tiles
- hob less shower, with grab rails, a shower chair or similar and hand held shower hose
- use heat lamps and warm the room prior to bathing
- towel warmers
- level floor surfaces
- non-slip floor tiles or treatments
- grab rails, powder coated provides more grip (Calkins, M 2001)
- keep access ways free from clutter
- wide entry doorway with outward swinging or sliding door or hinges to allow removal of door/easy emergency access to bathroom
- removal of shower screens and replace with shower curtains if appropriate

- power point safety plugs may reduce electrical hazards
- mag locks are a magnetic lock system which can be used on drawers and cupboards. The locking mechanism is hidden and therefore doesn't draw attention to the drawer or cupboard being locked
- duress alarm for emergency contact with a call centre or a nominated person; this is a standalone product that can be installed in the home without any hard wiring, making it perfect for areas such as bathrooms and toilets
- safe storage of medications, chemicals, hairdryers, electric razors
- ceiling heater/exhaust fan. All heating elements should be wall or ceiling mounted to avoid the possibility of coming in to contact with water
- use laminate signs or posters of bathing/grooming steps and hang them where the person can see them during the different stages of each task. If reading is difficult use pictures or drawings.
- floor drains
- utilise an electric monitor (e.g., infant monitor) in the bathroom
- close doors/curtains or blinds to create a feeling of privacy
- cover mirrors if the person doesn't recognise themselves
- allow plenty of time and provide reassurance
- allow the person to feel the water before bathing or showering and providing reassurance that water 'feels nice'
- soft calming music may be helpful in the background
- choose the best time of day for the person for bathing i.e. when they are most relaxed and try to be consistent with the pre-dementia bathing routine. Consider the type of bathing the person is used to such as shower, bath, sponge bath
- consider alternative bathing schedules such as daily sponge bath or semi-weekly tub bath
- break down the task to manageable simple steps. Gently explain each step
- encourage the person to complete as many steps as possible independently
- offer limited choices

- lay out items that are required for task for example soap, washcloth, towel in the order they will be required
- hand items one at a time to care recipient and name the object
- use simple clear one step directions e.g., 'lift your arm over your head'
- place items within easy reach to accommodate reduced mobility
- use brightly coloured soap, towels etc., to provide visual emphasis
- be familiar with the persons routine and usual level of involvement
- try to complete tasks at same time every day and use temporal cues such as 'after breakfast we.....'. Scheduling tasks for periods of the day when other family members don't need the bathroom will allow the person to take the necessary amount of time to complete the task
- personalise the experience
- maintain dignity
- distraction from the task may be achieved by putting laminated pictures in the shower area
- demonstrate for the care recipient what you want them to do or use hand over hand techniques
- don't ask if the person wants to 'brush their hair now?' instead use a directive statement such as 'we are going to brush your hair now'
- store all items for one specific task in a clearly marked container. The label could be a picture of the person performing the task, a drawing or picture of another person performing the task, a drawing of the objects or a label specifying the task or objects
- remove items belonging to other people or any items the person does not use daily
- put grooming items out in the sequence they will be used
- try to use only products and product packaging that is familiar to the person
- purchase several identical personal care items so that familiar replacements are available
- supervision or assistance maybe required when using a traditional razor, people who are used to using electric razors will shave independently for longer

- if possible utilise another room when using electrical appliances. Removal of electrical appliances from the bathroom may be necessary to avoid electrocution
- discuss with a doctor possible treatments for ear wax
- schedule regular dental visits, remind people to brush their teeth or assist them with the task
- visit a podiatrist, consider if the person enjoys having their nails painted or manicured
- use positive reinforcement and provide compliments regards their level of cleanliness and amount of effort they demonstrated
- if the person performs the tasks in an unorthodox but effective way do not correct them
- if family unable to cope with demands of bathing refer to social work for linkage to services
- utilise a schedule/care plan of what tasks each carer (voluntary or paid) will assist with or complete during their visit.

Useful resources:

- The National Dementia Behaviour advisory Service 24 hours 7 days a week service 1300 366 448
- Commonwealth Carer Respite Centre 1800 059 059
- Commonwealth Carer Resource Centre 1800 242 636
- [www.dementiatechnology.org.au](http://www.dementiatechnology.org.au) home checklist, DVD, website virtual tours, posters and help sheets
- Independent Living Centre [www.ilc.com.au](http://www.ilc.com.au)
- The National Dementia helpline 1800 100 500 or visit Alzheimer's Australia at [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Alzheimer's Australia hygiene help sheet [http://www.alzheimers.org.au/common/files/NAT/20050700\\_Nat\\_HS\\_2.17Hygiene.pdf](http://www.alzheimers.org.au/common/files/NAT/20050700_Nat_HS_2.17Hygiene.pdf)
- Alzheimer's Australia dental care help sheet [http://www.alzheimers.org.au/common/files/NAT/20050700\\_Nat\\_HS\\_2.14DentalCare.pdf](http://www.alzheimers.org.au/common/files/NAT/20050700_Nat_HS_2.14DentalCare.pdf)
- Alzheimer's Australia Bathroom and Toilet help sheet <http://www.alzheimers.org.au/common/files/NAT/20100920-Nat-Helpsheet-Bath-Toilet-environment-and-dementia.pdf>.

## Dressing

Dressing is a very complex task with numerous steps involved. It can be overwhelming for people with cognitive impairment. Assisting someone to dress can be very time consuming and emotionally challenging if the person is not cooperating.

Possible problems or concerns:

- forgetting how to dress
- forgetting to change clothes
- dressing in the incorrect order (e.g., underwear over trousers)
- wearing extra layers as judgment and sensation of temperatures may be impaired
- may recognise the item of clothing but forget which body part goes into clothing item
- environmental distractions e.g., noise, lights, clutter, temperature
- lack of privacy
- difficulty with clothes selection
- difficulty manipulating clothes fasteners e.g., buttons, snaps, hook and eye, zippers
- undressing frequently.

Possible solutions:

- verbal prompting or reminders of how to dress. Post steps for dressing on a large poster in the place where the person usually dresses. If reading is difficult use pictures or drawings
- encourage independence with dressing. If person isn't able to complete the whole task allow them to complete whatever steps they can
- be patient and allow as much time as is necessary for the person to complete steps
- encourage the person to change regularly. Tactfully remove soiled clothes at the end of each day and substitute with clean ones
- set out clothes in the sequence they are to be put on or pre-package a complete outfit so that the person does not have to search for items of clothing

- if physical assistance is being provided hand items one at a time to the person
- use simple one step instructions e.g., 'pull up your pants'
- demonstrate to the person what you want them to do or use hand over hand techniques
- arrange closets and drawers so that like items are kept together
- install a counter top or shelf to arrange items for dressing
- break task down into manageable steps
- remove unnecessary clutter
- a mirror maybe useful for providing visual feedback
- ensure environment provides adequate light and temperature
- store non seasonal, ill fitting or little used clothing
- close the door and install window treatments to create a feeling of privacy
- assist from a distance and be involved only when required
- limit number of choices provided
- utilise colour contrast for people with visual problems e.g., light colour clothing on dark bedcover
- if client is wearing extra layers or seasonally inappropriate clothing, pack away extra clothing so that it is no longer visible
- select clothing that doesn't require ironing and is washable
- replace clothes fasteners with Velcro tape or elastic waist bands
- purchase clothes with simple patterns and with solid contrasting colours
- purchase slip on shoes with non-slip soles rather than laces and buckles
- purchase a couple of the same outfits. In the past people did not change their clothes as frequently as people do today. Caution should be taken not to impose current values into people's daily care
- install a curtain or screen to hide distracting items
- evaluate why the person maybe undressing frequently, do they need to use the toilet?; are they too hot?, are they tired and getting ready for bed?
- utilise distraction techniques or activities if the person is not cooperating during the task

- compliment the person on how he or she looks as well as the amount of effort they demonstrated
- ignore mistakes if they are of no significant consequence e.g., clashing colours
- if family are not coping with the dressing demands refer to social work for linkage to services, respite and day centres
- utilise a schedule/care plan of what tasks each carer (voluntary or paid) will assist with or complete during their visit.

Useful resources:

- The National Dementia Behaviour advisory Service 24 hours 7 days a week service 1300 366 448
- Independent Living Centre [www.ilc.com.au](http://www.ilc.com.au)
- Commonwealth Carer Respite Centre 1800 059 059
- Commonwealth Carer Resource Centre 1800 242 636
- Referral to social work
- The National Dementia helpline 1800 100 500
- Alzheimer's Australia at [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Alzheimer's Australia dressing help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20050700\\_Nat\\_HS\\_2.15Dressing.pdf](http://www.alzheimers.org.au/common/files/NAT/20050700_Nat_HS_2.15Dressing.pdf).

## **Toileting and Continence**

People living at home with dementia may experience a number of difficulties associated with using the bathroom/toilet including perceptual difficulties, falls, continence problems, hygiene difficulties, anxiety or behavioural problems such as placing inappropriate items in the toilet

Possible problems or concerns:

- difficulty locating toilet
- difficulty transferring from toilet
- distance to the bathroom
- difficulty locating/reaching toilet paper
- difficulty undressing
- urinating in places other than toilet
- falls
- difficulty urinating /retention
- difficulty sitting still to use toilet
- incontinence
- constipation or diarrhea – may be overflow diarrhea
- difficulty following directions/instructions.

Possible solutions:

- difficulty urinating /retention – refer to incontinence nurse (for bladder scan)
- simplify clothing. Use Velcro tape instead of buttons and zippers. Try hook and loop fasteners or elastic waistbands for trousers and wrap around skirts. Select clothing that is easily washable and does not require ironing
- remove any confusing objects from around or on the toilet or commode such as washcloths, reading material or objects that may be mistaken for the toilet as these objects may create confusion regards the purpose of the room

- use visual cues to assist with locating the toilet. Place a sign or label on the toilet door such as a picture or a photograph of the toilet in a prominent position. Leave the toilet door open and close all other doors leading to the toilet to discourage urinating in other rooms. Paint the bathroom/toilet door a contrasting colour e.g., dark blue to make it stand out in a lighter coloured hallway. Using large arrows to direct to the toilet from the living room or bedroom
- utilising sensor lights or night lights to avoid having to enter a dark room to find the light switch. Glow in dark strips placed around light switches or in hallway to assist in finding the light switch or direct the person to the bathroom
- eliminate as many extraneous objects as possible and remove clutter from passageways or stairways
- place objects within triangle of efficiency (nose, right elbow, left elbow) to accommodate reach limitations associated with ageing
- use contrasting door knobs
- colour contrast toilet seat with bowls and floor e.g., navy blue seat
- stick contrasting tape on rails to help locate them
- smart toilets can be tailored to meet personal needs. They use technology to measure blood pressure, heart rate and sugar in urine. Information is gathered and sent to the GP or health professional. An altered seat can be utilised that cleans and dries sensitive body areas or has a heated seat
- correct toilet height
- ensure toilet seat is securely fastened
- remove mats
- install grab rails or equipment to assist with transfers
- a commode may helpful in bedroom
- use a contrasting colour for the toilet paper and the wall
- try not to let the person become accustomed to wet clothing
- give a drink of water or run a tap
- if the person is restless and will not sit on the toilet allow them to get up and down a few times. Try distraction techniques on the toilet or calming music
- monitor persons fluid and food intake

- safety gates can be installed at stairways
- remove lock from bathroom
- install bells or alarms on doors, cabinets or drawers to alert the caregiver when a person is opening them
- consider keeping a voiding diary (frequency and amount) which can then assist with establishing a voiding routine e.g., every two hours. Once a routine is established try to avoid unnecessary changes
- use simple one step instructions using statement form rather than questions e.g., 'take off your pants'. Only give the next instruction once the first instruction has been completed
- use positive reinforcement to promote independence
- if family are not coping with the toileting demands refer to Continence Clinic / Continence Nurse , social work for linkage to services, respite and day centres. Continence aids subsidies are available. Utilise a schedule/care plan of what tasks each carer (voluntary or paid) will assist with or complete during their visit
- referral to a physiotherapist may be indicated if the person with dementia is experiencing difficulty with mobility and transfers, is unsteady, demonstrates poor balance or low endurance or if the care giver is experiencing physical strain from helping the person mobilise and transfer.

