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Introduction
Welcome to the Certificate 1V unit CHCAC416A – Facilitate support responsive to the specific nature of dementia.

At this level of training you will be expected to have a broad knowledge of dementia and current models of care and be responsible for support and outcomes related to other staff members. It will be part of your responsibilities to ensure that other staff members also have access to this knowledge and develop awareness and required skills in regard to supporting people with dementia in a way that is empathetic and appropriate.

You will also be expected to problem solve in a wide range of situations.

Assessment

The unit will commence with one day face to face training.

Assessment for this unit consists of a written component to test knowledge, completion of a project and observations completed by a supervisor/assessor in the workplace.

The trainers can be contacted at any time, either by email or telephone, throughout the undertaking of this unit for assistance.

Acknowledgements

This material is the result of collaboration between Alzheimer’s Australia WA staff in Education Services.
Course Overview

Course Name: Dementia Care Essentials Level 4 CHCAC416A
Nominal Duration: Twelve hours face to face
Target Audience: Support workers with dementia experience, supervisors, coordinators and other health professionals who interact with people with dementia. This course is not suitable for family members.
Purpose: This course is designed to provide the above with the following skills and knowledge —
  - Ability to prepare to plan support for people with dementia
  - Ability to develop and implement strategies which minimise the impact of behavioural and psychological symptoms of dementia
  - Ability to provide guidance and support workers and families to implement plan
  - Ability to complete documentation accurately

Assessment: Formal assessment will take the form of written assignments and evidence from the workplace. Appropriate training evaluation forms for participants are to be completed at the end of the course.
Overview of Dementia

What is dementia?

Dementia is not a normal part of ageing. Age is a risk factor, but not everyone over the age of 65 develops dementia. Dementia is not a disease (although we often refer to the different types of dementia as diseases) but rather a collection of symptoms, or a syndrome, that can be caused by a number of pathological changes in the brain. These symptoms are characterised by a decline in intellectual functioning that interferes with social and occupational functioning. Deterioration in cognitive functioning leads to a decline in the ability to perform basic and instrumental activities of daily living (Crisp & Taylor 2001).

Dementia is classified as the development of multiple cognitive deficits manifested by both:
- Memory impairment (impaired ability to learn new information or to recall previously learnt information), and one or more of the following cognitive disturbances:
  - Aphasia (language disturbance);
  - Apraxia (impaired ability to carry out motor activities despite motor function);
  - Agnosia (failure to recognise or identify objects despite intact sensory function);
  - Disturbance of executive functioning (i.e. planning, organising, sequencing, abstracting).

The Brain

In order to understand the behaviours you may see in the person with dementia, a basic understanding of the anatomy and physiology of the brain is required. A brief overview of the brain cell (neuron) and the brain sections or lobes follows:

This diagram has been adapted from Dementia-The Caring Experience: A guide for families and carers of people with dementia 2006, Australian Government Department of Health and Ageing.

The Neuron

Approx. 80-100 billion brain cells (neurons) make up the brain. There are many different types and they vary in size, length and function. The neuron’s basic role is the generation and conduction of electrical and chemical impulses from one cell to the next. In dementia this process of communication between cells is interrupted and cells are dying at an accelerated rate, thus the loss of abilities is progressive.
FRONTAL LOBES: The frontal lobes are situated behind the bone of our forehead above the eyes. There are two cerebral hemispheres, left and right, and in the middle portion of the frontal lobe region is the “initiator” or “starter motor” - it is this part of the brain that motivates us to act. If this area of the brain is affected, people can lose their “get up and go”. Example: A person may cease engaging in hobbies and sit in a chair all day – they may need extra encouragement to engage in an activity. The lateral surfaces of the frontal lobes help us to make plans, organise our day and learn new tasks. Example – this part of the brain is used to learn to drive a car. The orbitobasal area of the frontal lobes allows us to have insight into our behaviour and to receive feedback about our progress throughout the day. Example: Loss of insight may result in a person cooking food still wrapped in plastic and not understanding that this is harmful. This part of the brain also helps us to act in socially appropriate ways. If impaired, the person may act in an uninhibited way. Example: A person may begin using “bad language” for the first time in social situations.

TEMPORAL LOBES: These are the “filing system” or “database” of the brain. They deal primarily with memory functions. This part of the brain takes in what is heard and recognises what the language means, and is situated in our temple area on both sides. Particularly in Alzheimer’s disease, long term memory is preserved initially whereas short term memory is affected in the early stages. Example: A person can remember an episode that took place 40 years ago but cannot remember what they had for breakfast.

PARIETAL LOBES: The parietal lobes are situated on either side above the ears. The dominant side (which is the left side in 95% of right-handed people and the majority of left-handed people) deals with language, mathematics – anything to do with order or structure. Example: The dominant side controls our ability to read, and provides a sense of our body, which is our left arm and which is our right.