## **Incontinence**

Incontinence is the loss of control of the bladder or bowel function. Being in control of these functions depends on having an awareness of bodily sensations and the memory of how, when and where to respond. Incontinence is always a symptom of an underlying problem. The cause of the incontinence should always be investigated as it may be due to numerous medical reasons such as infection, constipation, hormonal changes and prostate enlargement. According to Dee Sutcliffe (2009) incontinence is one of the top three reasons that result in people being admitted to residential care.

Dementia can impact on a person's continence by interfering with their ability to:

- recognise the need to go to the toilet
- short term memory loss resulting in frequent urination
- be able to wait until it is appropriate to go to the toilet
- knowing when the bladder/bowel is empty
- locate the toilet
- recognise the toilet
- use the toilet correctly
- manage clothing
- attend to hygiene
- incontinence, may be urine retention with overflow, refer to incontinence nurse.

Alzheimer's Australia proposes the following suggestions for managing incontinence:

- be sure the person is drinking adequate fluids, preferably water, 5-8 glasses. Try to establish a regular routine for drinking fluids
- reduce the person's caffeine intake by using decaffeinated beverages
- observe the person's toileting pattern and suggest they use the toilet at regular times that follow their established pattern
- utilise protective garments or disposable pads
- utilise suitable aids or appliances.

Alzheimer's Australia proposes the following suggestions for managing constipation:

- try a high fibre diet (dietician referral maybe required) and ensure the person is having adequate fluids (see above)
- regular exercise
- try to establish a routine.

Continence subsidy schemes:

- CASS: Continence Aids Assistance Scheme
- CMAS: Continence Management Advisory Service.

Both schemes are available to clients in low level care facilities.

Useful resources:

- Commonwealth Carer Respite Centre 1800 059 059
- Commonwealth Carer Resource Centre 1800 242 636
- Referral to Continence Clinic or continence nurse
- Referral to social work
- Continence Advisory Service contact 9386 9777 country callers 1800 814 925 [www.continencewa.org.au](http://www.continencewa.org.au) or email [info@continencewa.org.au](mailto:info@continencewa.org.au)
- Carer continence kits are available from the Commonwealth Carer Resource Centre 1800 059 059
- National continence helpline 1800 330 066 is a service that provides information from trained continence nurses who can offer counseling, advice and referral to local services
- Alzheimer's Australia continence help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20050700\\_Nat\\_HS\\_2.18Continence.pdf](http://www.alzheimers.org.au/common/files/NAT/20050700_Nat_HS_2.18Continence.pdf)
- Alzheimer's Australia Bathroom and Toilet help sheet  
<http://www.alzheimers.org.au/common/files/NAT/20100920-Nat-Helpsheet-Bath-Toilet-environment-and-dementia.pdf>.

## Feeding

Maintaining good nutrition for people with dementia is challenging. A doctor should be consulted if the person has had a significant weight loss (such as 2.5 kgs in 6 weeks).

Possible problems or concerns:

- loss of appetite
- dehydration or inadequate nutrition
- develop an insatiable appetite or craving for sweets
- forget to eat or drink (amnesia) or when next meal is due
- difficulty expressing food preferences
- decreasing variety of foods that are eaten could potentially lead to a vitamin deficiency that could affect cognition
- eating again as they can't remember previously eating
- consuming too much caffeine or alcohol as they forget they have already had a drink
- difficulty understanding mealtime instructions
- forget how to swallow or chew
- experience a dry mouth or mouth discomfort e.g., ill fitting dentures
- inability to locate food, cutlery and crockery
- inability to recognise food and drink (agnosia)
- eating or drinking non-food products or substances
- eating spoiled food
- difficulty maintaining food hygiene practices
- difficulty using cutlery (apraxia)
- dysphagia which can result from changes to oral, oropharangeal or oesophageal function
- difficulty performing voluntary actions such as opening mouth to a utensil
- socially inappropriate mealtime behaviour such as cramming food into mouth, eating rapidly
- refusing to eat/ have assistance/sit at a table
- throwing food stuffs or hitting the person assisting
- delusional ideas about food stuffs or hallucinations
- unreliably reporting their nutritional intake.

Possible solutions:

- refer for medication review by nurse or GP.
- try to prepare familiar foods in familiar ways that are culturally appropriate
- involve the person with dementia in the preparation wherever practicable
- utilise appropriate verbal and visual cues to orientate to the activity
- try to make meal times simple, relaxed and calm
- prepare tasty strongly flavoured and aromatic foods that may stimulate an appetite. If there is no aroma from the food use a cinnamon or orange potpourri
- eliminate noxious odours
- try a glass of juice, wine or sherry, if medications permit, before a meal to stimulate the appetite
- check medications for side effects, some antidepressants cause a sweet craving. Offer ice-cream, egg nogs and milkshakes
- frequent small meals. Try 5-6 small meals a day
- have low calorie snacks available
- provide snacks that are easy to eat and don't need to be refrigerated so they can be left in place that is easily seen
- bright coloured plates and cups can increase food and liquid intake
- add colour contrasting to edge of table to increase visibility
- use placemats that colour contrast with the table top, plates, utensils
- arrange utensils and crockery in a consistent manner and keep setting as simple as possible. Placemats are available with place setting outlined on them
- select plates and cups that have colour contrasting edges or rims to improve visibility
- white plates eliminates distraction from patterns
- colourful food on white plates to make food easier to see
- encourage regular and independent eating and drinking
- non slip mats (rubber or dyacem)

- if spillage of liquids is problematic utilise a travel mug with lid
- straws with one way valves
- avoid bibs. Use a shirt, smock or apron. Try to use something the person usually would wear
- modified eating utensils e.g., knork a weighted fork that cuts food but not a person's mouth <http://www.knork.net/>, plates with lips or rims
- minimal reflections/glare from polished surfaces
- social experience/virtual dining: using a video link camera to eat a meal with others
- reminders or prompts for meals and medications e.g., alarm clock or phone call
- allow and encourage finger feeding when person is no longer able to manipulate cutlery. Present finger foods on a flat plate at a comfortable reaching distance
- reduce clutter: avoid lots of cutlery, crockery etc.
- keep background noise and activity to a minimum, turn off TV
- serve only one plate of food at a time
- allow time for the persons memory to respond
- hand over hand guidance initially to use cutlery may be required
- eat together so the person can copy you
- offer meals at regular times
- allow the person to eat when they are hungry
- encourage physical exercise
- encourage the person to wear their glasses or dentures
- have regular dental check ups
- if assistance is required ensure the carer utilises appropriate feeding techniques such as allowing sufficient time to chew and swallow, not over loading the person's mouth, using hand over hand techniques
- referral to a speech therapist may be required for chewing and swallowing difficulties (dysphagia)
- referral to a dietician maybe required. Nutritional supplement drinks may be prescribed

- for chewing problems try light pressure on the lips or under the chin, tell the person when to chew, demonstrate chewing, offer small bites
- for swallowing problems remind the person to swallow, stroke throat gently, check mouth to see food has been swallowed, avoid foods that are hard to swallow, moisten foods
- cut food into small pieces if over stuffing is an issue
- monitor food temperatures
- maximise food intake when cognition is at its best
- if family are not coping with the eating and feeding demands refer to social work for linkage to services, respite and day centres.

Useful resources:

- The National Dementia Behaviour Advisory Service 24 hours 7 days a week service 1300 366 448
- Independent Living Centre [www.ilc.com.au](http://www.ilc.com.au)
- The National Dementia helpline 1800 100 500
- Alzheimer's Australia at [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Referral to a dietician or speech therapist
- Alzheimer's Australia eating help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_2.12Eating.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_2.12Eating.pdf)
- Alzheimer's Australia nutrition help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_2.13Nutrition.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_2.13Nutrition.pdf).

## Sleep

Sleep problems are often regarded as one of the most difficult symptoms of dementia. The person with dementia, their families and carers all require adequate sleep. People living with dementia may experience frequent sleep disturbances, which can occur for numerous reasons. It is important to determine what is impacting the sleep disturbance. Is it the environment, the dementia or medications being used?

Possible problems or concerns:

- disturbance to the person's biological clock i.e. being awake and restless during the night and sleeping during the day
- no longer able to distinguish between day and night
- going to bed too early or sleeping too much during the day
- overtiredness impacting on a person's ability to fall asleep
- reduced activity resulting in reduced need for sleep
- glare or reflections from glass or mirrors can be disturbing
- temperature of bedroom: maybe too hot or cold
- nightwear that is too restrictive, hot or cold
- refusing to go to bed
- continence (see section on continence for solutions)
- inappropriate bed: too soft, high/low, lacking support
- medical conditions such as angina, congestive heart failure, diabetes, UTI, depression, sleep apnoea, pain, restless legs or leg cramps
- side effects of medications e.g., diuretics
- changes to the environment such as moving house, relocating furniture or being hospitalised can cause disorientation and confusion
- mirrors may create confusion
- agitation following an upsetting event/situation
- disturbing dreams
- feeling hungry.