The non-dominant side helps people orient themselves in a physical space and gives a sense of geography – walls, ceiling, floor, rivers, mountains, as well as an awareness of three dimensions. Example: A person with dementia may have difficulty crossing a threshold, or a shadow on the floor, as they have no sense of its depth or height.

Both parietal lobes acting together help us to recognise family member(s), objects and our surroundings. A person with impairment in this area may fail to recognise common objects, e.g. knife and fork, or the house or area they live in – this is called agnosia. This part of the brain also enables us to carry out planned or learned patterns of movement; and impairment may cause difficulty with putting clothes on in the correct order, and difficulty using appliances or following instructions – this is called apraxia.

OCCIPITAL LOBE: Situated at the back of the brain is the occipital lobe. Although the eyes are the source of visual information, it is the occipital lobes which provide interpretation of what is seen. Damage to this area of the brain can cause hallucinations, and in conjunction with the parietal lobes, make recognising faces/objects difficult.

LIMBIC REGION: The limbic region is situated deep inside the brain. It plays a vital integrating role in the connection between emotions, behaviour and memories. As it controls vegetative function, damage to this area may also result in disturbed sleeping or eating patterns. Example: A person with dementia may not keep emotions such as fear or anger under control as they would normally, or may not recognise the feeling of hunger even when hungry. The hippocampus is part of the limbic system and is located inside the medial temporal lobe.

(Adapted from Dementia Care Essentials 2010.)
The Hippocampus

As already stated, the hippocampus is part of the limbic system and is located inside the medial temporal lobe. It plays an important role in encoding long-term memory and spatial navigation. Damage to the hippocampus can result in an inability to form long-term, episodic memories. In the early 1950s a young man suffering from intractable epilepsy underwent a bilateral resection of the medial temporal lobes which included a large removal of the hippocampus, the amygdalae and the overlying cortex. Ultimately successful in reducing the seizures, the surgical resection left the young man with no memory which persists to this day, some 6 decades later. This pioneered research into memory.

Alzheimer's disease may start in the hippocampus causing the early symptoms of memory problems and disorientation. With the loss of cells (neuronal death) the brain atrophies and the fissures or folds (sulci) between the tissues become wider. The fluid filled ventricles between the lobes become enlarged and there is amyloid, containing neuritic plaques present, and neurofibrillary tangles in the brain tissue. These changes cause the loss of electric conduction between the neurons thus the messages from one part of the brain to another become distorted.

An important chemical conductor or neurotransmitter is acetylcholine, or ACH. We now have medications that act by inhibiting an enzyme called acetylcholinesterase. By blocking this enzyme, the breakdown of acetylcholine released by the remaining healthy brain cells is slowed down, leaving more chemical messengers available to support normal brain function.

Plaques and tangles are also found on autopsy in people who do not have symptoms of dementia so the current research is focused on what turns these plaques “on” to become pathological. In people who have AD on autopsy, the plaques are most predominant in the cortex, the hippocampus and the amygdala. The hippocampus is crucial for information processing and memory functions so alterations in this area cause the memory problems of AD and other dementias. The amygdala is a collection of grey matter cells situated in the anterior portion of the temporal lobe of the brain. It appears to play an important part in the arousal and emotional states and is crucial in the understanding of depression.

It seems that there are a variety of factors that impinge on the person’s susceptibility to develop dementia and research on genes and familial issues is progressing.
Prevalence of Dementia

Dementia Projections
In 2015 it is estimated that about 342,800 people in Australia will be living with dementia. AIHW (2012) Dementia in Australia.

In 2015 it is estimated that in WA approximately 31,983 people will be living with dementia, and approximately 197 will be diagnosed each week with the condition. It is projected that by 2050 this figure will have jumped to 98,550 people living with dementia in WA. Source: (Australian Bureau of Statistics 2014)

Prevalence of Dementia by Age
The prevalence of dementia by age group in Australia is the number of people who have this syndrome at any point in time.

Currently this is approximately:
- 65-69 years : 1 in 100
- 70-74 years : 3 in 100
- 75-79 years : 6 in 100
- 80-84 years : 12 in 100
- 85-89 years : 20 in 100
- 90-94 years : 32 in 100
- 95 years & over : 39 in 100

These figures can be more easily understood when viewed as a graph. Note that slightly more men than women are affected between ages 60 and 74, but after age 75 more females than males develop dementia.

Although the prevalence increases dramatically as we age, dementia is still not a natural part of ageing. These figures and projections are drawn from the following report:

Prevalence of Dementia in Indigenous Australians

- Prevalence in dementia for remote dwelling indigenous people (45+ years) is 12.4% compared to a rate of 2.6% in the Australian population. In some regional areas this is expected to exceed the projected increase in the metropolitan region.
- Research in the Kimberley Region suggests that the prevalence rates of dementia among remote and rural Indigenous people could be 4-5 times higher than those in the Australian community more generally.

Evidence of the high prevalence rate of dementia among rural and remote Indigenous people became apparent when the Dementia and Cognitive Impairment in Kimberley Indigenous Australians project was undertaken. The KICA, an assessment tool devised especially for Indigenous people of the Kimberley region, was developed as a result of this project. Also gaps in service provision for the people of the Kimberley region were identified.


Younger Onset Dementia

Although dementia most often occurs in people over the age of sixty-five, it can occur in people of a younger age with a recent case being reported in a person as young as 17 years of age. Currently there are approximately 25,100 people under the age of sixty-five in Australia who have been diagnosed with a dementia (Access Economics 2009).

Familial Alzheimer’s, (FAD) although a very rare form of dementia, seems to generally affect people at a younger age, and Frontal Lobe Dementia also generally affects younger people.

If dementia occurs in people of a younger age it has a significant impact on their way of life, causing them to retire from work much earlier than anticipated, or sometimes their support person will give up their job in order to care for them. These situations can often cause financial difficulties. Some of these families may still have children living at home and their lives too will be affected by the dementia of their parent.

Further reading:

Types of dementia
The most common form of dementia is Alzheimer’s disease, named after Alois Alzheimer who first described the symptoms he found in a woman he was treating in a paper presented at a meeting in 1907. In 1901 Dr. Alzheimer examined a fifty-one-year-old patient, Auguste Deter, who displayed some of the symptoms we now attribute to Alzheimer’s disease. Auguste displayed symptoms of being suspicious, getting lost in her own home and not recognising family members. Auguste also had difficulty speaking, was confused in relation to time and space, and had trouble manipulating tools. Dr. Alzheimer studied Auguste throughout her illness. When she died in 1906, he performed an autopsy examining the brain tissue. He described the brain tissue pathology, the paucity of cells in the cerebral cortex (outer layer of the brain), and clumps of filaments (“tangles”) between nerve cells. He described the extensive brain damage he found on autopsy and concluded there was a disease process present.

There are approximately 100 diseases that cause the symptoms of dementia and each type varies in its onset, symptoms and rate of progression.

**Alzheimer’s disease (AD)**

This form of disease accounts for approximately 60 percent of all dementia. It is a disease that causes progressive decline in the memory and cognition of the person and ultimately becomes so severe the person is unable to care for themselves. The onset of Alzheimer’s disease is insidious with the person often covering up memory loss and vagueness. When questioned the family can often report that the person’s memory lapses have been occurring for some years, but they did not realise things were going wrong until there was a dramatic event, such as dressing incorrectly or becoming lost whilst shopping.

Currently, there is no single diagnostic tool to diagnose Alzheimer’s disease. Diagnosis is therefore difficult and is based on the process of elimination of other treatable conditions that may be causing the symptoms exhibited, presence of cognitive impairment on testing and a history of change over time.

Alzheimer’s disease (AD) is characterized by cortical atrophy and loss of neurons starting in the hippocampus then out to the parietal and temporal lobes of the brain.

**Vascular cognitive impairment (VCI)**

Vascular cognitive impairment is thought to be the cause of a significant number of cases of dementia. This form of impairment is caused by problems in the circulation of blood through the brain causing strokes or sometimes mini-strokes called Transient Ischaemic Attacks (TIA) or other diseases affecting blood vessels. Whenever the blood supply to the brain is slowed or reduced by narrowing or clotting in blood vessels the small vessels may break, causing tiny hemorrhages. Vascular cognitive impairment was called multi-infarct dementia because of these multiple small bleeding sites. The available oxygen delivered to the brain cells declines and hypoxia results which compounds the damage.

Strokes are caused by larger vessel disruption and can result in severe brain damage resulting in paralysis and speech problems such as aphasia, dysphasia, memory change, emotional lability and personality changes, depending on the part of the brain damaged. Brain damage from external injury can also cause memory loss and other symptoms of dementia that can make diagnosis difficult. Sometimes a dual diagnosis of vascular cognitive impairment and Alzheimer’s disease can be made, and is referred to as ‘mixed dementia’.
A person who develops vascular cognitive impairment may also have a history of cardiovascular disease, e.g., circulatory problems, cardiac problems and diabetes. Heavy smoking may also contribute to the risk of vascular dementia. There could be neurological symptoms related to the areas of damage in the cortex i.e., change in gait, and fine motor movements disrupted. The speed of progression in vascular cognitive impairment varies from person to person. There may be a ‘stepped’ progression, with symptoms remaining at a constant level and then suddenly deteriorating.

Co-morbid conditions can increase a person’s risk of developing vascular cognitive impairment and these include:

- Medical history of stroke
- High blood pressure
- High cholesterol
- Diabetes, particularly type 11
- Heart problems
- Sleep apnoea (where breathing stops during sleep)
- Alcoholism
- Smoking
- Diet high in saturated fats

For further information on Vascular cognitive impairment visit: http://www.alzheimers.org.au

**Lewy Body Disease**

Lewy Body disease is a common neurodegenerative disease of ageing. This means that the disease causes gradual brain damage. For reasons not fully understood, it occurs when there is an abnormal accumulation of a protein called alpha-synuclein in brain cells. These abnormalities occur in specific areas of the brain, causing changes in movement, thinking and behaviour.