Possible solutions:

- establishing a sleep routine that is familiar and predictable
- keep a log or diary to determine any pattern in behaviour
- avoid having day clothes on display at night as this may trigger a response to get up
- avoiding drinks with caffeine in late afternoon/evening
- cut down on alcohol. Discuss any potential interaction between alcohol and medication with a doctor
- try to incorporate exercise into their daily routine
- listening to relaxing music, radio or television themes associated with preparing for bed
- fitting sheer net curtains to reduce glare/reflections or heavy window treatments to block external light sources
- oil filled column heaters with safety cut-off switch or air conditioning to heat/cool room prior to retiring
- choosing appropriate nightwear. Asking people to wear pyjamas when they are not used to wearing pyjamas/nightwear can cause confusion and distress
- choosing a bed that provides good support and is at a correct height will assist with independent transfers and better sleep
- offer alternatives to sleeping in bed such as on the couch
- if the person wanders at night, ensure the environment is safe to do so
- sensor mat detects absences from bed or chair
- sound and movement unit (baby monitor). The ethical and dignified use of a monitor can support independence for the person with dementia and peace of mind for their carer
- voice alert door entry can be utilised indoors or outdoors. This system allows up to six pre recorded messages that are activated when a person walks through a beam
- infrared door beams are small units that are placed near doorways or exits. A buzzer is activated when someone passes through the beam
- remove electric blankets
- continence support e.g., products mattress protector, sensor/night light

- water proof carpeting or furnishings
- keep the environment as consistent as possible
- utilising a contrasting top and bottom sheet may assist the person to locate their bed
- remove mirrors
- light snack before bed, or a herbal tea or warm milk
- try to avoid any tasks that maybe upsetting in the late afternoon
- gently remind the person it is night time and time to sleep
- a 'good night button' is an automated system that can be programmed to switch off all the lights and lock doors. Remote operation is also possible
- utilise respite and community services.

Useful resources:

- Commonwealth Carer Respite Centre 1800 059 059
- Commonwealth Carer Resource Centre 1800 242 636
- The National Dementia Behaviour advisory Service 24 hours 7 days a week service 1300 366 448
- Independent Living Centre [www.ilc.com.au](http://www.ilc.com.au)
- [www.dementiatechnology.org.au](http://www.dementiatechnology.org.au) –home checklist, DVD, website virtual tours, posters and help sheets
- The National Dementia helpline 1800 100 500
- Alzheimer's Australia at [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Alzheimer's Australia The bedroom help sheet  
<http://www.alzheimers.org.au/common/files/NAT/201000920-Nat-Helpsheet-Bedroom-environment-and-dementia.pdf>
- Alzheimer's Australia sleeping help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_2.16Sleeping.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_2.16Sleeping.pdf).

## Medication Management

Medication should be reviewed by a doctor regularly. Before considering any of the possible solutions listed below, medication needs should be discussed with a doctor as some medications are not able to be stored in dispensing packs.

Possible problems or concerns:

- forgetting to take medication
- taking medication but forgetting and then taking it again
- incorrect use of medication
- incorrect storage of medication
- using out of date medication or taking medication that is no longer required
- difficulty cutting or crushing medication
- difficulty opening bottles or containers.

Possible solutions:

- medical/nurse review re – need for medication, dose and frequency
- leave medications in a visible location (if safe)
- store medications in a lockable cabinet that can be mounted on a wall or in a cupboard
- mag locks: discreet magnetic locking system can be installed on drawers or cupboards
- link medication times to routine activities e.g., taking medications at meal times
- pill Cutter/Crusher: small plastic device designed to cut or crush uncoated tablets
- different devices are available to assist with opening containers or bottles. Visit ILC to view current products
- dosette boxes
- electronic medication reminder pill boxes: these are small enough to carry in a purse or pocket and are programmable to alert the person when it is time to take their medication

- 'Cadex Medication reminder watch' has the date and time in large font on the face; it is programmed to remind the wearer to take their medication. The name of the medication appears on the watch face. Health information and contact details can be stored on the device. <http://www.cadexwatch.com/>
- 'Blue Phone' is a phone that can be programmed with voice prompts to remind people to take their medication <http://www.bluephone.com.au/>
- 'Careousel automated medication dispenser' a lightweight circular unit which alerts the user via an alarm or flashing light when their next dosage is due. <http://www.safetyandmobility.com.au/ProductList.php?CategoryID=21>
- pre-packaged medication systems such as Webster packs are available from pharmacies at a cost. These are available in four different languages and with larger writing for people with visual impairment
- some community services will assist with medication management e.g., EACH or CACP
- the Commonwealth Government has produced a MediList card, which is specially designed to help people, or their carers keep track of their current medications and relevant instructions including dosage and when medication is to be taken. It is also a convenient way of communicating about medications to various health workers. The card is available as part of the Carer Support Kit which is free to carers.

Useful resources:

- Independent Living Centre [www.ilc.com.au](http://www.ilc.com.au)
- [www.dementiatechnology.org.au](http://www.dementiatechnology.org.au) home checklist, DVD, website virtual tours, posters and help sheets
- The National Dementia helpline 1800 100 500
- Alzheimer's Australia at [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Alzheimer's Australia Working with Doctors help sheet [http://www.alzheimers.org.au/common/files/NAT/20050700\\_Nat\\_HS\\_2.9WorkingWithDoctors.pdf](http://www.alzheimers.org.au/common/files/NAT/20050700_Nat_HS_2.9WorkingWithDoctors.pdf)
- Carers Australia 1800 242 636 for free Carers Support Kit that contains the MediList document
- PBS Information Line on 1800 020 613.

## Smoking

This section has been included to provide some strategies to assist in maintaining safety for people who wish to continue smoking, as it may be an activity that was previously enjoyed by the person.

Possible problems or concerns:

- the person may no longer respond to the dangers associated with smoking
- at risk of burning self
- igniting furniture, clothing, or flooring leading to a house fire.

Possible solutions:

- minimise clutter and remove potentially flammable materials from in and around the home
- develop a routine e.g., smoking after a meal
- sleeves with snug fitting cuffs
- provide supervision at all times when smoking
- store smoking implements in a lockable cabinet
- purchase clothes that are flame retardant. These are available from suppliers of work clothes. Some department stores may stock flame resistant clothing
- purchase flame retardant furniture and fixtures
- Utilise a smoker's apron. Information about these products is available from the ILC
- purchase child safety lighters
- use a heavy based ashtrays with a cigarette holder to minimise the chance of the ashtray being knocked over or a forgotten cigarette to fall onto the floor or furniture
- ensure there are working smoke detectors in the home and other fire safety equipment e.g., fire blankets
- place no smoking signs in areas of the home you want to remain smoke free
- assistance with stopping smoking is available from doctors or Quitline 13 18 48.

## **Instrumental Activities of Daily Living (IADL's)**

### **Meal Preparation**

Consider the functional and symbolic value of the kitchen. For many people it is the hub of the house.

Possible problems or concerns:

- stove accidents: leaving hot plates or oven on, burning food or saucepans dry, burns from touching hot plates, putting inappropriate things in a hot stove. All resulting in the potential to start a fire
- stove skills: forgetting how to use hot plates or oven, problems with setting temperature of hotplates or oven, problems reading/using dials or leaving gas on
- not turning off the kettle/electric jug or toaster
- eating or drinking harmful substances or out of date food stuffs e.g., concentrated food stuffs such as hot sauce or pickles, medications and vitamins, household cleaning products, disinfectants, kerosene, insecticides or baits, cosmetics, alcohol or painting products
- forgetting to eat or drink
- forgetting where items are kept resulting in difficulty locating and replacing food or kitchen items
- taps: difficulty turning on/off taps, scalds or burns from hot tap, forgetting which tap is hot and cold, leaving taps running, overflowing sink
- difficulty judging edge of bench tops or furniture resulting in broken crockery, spills and skin injuries from bumping into things
- inappropriate use of sharp objects.

Possible solutions:

- use written reminders such as 'turn off the stove' and place them in a location the person will be seen
- sensors can be used to detect extreme temperatures and turn off gas or electrical appliances. New appliances may have this technology incorporated
- stove-top monitors
- electric or gas auto cut off safety device for oven or stove
- plug in gas alarms. These plug into a power point and detect escaping gas or unignited gas
- vigil electric or gas isolation system is a stove isolation system that automatically switches off after 20 minutes. There is a bypass switch that allows others to use the stove for up to 2 hours. These should be installed by a licensed fitter
- induction cook-tops use a magnetic field to heat saucepans and their contents and the cook-top stays quite cool
- oven guard to prevent contact burns
- have circuit breakers/isolation switches installed
- keep emergency phone numbers, first aid and poisons information by the phone or in the kitchen. Include the persons address and a description of where they live
- ensure smoke detectors/fire extinguishers are in good working order. Batteries should be changed every six months on smoke detectors and they should be vacuumed monthly to clear from dust build-up
- ensure safe storage of chemicals and other hazardous products
- reduce clutter on bench tops and cupboards
- store frequently used items in a prominent location that is easily accessible
- use labels or signs with words or pictures on cupboards and drawers
- open shelving or remove cupboard doors to assist with locating contents
- use clearly labeled or transparent containers
- if it is no longer safe for the person to participate in kitchen tasks, consider providing a chair so that the person can observe the carer complete the tasks

- when it becomes too hazardous for the person to be in the kitchen area consider using a lock on the door or blocking entry with furniture, a safety gate or barn door
- use D shaped handles on drawers
- easy cookbooks and shopping list
- flood prevention and detection e.g., water overflow prevention device in sink, pressure release plug, tap caps
- non slip flooring
- simplified appliances e.g., microwave with dial or large clear buttons, kettle with safety cut off and retractable cord, signs with step by step instructions for appliance use
- provide written directions for using common household items and appliances
- shallow depth fridge with freezer underneath
- thermo mixing valve or hot water cut off device to prevent scalds/burns
- make meals a shared social experience wherever possible
- ensure adequate lighting in kitchen, at table or counter
- use an electric monitor in the kitchen or dining area to assist with detecting or monitoring when the person is in those areas
- purchase a kettle that has an automatic cut-off switch to prevent it from boiling dry
- purchase appliances with retractable or spiral safety cords
- appliance locks can be used on microwaves, fridges and ovens. These can be purchased from hardware stores or stores that sell children's safety products
- delivered meals such as Meals on Wheels and Home Chef
- home support to assist with meal preparation, serving and prompting to eat
- pre-prepared meals from the supermarket
- family and friends helping to prepare meals or delivering food
- preparing large quantities of food and freezing meal size portions
- home delivery from restaurants
- eating out: you should check that the person with dementia is comfortable with the venue etc.
- stock up on healthy snacks that don't require preparation such as yoghurt, cheese and dried fruit.

Useful resources:

- Independent Living Centre [www.ilc.com.au](http://www.ilc.com.au)
- [www.dementiatechnology.org.au](http://www.dementiatechnology.org.au) home checklist, DVD, website virtual tours, posters and help sheets
- The National Dementia helpline 1800 100 500
- Commonwealth Carer Respite Centre 1800 059 059
- Commonwealth Carer Resource Centre 1800 242 636
- Referral to social work
- Alzheimer's Australia at [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Alzheimer's Australia The kitchen help sheet <http://www.alzheimers.org.au/common/files/NAT/20100920-Nat-Helpsheet-Kitchen-environment-and-dementia.pdf>.

## Cleaning

Possible problems or concerns:

- difficulty remembering to clean areas of the home
- lack of initiative
- changes to vision: reduced ability to see areas that may need attention
- misusing cleaning products
- falls or slips in wet areas.

Possible solutions:

- family/friends assist with cleaning or provide supervision
- referral to social work for linkage to community services
- simplifying the task
- simplifying equipment
- encourage the person to complete the parts of the tasks that they are able to do safely
- safe storage of hazardous products.