Lewy body disease includes three overlapping disorders:

- **Dementia with Lewy bodies**
- **Parkinson’s disease**
- **Parkinson’s disease associated dementia**

This overlap results in the disease being called a spectrum disease. Lewy body disease and its accompanying disorders can present diagnostic challenges. Lewy body disease is still not well known. Also, people with Lewy body disease can present with a variety of problems in the early stages. They may have problems with autonomic (the system that automatically regulates bodily functions), cognitive (thinking), behavioural or motor functions.

One of the Lewy body disorders (Parkinson’s disease) does have a public profile and established protocols for its diagnosis and treatment. It is not surprising therefore, that people who experience the motor or physical symptoms in the early stages of their illness seek advice from medical practitioners who specialise in movement disorders. If a diagnosis of Parkinson’s disease is made, with time, a subsequent diagnosis of Parkinson’s disease associated dementia may result. Average time living with PD until diagnosis of dementia is 14-16 years. Getting a diagnosis can be more challenging when the motor signs are not as evident. Often the person dismisses the concerns of others, presents well at a GP consultation and performs well on initial screening tests such as the Mini Mental State Examination. A ‘watch and review’ plan is sometimes suggested or medication is offered for the most pressing complaint.

For further information: call 1800 644 189 or go to:

Parkinson’s Australia: http://www.parkinsons.org.au
Fronto-temporal Lobar Degeneration (FTLD)

This disease affects the frontal and temporal areas of the brain and therefore personality, behaviour and language. Portions of the frontal and temporal lobes of the brain atrophy or shrink and this shows on scans as tissue loss.

In FTLD, the person may start behaving oddly or inappropriately in public places or around strangers. Social skills like tact and empathy may be lost. They may lose interest in everything, or they may suddenly need to be active all the time. They often lose the ability to make informed and safe decisions about tasks, such as managing finances or driving a car. Loss of the ability to control socially acceptable behaviour e.g. undressing in public, making sexual advances inappropriately or becoming loud and aggressive are the result of damage to the frontal lobe. Some people have personality differences all their lives that are seen to be ‘difficult’ and these traits do not go when they age.

FTLD is one of the causes of younger onset dementia. Due to the younger age of people with this form of dementia it is often misdiagnosed as a psychiatric problem or as AD. From the onset of the disease, life expectancy is two to fifteen years, with an average of six to twelve years. Death usually comes from another illness such as infection.

For further information on Fronto-temporal lobe dementia visit: http://www.alzheimers.org.au

Pick’s Disease is the major sub-type of FTLD.

Pick’s disease accounts for 20% of cases of Fronto-temporal lobar degeneration. In Pick’s disease neurons in the affected areas contain inclusions called Pick bodies and there is loss of brain tissue. The disease usually affects younger people (up to age 70) and women more often than men, but the progression is much the same as for Alzheimer’s disease. Memory loss is slower to manifest but will occur over time. The loss of concern and care about appearance and social mores is more pronounced and echolalia (automatic repetition of words said to the person) as well as impulsivity, perseveration (repeating actions/words and inability to cease this activity), and difficulty with problem solving occurs.

For further information on Pick’s Disease visit:
National Institute of Neurological Disorders and Stroke
http://www.ninds.nih.gov/disorders/picks/picks.htm

Alcohol related dementia (Wernicke-Korsakoff syndrome)

This form of dementia is related to excessive consumption of alcohol and usually a deficiency of vitamin B1 caused through poor eating and liver damage. The onset is usually after some years of heavy drinking and can occur at any age. At an early stage of the disease, problems may be reduced or reversed if the person abstains from alcohol, improves their diet and replaces vitamins, especially thiamine, also known as vitamin B1. Thiamine is important to limit some of the toxic effects of alcohol, and is an important supplement for heavy drinkers. Memory loss, loss of social skills, planning ability, organising and judgment and often balance are affected. Confabulation is common and polyneuritis may be present. The damage is permanent but sometimes areas can show improvement after stopping drinking and taking thiamine (vitamin B1). The psychotic behaviour of this syndrome does not always improve with treatment and this is often the reason for admission to care.