Useful resources:

- Independent Living Centre [www.ilc.com.au](http://www.ilc.com.au)
- [www.dementiatechnology.org.au](http://www.dementiatechnology.org.au) home checklist, DVD, website virtual tours, posters and help sheets
- The National Dementia helpline 1800 100 500
- Alzheimer's Australia at [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Commonwealth Carer Respite Centre 1800 059 059
- Commonwealth Carer Resource Centre 1800 242 636
- referral to social work.

## Laundry

Possible problems or concerns:

- access to hazardous or poisonous substances
- potential for burns or scalds
- potential for flooding
- potential fire hazards
- potential electrocution.

Possible solutions:

- securely store cleaning products, bleaches, poisons and detergents
- lockable cabinets or Mag locks on cupboards and drawers
- flood prevention and detection: devices such as flood detector, pressure sensitive sink pug (magi plug)/water overflow prevention device for the sink
- fire prevention/lint filters
- thermostatic mixing valves or hot water cut off device to prevent scalds
- appliances: labels and signs or appliance locks, isolation switches, gas detectors, auto-cut off devices
- combined washer/dryer
- iron with automatic cut off switch if left unattended or face down
- iron safe: a small storage unit that the iron can be placed in as it takes approximately 30 minutes for the iron to cool down after use. Using the iron safe will prevent burns
- ironing cabinets to store ironing board out of view or to remove trip hazard
- tap cap: a cover that is designed to fit over round tap handles and prevent the tap from being used
- pressure sensitive sink plugs or magi plugs to prevent overflow
- appliance locks
- combined washer/dryer may assist a person to remain independent with completing laundry
- flood detectors.

Useful resources:

- Independent Living Centre [www.ilc.com.au](http://www.ilc.com.au)
- [www.dementiatechnology.org.au](http://www.dementiatechnology.org.au) home checklist, DVD, website virtual tours, posters and help sheets
- Commonwealth Carer Respite Centre 1800 059 059
- Information about subsidised help with laundry may be available from the Carers Respite Centre
- Commonwealth Carer Resource Centre 1800 242 636
- referral to social work
- The National Dementia helpline 1800 100 500
- Alzheimer's Australia at [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Alzheimer's Australia The laundry help sheet  
<http://www.alzheimers.org.au/common/files/NAT/20100920-Nat-Helpsheet-Laundry-environment-and-dementia.pdf>.

## Shopping

Possible problems or concerns:

- unable to remember what items need to be purchased
- buying duplicate items
- difficulty accessing shops
- difficulty navigating their way around the shop
- difficulty handling money (refer to financial management section)
- difficulty unpacking groceries.

Possible solutions:

- lists become important for people with early stage dementia to avoid forgetting items or buying duplicates
- it may be possible to ask a trusted shop keeper to hold a standard list at the shop to help avoid duplicating items or buying unnecessary items
- home delivery is available at numerous major retail outlets
- internet shopping maybe a suitable alternative. Family or carers can order for the person
- label items fridge, pantry etc., to assist the person in participating in unpacking the groceries
- if possible buy the same brands, containers and labels to help the person recognise the product
- referral to social work for linkage with community services to assist with shopping.

Useful resources:

- The National Dementia helpline 1800 100 500
- Alzheimer's Australia at [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Independent Living Centre [www.ilc.com.au](http://www.ilc.com.au)
- [www.dementiatechnology.org.au](http://www.dementiatechnology.org.au) home checklist, DVD, website virtual tours, posters and help sheets
- Commonwealth Carer Respite Centre 1800 059 059
- Commonwealth Carer Resource Centre 1800 242 636
- referral to social work.

## **Gardening and Outdoor Areas**

Outdoor areas are important to consider for two reasons: (1) safety and security and (2) enjoyment and pleasure. An unmaintained garden can be a sign that a vulnerable person lives in the home. Gardening tasks such as watering, viewing flowers and trees, digging and planting promote an overall sense of wellbeing. Gardens should be designed to be safe, secure and private, with non-poisonous, pleasant smelling plants that are cared for easily. Ideally the secure garden would lead directly from the back door with a circular path returning to that starting point.

Possible problems or concerns:

- falls
- poisoning
- wandering away from home
- electrocution or injury from power tools.

Possible solutions:

- easy access: easy to open doors
- sensory: absence of paving glare, use of appealing textures, activity paths for walking, fishpond to watch
- non toxic plants or plants that don't drop leaves, berries,
- consider removing water features and sharp spiky plants
- visual access to encourage outdoor activity without glare
- visual appeal
- use polarised sunglasses
- automated watering system
- raised garden beds or activity bench
- comfort: shade, seating with arm rests and backrests
- safety/Security: smooth level surfaces, absence of physical hazards
- pathways, stairs and ramps: level, sheltered, clearly lit, non-slip, contrasting edges, visible both day and night and free from hazards

- solar powered garden lights
- glow in the dark guidance strips
- a garden shed can be a memory cue for gardening activities
- lockable storage of chemicals and electrical/hazardous tools
- remove hazardous substances (chemicals and petrol) and complex tools
- yard free from rubbish and well maintained
- garbage disposal: local services may assist. Discuss with a social worker.

Useful resources:

- The National Dementia helpline 1800 100 500
- Alzheimer's Australia at [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Independent Living Centre [www.ilc.com.au](http://www.ilc.com.au)
- [www.dementiatechnology.org.au](http://www.dementiatechnology.org.au) home checklist, DVD, website virtual tours, posters and help sheets
- Commonwealth Carer Respite Centre 1800 059 059
- Commonwealth Carer Resource Centre 1800 242 636
- referral to social worker.

## Managing Finances

As dementia progresses the person's ability to make legal and financial decisions will decrease.

Possible problems or concerns:

- forgetting to pay bills
- unsafe storage and disposal of financial information e.g., deeds to the home, shares or bonds
- unsafe management of finances.

Possible solutions:

- establish a routine and pay bills as soon as they arrive
- use a diary to track when bills are due and have been paid
- set up computer reminders
- separate sections on a notice board for bills due or bills paid may assist with organising payments
- using a bill organiser or folder such as a ring folder with separate sections or an expander file that can be customised
- setup automated payments or a fixed payment system. Discussing suitable options with the financial institution will ensure the best possible solution
- using a Doorganiser: a canvas wallet for storing bills that need to be paid
- utilising a lockable box or safe to store important papers
- plan ahead and obtain legal and financial advice while the person with dementia can still participate in the discussions
- enduring Power of Attorney (EPA). Should be arranged early – when mild cognitive loss. This allows another person to manage the individual's financial affairs, if they are no longer capable
- make or update Will, of the person with dementia, while they are considered capable of doing so. Consider Enduring Power of Guardianship

- guardianship may be appointed by the state government to act on behalf of the person who has lost the ability to make their own decision
- contacting Centrelink regards pharmaceutical allowance, rent assistance, telephone allowance, bereavement payment, pensioner concession card, non-pension concessions.

Useful resources:

- The Public Trustee, community legal centres, a solicitor or law society can assist with making a Will
- Alzheimer's Australia, a solicitor, The Law society, The Office of Public Guardian or The Office of Public Advocate can assist with information regarding the arrangement of an EPA. The Department of Health and Ageing 1800 020 103 can provide contact details for the aforementioned services
- Independent Living Centre [www.ilc.com.au](http://www.ilc.com.au)
- [www.dementiatechnology.org.au](http://www.dementiatechnology.org.au) home checklist, DVD, website virtual tours, posters and help sheets
- The National Dementia helpline 1800 100 500
- Alzheimer's Australia at [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Centrelink 13 27 17 [www.centrelink.gov.au](http://www.centrelink.gov.au)
- Centrelink's financial information service 12 23 00.

## Using the Telephone

Refer to communication section for tips and advice regards communication difficulties.

Possible problems or concerns:

- difficulty remembering important phone numbers
- difficulty using phone
- difficulty understanding what is being said
- dialing incorrect numbers
- forgetting what the purpose of the phone call is/was.

Possible solutions:

- keep a notebook and pen beside the phone to record messages
- write down messages whilst talking with the person, ask them to repeat the information if necessary. Repeat what you have written to the person to check for accuracy
- request people speak slower, louder
- have a regular spot in the home to store messages like the hall table
- purchase a phone with larger buttons
- display emergency and commonly used numbers by the phone
- if living alone, the phone number of the main carer or relative could be programmed into the phone memory and labeled simply. This can be done using the memory dialing function on standard touch telephones.
- smart caller blue phone or picture phone. These phones have larger buttons, option of one touch dialing which can be personalised by a photo. Some models may include alarms that can be set for reminders. <http://www.bluephone.com.au/>
- contacting Centrelink regards telephone allowance.

Useful resources:

- Independent Living Centre [www.ilc.com.au](http://www.ilc.com.au)
- [www.dementiatechnology.org.au](http://www.dementiatechnology.org.au) –home checklist, DVD, website virtual tours, posters and help sheets
- The National Dementia helpline 1800 100 500
- Alzheimer's Australia at [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Centrelink 13 27 17 [www.centrelink.gov.au](http://www.centrelink.gov.au).

## **Pets**

Dogs, cats and other pets are cherished by many people as they provide companionship, comfort, and unconditional love. For people living with dementia maintaining a pet has been an important role and responsibility and may have assisted in defining who they are. Animal interaction has a beneficial effect on a person's wellbeing and may also minimise the confusion experienced by the onset of dementia or assist with reducing agitation.

Possible problems or concerns:

- difficulty caring for the pet
- mistaking pet food for human food
- difficulty tidying up after pet (hair, bodily functions)
- potential trip/fall hazard
- pet running away or onto a road
- inappropriate matching of pet and person
- getting lost when walking the pet
- lack of people available to care for pet if person is hospitalised.

Possible solutions:

- visual cues such as a sign to remind the person to feed their animal
- automatic pet feeders
- use a calendar to record when pets should receive worm or flea treatments. Some veterinary surgeries will contact pet owners to remind them
- ensure all pet food is clearly labeled and stored correctly
- ensure fencing is maintained and doors are closed
- install pet doors to allow pet to enter and exit home
- ensure pets are micro chipped
- discuss suitable breeds with a veterinarian
- see wandering section for solution to getting lost
- emergency pet care services offer to pick up and care for pets while their owners are hospitalised
- animal assisted therapy: dogs are trained to assist people living with dementia. Further information is available from disability services
- robotic pets.

Useful resources:

- The National Dementia helpline 1800 100 500
- Alzheimer's Australia at [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Independent Living Centre [www.ilc.com.au](http://www.ilc.com.au)
- [www.dementiatechnology.org.au](http://www.dementiatechnology.org.au) home checklist, DVD, website virtual tours, posters and help sheets
- Alzheimer's Australia Pets help sheet  
<http://www.alzheimers.org.au/common/files/NAT/20101020-Nat-Helpsheet-Pets.pdf>.

## Community and Leisure Activities

Engaging in leisure activities provides physical, social and emotional benefits that positively affect our health. People with dementia gradually withdraw from leisure activities or engaging in society and may become socially isolated.