For further information on Alcohol Related Dementia visit:
Health A to Z: Your Family Health Site
http://www.healthatoz.com/healthatoz/Atoz/ency/korsakoffssyndrome.isp
Huntington’s disease (HD)

Huntington’s disease is a rare inherited disorder that causes degeneration of both the brain and body. It usually occurs in people between 30 and 50 years, and has physical symptoms of tremor, progressing to involuntary movements of the limbs (rigidity and akinesia) that is severe, and jerking of facial muscles. The symptoms include: memory loss, personality changes, slurred speech, impaired judgment and psychiatric problems. Dementia prevails eventually and the person experiences severe physical decline. The disease produces localised death of brain cells and the most severely affected areas are the caudate nucleus and the putamen. There is a suggestion that there is an imbalance of acetylcholine and dopamine, although dopamine is not affected in the same way as in Parkinson’s disease. Depression and personality changes are most common in the early stages, often accompanied by memory loss, impulsive behaviour, moodiness, anti-social behaviour and restlessness. Genetic testing is available for families who may be carriers of the disease and the ethical ramifications of this are profound. If a person is a carrier of the gene then there is a 50% chance that their children/offspring will also inherit the disease.

For further information on Huntington’s disease visit:
National Institute of Neurological Disorders and Stroke
http://www.ninds.nih.gov/disorders/hintington/hintington/htm

Acquired Immuno Deficiency Syndrome (AIDS)

AIDS results from infection by the Human Immunodeficiency Virus and occurs when the body is overwhelmed by the viral load (amount of virus) and AIDS defining illnesses and opportunistic infection occurs. Part of the AIDS illness can be the development of the aids/dementia complex which is a syndrome of cognitive and motor dysfunction caused by HIV itself rather than opportunistic infection. The symptoms are impairment of concentration and attention, slowing of mental speed and agility, slowing of motor speed and apathetic behaviour. Slowing of the disease may be helped by the use of antiretroviral therapies but usually the person succumbs to the escalating virus attack.

With Acquired Immuno Deficiency Syndrome Dementia the rate of progression varies from person to person. However the disease can lead to complete dependence and death.

For further information on AIDS related dementia visit:
The Australian Federation of AIDS Organisations:  http://www.afao.org.au

Creutzfeldt-Jacob disease (CJD)

Creutzfeldt-Jakob disease is a very rare, rapid and progressive neurological disease that can affect people between the ages of 50 and 70 years. The infective agent or prion causing this form of dementia may be related to ‘Mad Cow Disease’ or ‘Scrapie’ in sheep and is a very rare fatal disorder. Infection has been transmitted by corneal transplants from an infected person or in the past, human growth hormones made from animal cells and used in the treatment of endocrine disorders. The symptoms of the disease include: failing memory, changes in behaviour and lack of muscle co-ordination. As the brain damage progresses, the motor and visual areas of the brain are affected and involuntary movement with blindness occurs. The person eventually becomes comatose and death occurs fairly rapidly. This disease is diagnosed by its rapid course and resistance to antibiotic or other therapy.

For further information on Creutzfeldt-Jacob disease visit:
Common Symptoms of Dementia

Alzheimer’s Australia has listed ten possible warning signs of common symptoms which may indicate dementia:

- recent memory loss that affects job skills
- difficulty performing familiar tasks
- problems with language
- disorientation of time and place
- poor or decreased judgment
- problems with abstract thinking
- misplacing things
- changes in mood or behaviour
- changes in personality
- loss of initiative

Many conditions have some of these symptoms so the need for professional assessment is essential. The diagnosis is made by eliminating treatable conditions that have similar symptoms to dementia such as stroke, medication effects, dehydration, hormone disorders (thyroidism), infections, depression or mental illnesses, alcoholism, brain tumours and the effects/or side effects of recreational hallucinogenic drugs.

Diagnosing dementia

An assessment to diagnose dementia may include the following:

- A detailed medical history provided, if possible, by the person with the symptoms as well as a close relative or friend. This helps to establish whether there has been a slow or a sudden onset of symptoms and their progression

- A thorough physical and neurological examination, including tests of the senses and movement function to rule out other conditions, and to identify any medical conditions which may worsen the confusion associated with dementia

- Laboratory tests, including a variety of blood and urine tests to identify any possible illness which could be responsible for the symptoms

- Neuropsychological testing to identify retained abilities and specific problem areas such as comprehension, insight and judgment

- Other specialised tests such as chest x-ray, ECG or CT scan

- A mental status test to check the range of intellectual functions such as memory, the ability to read, write and calculate which may be affected by dementia

- Psychiatric assessment to identify treatable disorders such as depression which can mimic dementia, and to manage any psychiatric symptoms such as anxiety or delusions which may occur