### Possible solutions

- place one interesting activity, game or item in a prominent position where it will be noticed. Once interest declines replace with another item of similar skill level and interest
- choose activities that are familiar, repetitive, require one step directions or tap into former interests or hobbies
- choose movies and music that are era specific for the person
- simplify one area of the home (indoors or outdoors) where the person with dementia can potter and roam freely
- utilise an electronic monitor to make supervision easier
- plan leisure as a part of the daily routine
- encourage exercise and activities that require no strenuous gross motor actions. Walking with another person is an excellent activity. Try to choose a circular route as it can be difficult to get someone with impaired memory to turn around. You can try stopping, distracting with an object e.g., tree, flowers and then walking in the direction that you want to continue
- avoid competitive games or activities. Choose activities that meet the person's capabilities
- simplify the rules of the game to encourage success
- utilise talking books if reading has become difficult
- make a family history book
- family photo boards. Use captions to assist with memory/orientation
- talking photo albums: available from specialty photographic stores
- digital photo frames
- make DVD's from family photos
- utilise easy cookbooks i.e. large font, spiral bound with step by step instructions

- set up the computer so that the person with dementia logs on by using the icon with their name. The account can be set up with internet sites relevant to the person's interests. The size of the text and number of sites that can be visited can be modified or restricted
- automated home system can communicate with and operate home entertainment systems. It can be programmed to be turned on at a specific time of the day and can be tailored to the person's interests. It operates via a touch screen
- encourage the person to watch the activities of the neighbourhood from a window or veranda
- travel away from home is encouraged if the person can tolerate the changes. Try to preserve the daily routine, plan frequent rest breaks, take a third person if able to assist with the caring role. Take a recent photo of the person in case they become lost. A card with the care givers details and person's details can be placed in a pocket or purse. When traveling bring a security item for the person with dementia
- if using air as mode of travel notify the airline that you are travelling with somebody with memory impairment
- utilise community day centres
- join a group for people with dementia.

Useful resources:

- Independent Living Centre [www.ilc.com.au](http://www.ilc.com.au)
- [www.dementiatechnology.org.au](http://www.dementiatechnology.org.au) home checklist, DVD, website virtual tours, posters and help sheets
- The National Dementia helpline 1800 100 500
- Alzheimer's Australia at [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Alzheimer's Australia Keeping involved and active help sheet [http://www.alzheimers.org.au/common/files/NAT/20050700\\_Nat\\_HS\\_8.7KeepingInvolvedActive\(1\).pdf](http://www.alzheimers.org.au/common/files/NAT/20050700_Nat_HS_8.7KeepingInvolvedActive(1).pdf)
- Alzheimer's Australia activities help sheet [http://www.alzheimers.org.au/common/files/NAT/20050700\\_Nat\\_HS\\_2.5Activities.pdf](http://www.alzheimers.org.au/common/files/NAT/20050700_Nat_HS_2.5Activities.pdf)
- Commonwealth Carer Respite Centre 1800 059 059
- Commonwealth Carer Resource Centre 1800 242 636
- referral to social work.

## Transport and Driving

For the person with dementia driving and relinquishing their driver's licence may be an extremely sensitive subject. If family have concerns about the person's ability to drive, they should discuss these with the person's GP or equivalent. Similarly when completing their assessment and intervention, if an OT at Osborne Park Hospital is made aware of any concerns with regards to driving and safety issues these should be discussed with the consultant or the referring GP. A diagnosis of dementia does not always mean that a person is immediately incapable of driving. Dementia can cause loss of memory, limited concentration, reduced judgement and sight problems which may affect a person's judgement and ability to drive safely over time (Lovell and Russell, 2005).

Warning signs for family/friends that dementia may be affecting a person's driving:

- vision: Can they see things coming straight at them or from the sides?
- hearing: Can they hear the sound of approaching cars, car horns and sirens?
- reaction time: Can they turn, stop or speed up their car quickly?
- problem solving: Do they become upset and confused when more than one thing happens at the same time?
- coordination: Have they become clumsy and started to walk differently?
- alertness: Are they aware and can they understand what is happening around them?

Other considerations:

- can they tell the difference between left and right?
- do they become confused on familiar routes?
- do they understand the difference between Stop and Go lights?
- are they able to stay in the correct lane?
- can they read a road map and follow detour routes?
- has their mood changed when driving? Some previously calm drivers may become angry or aggressive.

Dementia is listed as one of the medical conditions that must be reported to the Department of Transport. The Department of Transport have developed a brochure 'Mandatory Reporting of Medical Conditions', copies of which are available in the Osborne Park Hospital OT department. Further information can be obtained via the following link <http://www.transport.wa.gov.au/licensing/20395.asp> or by contacting The Department of Transport office on 1300 852 722.

People deemed safe to continue driving may be eligible for an ACROD permit. ACROD applications may be completed by OT's and can be downloaded from the ACROD parking program website [www.app.org.au](http://www.app.org.au)

Eventually the person with dementia will have to stop driving. Some people decide to voluntarily relinquish their licence or their doctors will sometimes recommend that a person should stop driving. If there is any doubt about a person's competence to continue driving an OT driver assessment should be conducted. This assessment involves both on-road and off-road components. Lovell and Russell (2005) recommend that people with dementia where deterioration of performance is expected reassessment occurs every six months. A list of driver assessment services is available from the Osborne Park Hospital OT department.

Some people find giving up driving to be one of the hardest things to do, as driving may be an important part of their independence. There are alternatives which may make the process less stressful.

These include:

- asking a family member or friend to give them a lift
- walking
- community transport or voluntary agencies. Check with the local council or phone the Commonwealth Respite and Carelink Centre on 1800 052 222
- taxi subsidy schemes may be available. Ask the person or their family to discuss with their GP or contact Centrelink
- using buses, trains or taxis – is more difficult as dementia increases.

## Public Transport

To travel alone on public transport a person with dementia needs to be able to:

- cross the street safely, with or without traffic lights
- recognise and board the correct bus/train
- recognise their correct stop
- ask for help if required
- deal with unexpected situations, such as cancellation of services.

To assist with planning a journey or checking timetables, visit the Transperth webpage <http://www.transperth.wa.gov.au/> Another alternative is a GPS car navigation system. The person with dementia would need to be familiar with this technology to use it correctly. GPS tracking technology is also available in various forms; for example this technology can assist the family in monitoring the person's movements.

If family members or friends are worried that the person with dementia will still drive even when their licence has been revoked or they are deemed not safe there are some useful strategies. The family can consider:

- removing car keys from the home
- have an immobiliser installed. Contact the National Motor Vehicle Theft Reduction Council for more details 1300 132 146
- encourage the person to sell their car
- a seat belt alarm can also be fitted to alert the driver if the seatbelt is not properly fastened.

Useful resources:

- The National Dementia helpline 1800 100 500
- The National Dementia Behaviour Advisory Service 24 hours 7 days a week service 1300 366 448
- ILC [www.ilcaustralia.org](http://www.ilcaustralia.org)
- For handouts regards technology and driving visit [www.dementiatechnology.org.au](http://www.dementiatechnology.org.au)
- Alzheimer's Australia [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Alzheimer's Australia driving help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_2.7Driving.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_2.7Driving.pdf)
- Alzheimer's Australia driving and dementia help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20050700\\_Nat\\_HS\\_8.4Driving.pdf](http://www.alzheimers.org.au/common/files/NAT/20050700_Nat_HS_8.4Driving.pdf)
- The medical standards for driving are contained in the document Assessing Fitness to Drive, which is available at [www.austroads.com.au/aftd](http://www.austroads.com.au/aftd). Dementia is listed under section 14
- The Australian Disability Parking Scheme /ACROD [www.app.org.au](http://www.app.org.au).

## Communication

We communicate to convey our thoughts, emotions or ideas. According to Nichols and Graham (2008) communication is made up of three parts:

- 55% is body language which is the message we give out by our facial expression, posture and gestures
- 38% is the tone and pitch of our voice
- 7% is the words we use.

Losing the ability to communicate can be one of the most frustrating and difficult problems for people with dementia, their families and carers. As the illness progresses, a person with dementia experiences a gradual lessening of their ability to communicate. They find it more and more difficult to express themselves clearly and to understand what others say. The attitude and behaviour of the person interacting with a person with dementia can impact positively or negatively on communication.

Possible problems or concerns:

- word finding difficulties
- speaking fluently, but not making sense
- reduced ability to understand what people are saying
- deterioration of writing and reading skills
- loss of the normal social conventions of conversations e.g., interrupt or ignore a speaker, or fail to respond when spoken to
- difficulty expressing emotions appropriately
- difficulty conveying needs
- inability to understand abstract or complex concepts
- pain may lower the persons tolerance threshold which may result in miscommunication
- environmental distractions e.g., noisy, crowded areas
- missing appointments or confused about daily schedule
- social isolation or changes to friendships.

Possible solutions:

- it is important to check that hearing and eyesight are not impaired. Check that hearing aids are functioning correctly and glasses are cleaned regularly
- a 'This is Your Life' book with information about the person's social, work and medical history, their likes and dislikes, etc., can help carers and service providers understand the person with dementia better and it also provides prompts and cues to assist conversation
- a 'communication book' by the phone or somewhere handy for family, carers and service providers to leave messages for each other can help everyone know what's been happening and who has been to visit
- utilise a diary, noticeboard or note book
- paint an area on the refrigerator with blackboard paint and use as a notice board
- Alzheimer's Australia has produced a card which can be offered discretely to service providers, shop assistants or receptionists to engage their support. The card, which is available free from Alzheimer's Australia, says: My companion has an illness which causes memory loss and confusion. Please understand any unusual behaviour.
- difficulty in maintaining friendships
- remember that people with dementia retain their feelings and emotions even though they may not understand what is being said, so it is important to always maintain their dignity and self esteem. Use touch to keep the person's attention and to communicate feelings of worth and affection.
- talk in a gentle, matter-of-fact way
- keep sentences short, focusing on one idea at a time
- utilise written messages. Use large clear letters
- allow plenty of time for what you have said to be understood. Silence can give time to think and respond
- try not to finish sentences or words for people. Give them time to complete it themselves
- it can be helpful to use orienting names whenever you can, such as "Your daughter Rosemary"
- you may need to use hand gestures and facial expressions to make yourself understood. Pointing or demonstrating can help.

- touching and holding the persons hand may help keep their attention and show that you care (noting cultural sensitivities).
- a warm smile and shared laughter can often communicate more than words can
- minimise distractions by turning off competing noises such as TV or radio
- stay still and in a direct line of sight while talking you will be easier to follow
- maintain regular routines to help minimise confusion and assist communication
- it is much less confusing if everyone uses the same approach. Repeating the message in exactly the same way is important for all the family and all carers
- utilise ear plugs for a visit to shopping centres, or other noisy places
- validation Therapy is based on the idea that once the person has experienced severe short term memory loss and can no longer employ intellectual thinking or make sense of the present; he or she is likely to go back to the past. This may be in order to resolve unfinished conflicts, relive past experiences or to retreat from the present over which they have little control. Some people will go in and out of the present. Validation Therapy avoids challenging their reality. This approach allows the person's dignity and self esteem to be maintained
- activities that involve music are an effective way of communicating with a person who has dementia. Music may unlock memories or feelings and can be used to aid reminiscence. Music can be used just for pleasure, as a calming aid or as a therapy. It is important to know what type of music a person likes. A music therapist maybe utilised to aid in addressing difficult behaviours
- reminiscence Therapy can be utilised to assist with relieving anxiety and distress. It is a way of reviewing past events that is usually a very positive and rewarding activity. It can be used with people who are non verbal. Careful monitoring of the person's reaction is required. If it is too distressing then another technique should be utilized.
- Automated home systems can use wireless or hard wired technology to operate appliances, water usage and security in the home as well as communicating this information to call centres. Some systems can monitor when people leave and return home and notify a carers if there are changes to the routine that indicate the person may be unwell or injured.