(Diagnosing dementia 1.2 Alzheimer’s Australia Help sheet)
Risk Factors

- **Age** – dementia is primarily age-related and although not a normal part of ageing, the risk increases as we age. Past the age of 60 the risk begins to increase significantly (as per prevalence statistics).
- **Hereditity** – a rare form of Alzheimer’s disease, Familial Autosomal Dominant Alzheimer Disease (FAD), accounts for approximately 5 to 10 per cent of all cases of AD. Known to be inherited, the disease will occur if the disease gene is present. FAD has a 50% probability of being passed directly from one generation to another through a dominant inheritance pattern. Fronto-temporal dementia also has an hereditary form – chromosome 17).
- **Family history** – having close relatives with dementia increases the risk.
- **High blood pressure** - if in evidence during mid and later life, and remaining untreated, is a risk factor for dementia.
- **High cholesterol, obesity and a diet high in saturated fats** – are all identified risk factors for both Alzheimer’s disease and Vascular dementia.
- **Smoking and excessive alcohol consumption** – increase the risk of Vascular dementia and are thought to also increase the likelihood of developing Alzheimer’s disease.
- **Lack of physical activity** – increases risk as contributes to other health risk factors such as obesity etc.
- **Lack of mental stimulation** – studies indicate that ongoing mental activity and education in mid to later life may assist in maintaining and developing neural pathways and perhaps delay the onset and impact of dementia.
- **Head injury or Down syndrome** – statistically people who have suffered head injury or damage to the brain are more likely to develop dementia in later life. Likewise, people with Down syndrome are also significantly more likely to develop the condition in mid to later life.

For further information on Dementia Risk Reduction visit: Alzheimer’s Australia - http://www.alzheimers.org.au

Current Medications Available for Dementia

- There are no current treatments that will halt or delay progress of irreversible dementia, nor a vaccine that will delay or prevent its onset.
- Pharmaceuticals on the market may slow down the progression of the symptoms in some people.
- Four drugs that are approved for use in Australia:
  - Aricept, Exelon and Reminyl work in a similar way, preventing the cholinesterase (enzyme) from breaking down a chemical (acetylcholine) in the brain. This results in increased concentrations of the chemical and in some people results in a temporary reduction in mild to moderate symptoms of Alzheimer’s disease.
  - The action of Ebixa is different to that of the other drugs. Ebixa blocks the chemical glutamate. Glutamate is released in excessive amounts when brain cells are damaged by Alzheimer’s disease, and this causes the brain cells to be damaged further. Ebixa may help to protect brain cells by blocking this release of excess glutamate.

- Three of the drugs used to slow the progression of AD act by increasing the amount of ACH in the transmission process are Donepezil (Aricept), Rivastigmine (Exelon) and...
Dementia Care Essentials CHCAC416A

Galantamine (Reminyl). These medications act by inhibiting an enzyme called acetylcholinesterase. By blocking this enzyme, the breakdown of acetylcholine, released by the remaining healthy brain cells, is slowed down leaving more chemical messengers available to support normal brain function.

- Another medication, Ebixa (Memantine) targets a different neurotransmitter, glutamate which is present in high levels in Alzheimer’s disease. Glutamate adheres to the neuroreceptor cells allowing calcium to move into the neuron causing damage. Memantine adheres to these cells and blocks the calcium from moving into the neuron.

- These drugs are effective in slowing the progression of symptoms for a period of time, but they do not stop the progress of the disease.

Areas of Research

- Causes and risk factors - as previously detailed
- Better and earlier diagnosis - skin tests and blood tests are being trialled, along with scanning equipment but to date no particular test is thought to be reliable or in regular use.
- Care considerations - many new models of care are being introduced for example, Eden Alternative, and Person-centred care. These models endeavour to encompass the needs of the person as a whole, and are not restricted to simply providing physical care. It is important to note that people with dementia have the same needs as everyone else.

Impact on Families

When someone is diagnosed with dementia it must be appreciated that such a diagnosis will have ramifications over a considerable period of time. Whilst diseases that affect the brain do shorten life span, a person may be expected to survive for a range of five to twelve years, or even longer.

Unfortunately societal attitudes also have a bearing on the impact of such a diagnosis for a family member in that there is still a stigma attached to any disease process that affects our mental functioning. This can mean that families are not always open about the diagnosis and may try to avoid relating the diagnosis to outsiders. Because of a general lack of understanding in regard to dementia, people who are not in day to day contact may not be aware of the impact on the person supporting a person with dementia.

As time goes on a person with dementia will need increasing amounts of support and will eventually not be able to cope with personal tasks of self care. They may lose the ability to speak, become immobile, incontinent and may need to be cared for in a residential facility.

A range of losses are also likely to be experienced especially by a spouse namely:

- Loss of role – a spouse becomes a ‘carer’, a child becomes a ‘parent’
• Loss of best friend – couples who always used to talk and do most things together may not be able to share as much with a spouse who has dementia
• Loss or change in intimate relationship – whilst sometimes the need for intimate contact may increase initially, in the long term this need will wane
• Loss or change of plans for the future
• Loss of, or grieving for the person that was – over time the person with dementia will not be able to function normally
• Physical and emotional fatigue – the sheer responsibility of caring in a physical sense, possibly taking on new roles such as finances or cooking and the mental strain of making all the decisions independently
• Lack of understanding from relatives and friends sometimes leading to social isolation

If the person with dementia is a younger person there are many other negative impacts such as:
• Possible financial hardship – person with dementia having to give up work - support person giving up work to care for the person with dementia
• Children may still be living at home – younger children will still need to be cared for – older children may find dementia in a parent difficult to cope with
• Future plans being changed dramatically

Can you think of other ways a diagnosis of dementia in the family may affect people?
Families

Guidance and Support for Families

It must be acknowledged that family members are engaged in a very difficult task when supporting a family member with dementia. Very often families are not fully aware of the effects of dementia, for example, the person really cannot remember how to do a task even though they may have just been taken through it. Family members may not understand that the person is not trying to be difficult, they simply no longer have the capacity to function as they used to.

Encouraging family members to attend an educational course on dementia will benefit many, and assist them in understanding the mysteries of dementia and how it affects functioning.

If we are providing services in the home, care workers have the opportunity to demonstrate good care practices. Generally a care worker would not give direct advice to a family member unless this advice was specifically sought.

Family members are a good source of information in relation to the person with dementia and their knowledge and expertise should be utilised to the full. They will generally be able to supply us with not only basic information on our client, but information in regard to the family composition, former jobs, hobbies and significant events, all of which will have had an influence on the life of the person with dementia. This information may help us be aware of what may influence some of the behaviours that a person exhibits during dementia.

Families, and particularly the principal carer of a person with dementia, should be encouraged to advise any organisation involved in caring for their person of any significant events that may happen whilst the person is still being cared for at home. Often in these circumstances the person with dementia will not be informed of, for instance, the death of a family member, however they will generally be attuned to the atmosphere in the household and understand that something is awry. This in turn, may affect their behaviour when the care worker attends the home, or the person with dementia attends the day centre. If the care staff are aware of these events then they are more able to support the person's responses and cope with any changed behaviours.

Moving into Permanent Care

When a person is placed in permanent care it can be an extremely distressing time for family members. Often the primary carer will feel guilty and ask themselves if they could have coped for longer, or they could or should have done a better job whilst caring. Family members deserve due acknowledgement that the job they were doing was very challenging and becomes a twenty-four hour a day job which is too difficult for one person to undertake long term.

All families are different and regardless of the kind of care was given, the situation is likely to have proved challenging. Many carers for a time feel quite ‘lost’ and will need time to adjust to the fact that everyday caring, all day, is now not required of them. This does not mean that they give up their role, but changes in their role are occurring. Research indicates that more homely placements tend to reflect less feelings of guilt, (Ritchie & Ledesert 1992, Woods & MacMillan 1994). Family members will also be going through a grieving process, even though the person is still living. They will be mourning for the person that was and we will need to mindful of this.
Families should still be involved in care decisions for their person and should be regarded as a vital member of the care team. It must be acknowledged that each family/family member will have a different commitment to their person in care and this will be dependant on a number of factors. For example, the facility may be a long way from where the family lives, especially if the family lives in the country, and visits may be few and far between. Some people will enjoy visiting each day, some weekly. Some people may still wish to involve themselves in the practical caring tasks such as assisting a person to eat or shower and others will just wish to make a more social visit. Other concerns may be that family members are not sure what to do when visiting, especially when their person can no longer speak, or does not recognise them. Staff should be willing to encourage families to visit and make them feel welcome, whilst understanding that sometimes it is often feelings of guilt that may provoke some criticism of care. Families should always be informed of the health and wellbeing of their person with dementia, and should be encouraged to take part in discussions that relate to the care of their person.

As a person approaches the end of their life it is imperative that family members are provided with the option of being involved. Often there are important ethical decisions to be made. It is possible that a person may have made their views clear in regard to end of life decisions before dementia progressed, or they may have completed an Advanced Care Directive which will stand as a guide to family members. This is likely to be a very stressful time for families and they will need to be well informed in regard to what to expect, and also will need to be aware of the different approaches to end of life matters.

Further Reading:
Palliative Care Australia – www.palliativecare.org.au
Support Services for People with Dementia

Support services available to people with dementia and their carers

- Aged Care Assessment Team (ACAT) teams provide assessments to help a person obtain a range of Commonwealth and State funded services to help an individual to continue living safely in their own home, or to enter a residential care facility. The team might include a doctor, nurse, social worker, occupational therapist or physiotherapist. Usually a general practitioner refers the person to the ACAT team and the general practitioner will still be the main person who provides ongoing medical care.

Assessment for Younger People with Dementia

Younger people with disabilities under the age of 65 years are eligible for assessment by an Aged Care Assessment Team. However, approval for aged care services should only occur where it is demonstrated that all disability service options have been exhausted and there are no other services that are appropriate to meet the person’s needs.

When a younger person with a disability is at risk of requiring either permanent or respite care in a residential aged care facility or via a Community Aged Care Package, Aged Care Assessment Teams and the Disability Services Commission have a commitment to work together with the person and their family/carer to determine the best way to meet that person’s individual support needs.