Tips for effective communication:

- approach the person in their line of sight
- sit or stand at their eye level
- use non verbal communication to gain the person's attention  
e.g., eye contact or gentle touch
- remain still and at eye level
- be calm, reassuring and keep body language open
- speak clearly and use simple language
- give one message/instruction at a time
- utilise visual and non verbal cues where appropriate
- incorporate active listening techniques such as paraphrasing, nodding
- validate the persons feelings
- consider any cultural or language barriers. Seek assistance if required.

### **Culturally and Linguistically Diverse Groups (CALD)**

CALD groups may have their own specific communication norms such as it is considered disrespectful to make eye contact with certain elders. Attitudes to personal space and touch may differ between CALD groups. The National Cross Cultural Dementia Network (NCCDN) provides advice to Alzheimer's Australia on dementia information provision, resource development and service delivery for CALD communities.

Interpreters, not family, are the appropriate communication method for all important information.

Dementia information is available in a number of languages from Alzheimer's Australia including Arabic, Armenian, Chinese, Croatian, Dutch, German, Greek, Hindi, Hungarian, Indonesian, Italian, Japanese, Khmer, Korean, Laotian, Latvian, Macedonian, Malay, Maltese, Polish, Portuguese, Romanian, Russian, Serbian, Spanish, Tagalog, Turkish, Ukrainian and Vietnamese from the following link <http://www.alzheimers.org.au/understanding-dementia/information-in-other-languages.aspx>

Resource kits and materials specifically designed for Aboriginal and Torres Strait Islander communities are available at the following links

- 'Understanding Dementia' <http://www.alzheimers.org.au/understanding-dementia/dementia-learning-resource-for-aboriginal-and-torres-strait-islander-communities.aspx>
- 'Looking out for Dementia' <http://www.alzheimers.org.au/northern-territory/looking-out-for-dementia.aspx>
- 'Dementia learning resource for Aboriginal and Torres Strait Islander Communities' is a learning package specifically designed for use with Aboriginal and Torres Strait Islander Communities. It was funded by the Department of Health and Ageing and Alzheimer's Australia. A copy is available in The Osborne Park Hospital OT department. For further information follow the link below <http://www.health.gov.au/internet/main/publishing.nsf/Content/Aboriginal+and+Torres+Strait+Islander+Health-11p>.

Useful resources:

- The National Dementia Helpline 1800 100 500
- The National Dementia Behaviour advisory Service 24 hours 7 days a week service 1300 366 448
- Alzheimer's Australia [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Alzheimer's Australia communication help sheet [http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_2.1Communication.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_2.1Communication.pdf)
- Alzheimer's Australia therapies and communication approaches help sheet [http://www.alzheimers.org.au/common/files/NAT/20050700\\_Nat\\_HS\\_2.2TherapiesCommApproaches.pdf](http://www.alzheimers.org.au/common/files/NAT/20050700_Nat_HS_2.2TherapiesCommApproaches.pdf)
- Christine Bryden's book *Who will I be when I die?*, the first book written by an Australian with dementia
- Referral to a speech therapist maybe beneficial in assessing a person's abilities and needs
- ILC NSW Helpful Handbook for Memory Loss available <http://www.ilcnsw.asn.au/assets/HelpfulHandbookForMemoryLoss.pdf>
- Alzheimer's Australia WA is currently researching a communication aid for people with dementia with word finding difficulties
- Free Carer Support Kit available in multiple languages and for young carers or aboriginal carers from Commonwealth Respite and Carelink Centres 1800 052 222
- National Aboriginal and Torres Strait Islander Dementia Advisory Group (NATSIDAG) information available via <http://www.alzheimers.org.au/understanding-dementia/aboriginal--torres-strait-islander-groups.aspx>
- Western Australian Centre for Health and Ageing (WACHA) Indigenous Dementia Services Study <http://www.wacha.org.au>
- Kimberley Indigenous Cognitive Assessment (KICA) <http://www.wacha.org.au/kica.html>
- Centrelink Information in other languages 13 12 02 [www.centrelink.gov.au](http://www.centrelink.gov.au).

## Memory and Orientation

Memory loss is one of the main symptoms of dementia. It is usually persistent and progressive. Remembering the date, day of the week or making sense of the environment are some of the difficulties people with dementia may experience. These difficulties can make attending appointments, remembering to take medications or pay bills difficult. The effort often results in anxiety, embarrassment or can compromise a person's safety.

Possible solutions:

- use a diary with day per page or notebook/communication book
- use a whiteboard or cork board to record important numbers, messages or daily tasks
- use labels or signs
- use clocks and watches with large numbers. If the person lives alone check the batteries regularly
- talking alarm clocks available from electronic stores
- automatic calendar clocks. These clocks usually show the time, date, day of the week and month
- orientation boards these usually require a carer to update the details
- label photos, talking photo albums, digital photo frames
- to assist with remembering important information when attending appointments prepare necessary documentation in advance and store in a location that is prominent. Utilise notes as a reminder to collect the information or ask someone else to attend with appointment
- a weekly timetable of regular visitors or appointments positioned near the clock/calendar can assist with orientation. Crossing off each visit or task when it is completed can further assist with orientation
- take photos of regular service providers such as day centre staff, community transport driver or the Meals-on-Wheels person. It may also be possible to get a photo of the social group at the day centre. Place photographs on the fridge or whiteboard alongside regular appointments or visits and label with names. Use them to prepare a person for visits

- the delivery of a daily newspaper may assist people to know the day and date. Removal of the old papers is required to avoid confusion
- wireless key/item locators are available from selected electronic stores. They are a set of four locators that can be attached to any item or object that a key ring can attach to or by using double sided Velcro. When the button is pressed the receiver sends a signal to the locator and sets off a beeping sound
- 'Doorganiser': a canvas wallet designed to hang from a door handle and store items such as glasses, keys, phones
- memory jogging devices can record multiple messages or memory prompts and play them back at defined times of the day
- reminder wrist watch: a watch that can be programmed with messages and alarms. It can be used to help the person remember medication or appointments
- mobile phones with a record and playback option may assist with locating items such as where the car is park in a busy shopping centre. Some phones allow for the transfer of Microsoft outlook express calendar from the computer to the phone
- talking labels are reusable magnetic cap that is the size of a tin can and is able to record a 10 second voice message that identifies the contents of the can.

Useful resources:

- The National Dementia helpline 1800 100 500
- Alzheimer's Australia at [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Living with Memory Loss Program- a support group for people living with early stage dementia, their family or friends run by Alzheimer's Australia.
- Alzheimer's Australia has two calendars available for people with dementia either living at home or in residential care ph 9388 2800
- Alzheimer's Australia memory changes help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20050700\\_Nat\\_HS\\_1.7MemoryChanges.pdf](http://www.alzheimers.org.au/common/files/NAT/20050700_Nat_HS_1.7MemoryChanges.pdf)
- Alzheimer's Australia memory aids in the home help sheet  
<http://www.alzheimers.org.au/common/files/NAT/20100920-Nat-Helpsheet-MemoryAids-in-thehome-environment-and-dementia.pdf>
- Alzheimer's Australia Keep your brain active mental exercise and dementia help sheet <http://www.alzheimers.org.au/common/files/NAT/20100920-Nat-UpdateSheet10-Keep-your-brain-active.pdf>
- Alzheimer's Australia Problem solving help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_5.2ProblemSolving.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_5.2ProblemSolving.pdf)
- referral to a memory clinic if deemed appropriate by the medical team.

## Wandering

Wandering manifests itself in many forms and may include trying to leave the home, aimless wandering or pacing, rummaging or looking for lost items or hoarding items. Wandering can be difficult for caregivers to manage and has been described as the most distressing aspect of cognitive impairment (Hornbrook, et al., 1994; Oddy, 2003). The Alzheimer's Association states that people who wander are at increased risk for falls, serious injuries, nursing home placement, being restrained, and death.

Possible causes of wandering:

- pain or discomfort e.g., constipation, inadequate seating
- mobilising to relieve stiffness but forget that is why they are mobilising and continue to move about
- on their way to a destination e.g., the toilet and forget where they are going
- restlessness as a side effect of some medications, or pain
- changes to sleep wake cycles
- boredom
- searching for someone or something familiar
- seeking attention/reassurance
- over stimulation from environment e.g., noise, activity, lighting
- relocation to unfamiliar environment.

Possible problems or concerns:

- leaving the home and getting lost or injured
- falls
- seeking tactile input
- searching for lost items
- hiding items
- restlessness
- frequent waking of carer.

Possible solutions:

- place a large 'stop' or 'authorised personnel only' sign on doors that leads outside may deter people using the doorway
- utilise an electronic monitor to supervise activities from another room
- place bells or alarms on key doors to alert others in the home that the doors are being opened
- disguising a doorway. Consider either painting the door and frame so that they blend in with surrounds, placing a full size mural on the door or using fabric or wallpaper. Fabric covering the doorknob also provides camouflage and discourages the door being opened
- infrared door beams: numerous models available prices vary. A built in buzzer is activated when someone walks through the beam. These products are available from electronic stores. A cheaper alternative is a croaking frog ornament that makes a noise when movement is detected
- install or change the locks on key doors
- chair or bed occupancy sensors are placed under a chair pad or on top of a mattress to monitor movement, they can also identify if a person has not gone to bed or gotten up in the morning. They are linked to a call centre and can be programmed with a time delay prior to raising an alert. These sensors have installation and ongoing costs
- Global Positioning Technology (GPS) and mobile phones: models vary in complexity and price. The tracking device is usually worn or carried by the person with dementia and signals are received by the carer either by text or following on a map on the computer. GPS has limitations as it can't track inside buildings or on some transport. Tracking capacity is also dependent on the service providers' coverage
- Medi-Trak: a small radio transmitter that emits a silent signal which can then be tracked with a directional-finding antenna
- security technology e.g., farm cams maybe used on remote or isolated properties
- portable fencing for remote properties and homesteads
- purchase a medic alert bracelet or have a card on the person at all times with their details (name, address, emergency contact person)
- register for the Safe2walk program

- the home safely program available through the National Dementia Helpline 1800 100 500: a stainless steel bracelet which has a toll free number and identification number linked to a police database
- ask neighbours to watch for the person wandering outside unsupervised
- change the environment to minimise clutter and provide a safe space for the person to wander. A simple environment is less distracting
- provide safe and acceptable outlets for wandering e.g., visiting a museum, shopping complex or strolling around the neighbourhood or yard
- if the person is constantly searching for lost or misplaced items purchase duplicates that can be produced when necessary
- replace valuable items with similar cheaper alternatives such as car keys can be replaced with old house keys
- keep car keys secure and stored safely
- provide a special place that items can be stored safely by the person with dementia
- provide objects that are interesting to touch and manipulate
- leave objects out for easy and safe access
- ensure opportunities for exercise each day. Provide exercise equipment
- utilise a chair with a rocking mechanism to provide tactile input and reduce restlessness
- engage in leisure activities or IADL's to distract from restlessness, wandering
- choose soothing and pleasant activities not activities that are exciting e.g., soothing music
- have a room in the home that has minimal stimulation. When the person becomes restless take them into this room for a rest
- establish a routine to prepare for sleep
- avoid drinks a couple of hours before bedtime to minimise the need to get up at night.

Useful resources:

- Safe2walk service [www.safe2walk.com.au](http://www.safe2walk.com.au)
- The National Dementia Behaviour advisory Service 24 hours 7 days a week service 1300 366 448
- The National Dementia Helpline 1800 100 500
- Alzheimer's Australia [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Independent Living Centre [www.ilc.com.au](http://www.ilc.com.au)
- [www.dementiatechnology.org.au](http://www.dementiatechnology.org.au) home checklist, DVD, website virtual tours, posters and help sheets
- The National Dementia helpline 1800 100 500 or visit Alzheimer's Australia at [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Alzheimer's Australia Wandering help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_5.4Wandering.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_5.4Wandering.pdf)
- Alzheimer's Australia Sundowning help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_5.5Sundowning.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_5.5Sundowning.pdf).

## Catastrophic Reactions

Catastrophic reactions can be unprovoked and are usually upsetting for both the person with dementia and the carer. Catastrophic reactions are reactions that are excessive emotional responses, such as hitting, crying, screaming or pacing, in response to minor stressors (Corcoran and Gitlin, 2001) or a perceived threat. Perceived threats can be external such as disturbing patterns of light or excessive questioning by a health professional or internal such as hallucinations or paranoia (Gitlin and Corcoran, 2005). It can be very difficult to determine what the stimulus was that provoked the reaction, however the person involved should try to determine the source and if possible eliminate or modify it to try and prevent further catastrophic reactions. Care giver coping strategies are reduced by the demands of caring for someone with dementia resulting in a decreased threshold to deal with catastrophic reactions.

Potential threatening stimuli:

- pain
- can be onset of delirium if acute – needs medical / GP review.
- fatigue
- unmet needs
- feeling of insecurity, anger, frustration or fear
- caregiver or health care worker irritation or impatience
- being rushed or hurried
- changes to routine or location
- activities that require close contact such as personal care
- strangers
- over stimulating environments e.g., excess noise, light
- invasion of personal space or possessions.

Possible solutions:

- establish a predictable routine inclusive of low stimulus periods
- establish a low stimulus environment. This could be a room that has calming visual stimuli and a comfortable chair. Conversation should be avoided but touch should be maintained
- look for early warning signs such as wringing of hands, unusual voice pitch, upset expression and provide intervention immediately
- the caregiver should ensure their safety at all times and should never fight back. They should remove themselves from the situation without turning their back on the person. If there is another person available ask them to stay with the person with dementia
- avoid exaggerated or nervous gestures
- reassurance should be offered
- avoid standing over the person with dementia, stay out of their personal space approximately 1 metre
- appear nonconfrontational
- gently tell the person what you want them to do rather than what you want them to stop doing
- never restrain the person with dementia. If possible allow them to choose where they wish to go in the home
- allow the person with dementia to express their feelings.

Useful resources:

- The National Dementia Behaviour Advisory Service 24 hours 7 days a week service 1300 366 448
- The National Dementia Helpline 1800 100 500
- Alzheimer's Australia [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Alzheimer's Australia Anxious behaviours help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_5.6AnxiousBehaviours.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_5.6AnxiousBehaviours.pdf)
- Alzheimer's Australia Aggressive behaviours help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_5.7AggressiveBehaviours.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_5.7AggressiveBehaviours.pdf)
- Alzheimer's Australia Agitated behaviours help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_5.8AgitatedBehaviours.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_5.8AgitatedBehaviours.pdf)
- Alzheimer's Australia Hallucinations and false ideas help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_5.9HallucinationsFalseIdeas.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_5.9HallucinationsFalseIdeas.pdf)
- Alzheimer's Australia Disinhibited behaviours help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_5.10DisinhibitedBehaviours.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_5.10DisinhibitedBehaviours.pdf)
- Alzheimer's Australia Creating a Calming environment help sheet  
<http://www.alzheimers.org.au/common/files/NAT/20100920-Nat-Helpsheet-CalmingEnvironment-environment-and-dementia.pdf>
- Alzheimer's Australia Changed behaviours help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_5.1ChangedBehaviours\(1\).pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_5.1ChangedBehaviours(1).pdf)
- Alzheimer's Australia Depression and Dementia help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_5.3DepressionDementia.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_5.3DepressionDementia.pdf) ; <http://www.alzheimers.org.au/common/files/NAT/20100920-Nat-UpdateSheet15-Depression-and-dementia.pdf>
- Behaviours booklet from Alzheimer's Association America  
[http://www.alz.org/national/documents/brochure\\_behaviors.pdf](http://www.alz.org/national/documents/brochure_behaviors.pdf).

## Pain Management

People with dementia experience pain just like any other person, however pain often goes unnoticed as the person may not be able to clearly communicate that they are in pain. Often the person displays a change in behaviour which isn't interpreted as a reaction to pain. Any indication of pain should be treated quickly and effectively by a doctor.

Potential causes of pain may include:

- osteoarthritis
- history of hip and other types of fractures
- back pain
- cancer
- constipation
- dental problems
- infections
- migraines or headaches
- pressure ulcers.

Possible problems or concerns:

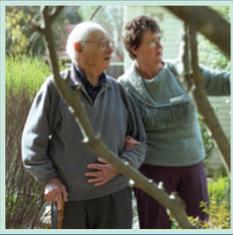
- unable to effectively communicate source of pain or degree of pain
- person may use facial expressions to indicate soreness
- unable to interpret pain signals accurately
- changes in behaviour such as withdrawn, agitated, screaming/ moaning or pacing
- sleeping more than usual
- crying
- reluctance to move
- forgetfulness
- reduced attention
- interrupted sleep/wake cycles
- reduced independence/difficulty completing activities
- delirium.

Possible solutions:

- ask people about their pain at regular intervals and use language that may assist the person to describe their feelings such as discomfort, uncomfortable, hurting, aching or sore
- discuss any concerns regarding pain with the person's doctor, so that the person can be examined and any suitable treatment arranged
- if medication is prescribed to relieve pain it may be important that it is administered regularly, rather than just when signs of pain are present
- massage, warm shower/bath, heat packs.

Useful resources:

- The National Dementia Behaviour advisory Service 24 hours 7 days a week service 1300 366 448
- The National Dementia helpline 1800 100 500
- Alzheimer's Australia at [www.alzheimers.org.au](http://www.alzheimers.org.au)
- Alzheimer's Australia Pain help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20050700\\_Nat\\_HS\\_2.11Pain.pdf](http://www.alzheimers.org.au/common/files/NAT/20050700_Nat_HS_2.11Pain.pdf).



## The Caring Role for Families and Planning for the Future

### The Carer

Caring for those with dementia can be both physically and emotionally demanding. Carers can feel overwhelmed, as a higher level of assistance with all aspects of daily living is required as the dementia progresses. The following section lists possible effects, solutions and resources that can assist with continuing to care for a person with dementia at home. Eventually the level of care maybe too great and the person may be required to move into a residential facility. Assistance with making this difficult decision is available from various community agencies (contact details are listed below). A list of useful agencies and help sheets addressing several of the problems experienced by carers are also available at the end of this chapter.

Possible effects on the family/carer:

- lack of accurate information about dementia
- emotional and physical degradation
- fatigue or interrupted sleep
- stress and worry. (Symptoms of stress may include poor eating, poor digestion, headaches, mood swings, slowed thinking, being easily upset)
- depression and anxiety
- grief which may start with the diagnosis of dementia and continue after the person dies
- guilt
- frustration or anger

- reduced ability to cope
- feelings of loss
- no longer engaging in activities that were previously enjoyed
- isolation and potential boredom
- lack of social support
- lack of formal support services
- changes to relationship including intimacy and sexuality
- changes to health including possible substance abuse
- fear for personal safety
- resistance to accepting assistance
- person with dementia being resistant to support services or residential care
- changes to income/employment.

Possible solutions for carers:

- contact Alzheimer's Australia to utilise their support groups, education resources and counseling services
- regular respite or In-home respite – social work referral
- keep in touch with friends and family
- ask for help from friends, family or neighbours
- keep regular appointments with a medical practitioner so that the carer's emotional and physical health can be monitored
- discuss with the person and their GP or other health professional completing an Advanced Health Care Directive or Living Will (Palliative Care Dementia Interface: Enhancing Community Capacity, 2007). Important to complete as early as possible.
- utilise headphones to listen to music or the television to provide a brief respite from constant questioning or verbal perseveration
- retain a private area in the home that can be used for short periods of respite that the person with dementia cannot easily enter (e.g., ensuite, second living area, granny flat)
- schedule some time for themselves each day (e.g., cup of tea, soak in bath)

- utilise an electronic monitor or gates on doorways to assist with supervision
- have objects or activities available to use to distract the person with dementia
- keep a list of all strategies that work
- accept help from others (formal or informal). Keep a list of strategies, communication tools and signals indicating that the person may be upset to assist with a smooth transition of carers
- utilise energy conservation techniques. Handouts available from Osborne Park Hospital OT department
- try relaxation and stress management techniques. Handouts available from Osborne Park Hospital OT department
- try to nap everyday or have someone else stay a couple of nights a week to enable the carer to get some uninterrupted sleep
- schedule daily exercise
- utilise positive reinforcement and praise when communicating with the person with dementia, as this will encourage the carer to focus on positive aspects of the person
- free Carer Support Kit from Commonwealth Respite and Carelink Centres 1800 052 222
- free Emergency Care Kit is available from Commonwealth Respite and Carelink Centres 1800 052 222
- contact Commonwealth Respite and Carelink Centres to determine what local programs and services exist
- utilise respite from family or friends
- Utilise formal respite services. Information is available from Commonwealth Respite and Carelink Centres
- attend a senior citizen centre with the care recipient to provide partial respite and to encourage social interaction
- contact Centrelink regarding carers payment, carer allowance, pharmaceutical allowance, rent assistance, telephone allowance, bereavement payment, pensioner concession card, non-pension concessions.

## **Help for People Living at Home with Dementia**

A diagnosis of dementia does not automatically mean that the person is immediately incapable of caring for themselves. The type of support needed depends on the individual situation, circumstances and their preferences. It may be possible for more family members to become involved in all aspects of the persons care. If this is not a possibility or if extra assistance is required then community support will be required. There are many organisations that support people with dementia, their carer's and family. Each organisation has an assessment procedure which may include the need for a referral from a medical practitioner. Services may be provided at no charge, by donation, minimum charge or fee for service. The availability of services in each area will determine the amount of formal support that can be offered and some services have waiting lists. Social workers will be able to assist with knowledge of local services, their referral process and waiting lists. Alternatively people should be encouraged to contact their local Commonwealth Respite and Carelink Centre.

The following website provides information about help lines, networks, support groups, community care programs and other services available to assist with maintaining a person with dementia to remain at home:

The Aged Care Australia website, accessible by the following link <http://www.agedcareaustralia.gov.au/internet/agedcare/publishing.nsf/Content/Help%20for%20people%20living%20with%20%20dementia-1>. Information about the following list of services can be accessed by clicking on link below or visiting the Aged Care Australia web page.

- The National Dementia Helpline ⓘ
- Commonwealth Carelink Program ⓘ
- Dementia and Memory Community Centres (DMCC) ⓘ
- Early intervention and support programs
- Non-clinical advice, counselling and professional support
- Education and training programs
- Awareness raising and information activities
- Support for special needs groups
- Dementia Behaviour Management Advisory Services (DBMAS) ⓘ
- The Department of Veterans' Affairs ⓘ
- Alzheimer's Australia ⓘ
- Community care programs for people with dementia
- Home and Community Care (HACC) program ⓘ
- Community Aged Care Packages (CACP) ⓘ
- Extended Aged Care at Home (EACH) ⓘ
- Extended Aged Care at Home Dementia (EACH D) ⓘ
- Day Therapy Centres.

## Residential Care

The risks associated with a person with dementia living alone should be regularly reviewed by family, carers and professionals. There may come a time when the person with dementia needs to move into a residential care facility. The person's own wishes and concerns should be considered. Aged Care Assessment Teams provide assistance to older people in determining their needs for home based supports or residential care options. A person must have a current ACAT assessment in order to access residential care.

Possible reasons for residential care:

- family/carer no longer able to cope with the demands of caring for the person at home
- doubly incontinent
- bed bound
- often becoming lost or wandering
- aggression towards family/carer
- deteriorating health of family or carers
- housing no longer suitable
- services required are no longer available
- the amount of assistance required from services is not available
- types of care available:
  - low level care: provides accommodation, personal care and some nursing care
  - high level care: provides continuous nursing care
  - dementia specific units. These can be either low or high level care. Not all people with dementia require a dementia specific unit.

The decision to move into a residential facility is a sensitive decision that involves complex emotions and feelings for all involved. It is best to plan for the move into a care facility by communicating with all parties involved and involving the person with dementia. All government funded residential care facilities must abide by the Charter of Residents' Rights and Responsibilities. Copies of this charter are available from all government funded residential facilities. Information regarding advocacy services are also available by contacting the Aged and Community Care Information Line 1800 500 853.

## Useful Resources for Carers

- information about local day centres or respite services can be sourced through Commonwealth Respite and Carelink Centres on 1800 052 222 or visit [www.commcarelink.health.gov.au](http://www.commcarelink.health.gov.au) . For emergency respite outside of business hours call 1800 059 059
- free Carer Support Kit available from Commonwealth Respite and Carelink Centres 1800 052 222
- Commonwealth Carer Resource Centre on 1800 242 636
- The National Dementia Behaviour Advisory Service 24 hours 7 days a week service 1300 366 448
- The National Dementia Helpline 1800 100 500
- National Carer Counselling program 1800 242 636
- Aged and Community Care Information Line 1800 500 853
- Palliative Care Australia [www.pallcare.org.au](http://www.pallcare.org.au)
- Alzheimer's Australia [www.alzheimers.org.au](http://www.alzheimers.org.au)
- music relaxation CD's are available from most Alzheimer's Australia libraries or local libraries
- Alzheimer's Australia caring for someone who lives alone help sheet [http://www.alzheimers.org.au/common/files/NAT/20050700\\_Nat\\_HS\\_2.4CaringLivesAlone.pdf](http://www.alzheimers.org.au/common/files/NAT/20050700_Nat_HS_2.4CaringLivesAlone.pdf)
- Alzheimer's Australia Health and safety for carers help sheet <http://www.alzheimers.org.au/common/files/NAT/20100920-Nat-Helpsheet-Health-and-Safety-for-Carers.pdf>
- Alzheimer's Australia Information for family and friends help sheet [http://www.alzheimers.org.au/common/files/NAT/20050700\\_Nat\\_HS\\_1.6FamilyFriends.pdf](http://www.alzheimers.org.au/common/files/NAT/20050700_Nat_HS_1.6FamilyFriends.pdf)
- Alzheimer's Australia Intimacy and sexual issues help sheet [http://www.alzheimers.org.au/common/files/NAT/20090700\\_Nat\\_HS\\_2.19IntimacySexualIssues.pdf](http://www.alzheimers.org.au/common/files/NAT/20090700_Nat_HS_2.19IntimacySexualIssues.pdf)
- Alzheimer's Australia making the most of respite care help sheet [http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_2.6RespiteCare.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_2.6RespiteCare.pdf)
- Alzheimer's Australia Later stages of Dementia help sheet [http://www.alzheimers.org.au/common/files/NAT/20050700\\_Nat\\_HS\\_2.20LaterStagesDementia.pdf](http://www.alzheimers.org.au/common/files/NAT/20050700_Nat_HS_2.20LaterStagesDementia.pdf)

- Alzheimer's Australia Palliative care and Dementia help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20091000\\_Nat\\_HS\\_2.21PalliativeCareDementia.pdf](http://www.alzheimers.org.au/common/files/NAT/20091000_Nat_HS_2.21PalliativeCareDementia.pdf)
- Alzheimer's Australia Taking a break help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_3.1TakingABreak.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_3.1TakingABreak.pdf)
- Alzheimer's Australia Taking care of yourself help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_3.2TakingCareYourself.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_3.2TakingCareYourself.pdf)
- Alzheimer's Australia Feelings help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_3.3Feelings.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_3.3Feelings.pdf)
- Alzheimer's Australia Men and caring help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20090400\\_Nat\\_HS\\_3.4MenCaring.pdf](http://www.alzheimers.org.au/common/files/NAT/20090400_Nat_HS_3.4MenCaring.pdf)
- Alzheimer's Australia Coping after the death of someone with dementia help sheet [http://www.alzheimers.org.au/common/files/NAT/20050700\\_Nat\\_HS\\_3.5CopingAfterDeath.pdf](http://www.alzheimers.org.au/common/files/NAT/20050700_Nat_HS_3.5CopingAfterDeath.pdf)
- Alzheimer's Australia information and support help sheet  
[http://www.alzheimers.org.au/common/files/NAT/20050700\\_Nat\\_HS\\_4.6InformationSupport.pdf](http://www.alzheimers.org.au/common/files/NAT/20050700_Nat_HS_4.6InformationSupport.pdf)
- Centrelink 13 27 17 [www.centrelink.gov.au](http://www.centrelink.gov.au)
- Department of Veterans' Affairs 13 32 54 or 1800 555 254 for non metropolitan callers
- the Age Page is near the front of most telephone directories. It lists contact numbers for numerous services and agencies that can assist with issues relating to ageing.



## List of Abbreviations

**Table 5: List of Abbreviations**

| Abbreviation | Title  |
|--------------|--|
| ACAT         | Aged Care Assessment Team                      |
| ADC          | Aids dementia Complex                          |
| AD           | Alzheimer's disease                            |
| ADL          | Activities of daily living                     |
| AIDS         | Acquired Immune Deficiency Syndrome            |
| AMPS         | Assessment of Motor and Process Skills         |
| CACP         | Community Aged Care Package                    |
| CALD         | Culturally and Linguistically Diverse          |
| CAMCOG       | Cambridge Cognitive Examination                |
| CJD          | Creutzfeldt Jacob Disease                      |
| DBMAS        | Dementia Behaviour Management Advisory Service |
| DMCC         | Dementia and Memory Community Centres          |
| DLB          | Dementia with Lewy Bodies                      |
| EACH         | Extended Aged Care at Home                     |
| EACH-D       | Extended Aged Care at Home- Dementia           |

|          |  |
|----------|--|
| EBP      | Evidence Based Practice  |
| EPA      | Enduring Power of Attorney   |
| FTD      | Frontotemporal Dementia  |
| GPS      | Global positioning Technology  |
| HACC     | Home and Community Care  |
| HDS      | Hierarchic Dementia Scale  |
| HD       | Huntington's Disease   |
| ILC      | Independent Living Centre  |
| KICA     | Kimberley Indigenous Cognitive Assessment                              |
| MBI      | Modified Barthel Index   |
| MMSE     | Mini Mental State Examination  |
| NCCDN    | The National Cross Cultural Dementia Network                           |
| NATSIDAG | National Aboriginal and Torres Strait Islander Dementia Advisory Group |
| NDSP     | National Dementia Support Program                                      |
| NHMRC    | National Health and Research Council                                   |
| NRCP     | National Respite for Carers Program                                    |
| OPH      | Osborne Park Hospital  |
| OT       | Occupational Therapist(s)  |
| PD       | Parkinson's Disease  |
| RUDAS    | Rowland Universal Dementia Scale                                       |
| TIA's    | Trans Ischemic Attack  |
| VD       | Vascular Dementia  |
| WACHA    | Western Australian Centre for Health and Ageing                        |
| WA DTSC  | WA Dementia Training Study Centre                                      |



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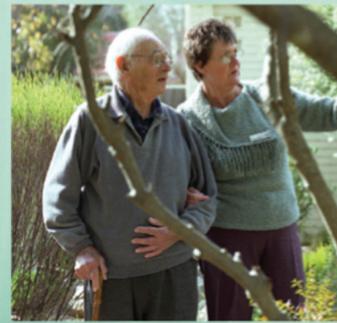
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## Dementia: Osborne Park Hospital Guide for Occupational Therapists in Clinical Practice



Dementia is the leading cause of disability in people aged over 65 years and spending on dementia is set to outstrip all other health conditions (\$83 billion dollars or approximately 11% of the entire health and residential aged care sector spending in the 2060's). Access Economics 2009.

Dementia: Osborne Park Hospital Guide for Occupational Therapists in Clinical Practice is an evidence based, ready reference guide for clinicians working in hospital and community settings to assist them improve outcomes and provide quality service for people with dementia and their carers. It was developed by clinicians for clinicians. The Guide's provides practical, evidence based information to assist clinicians develop and utilise best practice assessment and management strategies to assist their clients.

The Guide is creating interest and acclaim from medical consultants, nursing and allied health clinicians, research and educational bodies and health policy officers (both state and federal) around Australia.

"To our knowledge there was, and is, no comparable resource available in Australia or in other parts of the world, and as such is both innovative and will lead to excellence in occupational therapy services through the consistent use of current evidence-based interventions. Heather Freegard, Project Coordinator, WA Dementia Training and Study Centre, Curtin University.