It is expected that local level processes will be developed jointly by the Aged Care Assessment Team and Disability Services Commission staff, working collaboratively to achieve the best outcomes for younger people with dementia.

The Commission has established a Disability and Aged Care Coordinator to support this initiative. This person is contactable on 9426 9696 or 1800 998 214 or email: acatreferral@dsc.wa.gov.au

Accessing Services

You can now go to a website My Aged Care (www.myagedcare.gov.au) for information on services or ring 1800 200 422 and advise them that you are calling from Western Australia and they will transfer you back to the ACCESS POINT in Perth for local information. This is the entry point to all services.

The Home and Community Care (HACC) program provides many home care services:

- Transport, home help, personal care, home nursing, respite, paramedical services etc.
- Most local governments provide HACC services and publish a community services directory.

Care Packages

A four tiered system has been developed recently consisting of the following:

- Level 1 – a new package to support people with basic care needs
- Level 2 – a package to support people with low level care needs, similar to the previous CACP
- Level 3 – a new package to support people with intermediate care needs
- Level 4 – a package to support people with high level and special care needs – including those with dementia

An ACAT assessment is required to access a care package.
Residential Care

- Short-term residential care – respite care in a residential care facility to give the carer a break from their caring role.
- Permanent residential care – residential care facilities can provide ongoing nursing care; ageing in place allows for a person to live independently but get help with meals and laundry, and personal care such as dressing, medication and showering. (An up-to-date assessment by the ACAT team is required when making application for residential care.)

Other Services

- Commonwealth Respite and Carelink Centre - Freecall 1800 059 059 – Emergency respite number
- Department of Veterans Affairs (DVA) – A range of services is available. Details of these can be found on www.dva.gov.au
- Silver Chain, Perth Home Care & other agencies – offer a range of support services including crisis care, nursing, personal care, home support, respite, palliative care, grief support and mental health support
- Centre Link
- Commonwealth Respite and Carelink Centre 1800 052 222 for information on services available in your area, eligible criteria, general cost and how to contact them
- Shire Community Services- Provide information of services delivered in your area
- Continence Helpline -1800 330 066
- Independent Living Centre-provide information on items designed to promote safe living
- Meals on Wheels – contact your local Shire
- Multicultural services – community support and/day centres

- **Advocare** – Advocates and protects the rights of people living in aged care facilities, receiving community care services
  Contact information:
  1/190 Abernethy Rd, Belmont, WA 6104 - 08 9479 7566
  www.advocare.org.au

Alzheimer’s Australia WA Services

- Alzheimer’s Australia WA – provides representation and support for individuals with dementia and their carers at a personal, community and political level. Services include respite and social support; support and counselling; education/training; advice on behaviour management and consultancy/research. Contact information: 9 Bedbrook Place, Shenton Park, telephone 9388 2800.
Models of Care

Best Practice – Models of Care

Over the years the way we care for people with dementia has changed significantly. Decades ago we put people in asylums assuming that they had gone ‘mad’ and not so long ago it was believed that dementia was something that just happened as one got older and was referred to as senile dementia. We now know that dementia is caused by a disease process and that the physical effect of this process, because it affects the brain, in turn affects mental functioning. It helps if we think of a disease process that may affect our leg for instance causing us to limp, in the same way a disease affecting our brain will cause us to ‘limp’ in regard to brain function.

Person-centred Care

The foundations of PCC are based on the work of the late Professor Tom Kitwood, head of the Bradford Dementia Group in the UK from 1992 to 1998. The concept is based on meeting the needs of the whole person in order to create a feeling of wellbeing. When Professor Tom Kitwood was asked to undertake a study involving people with dementia he identified many shortcomings in the way they were treated and eventually developed what we refer to as Person-centred Care.

Traditionally dementia was placed within the fields of medicine and psychiatry, which led to an over-emphasis on the ‘treatment’ of people with dementia. This model lacked the recognition of the person with the illness; who they are, their life before the illness and how they currently feel. The approach also overlooked the influence of the social and physical environments of a person with dementia. Person-centred care on the other hand, seeks to view the person with dementia as a whole and addresses the influence of factors beyond the physical changes in the brain.

Personal value

The prime task of person-centred dementia care is to maintain personhood in the face of a person’s declining mental powers according to Kitwood. This can be achieved by meeting the five areas of emotional need. If one need is met, this will likely have a flow-on effect on the others. For example, a person who feels more secure in attachment is likely to be able to give more attention to an occupation, being less distracted by anxiety or fear. In turn, a greater sense of occupation is likely to create a better sense of identity for the individual.

As the complete “cluster” of emotional needs is met, it is likely that the person’s entire sense of self-worth, of being valued and valuable to others, will be enhanced, as well as providing a sense of personal control and empowerment.

At some point in this meeting of needs, a person may be empowered to move from fear, grief or anger into the domain of positive experience and wellbeing. Kitwood expressed this sense of well-being as a feeling of being “loved”.


Creating a Balance
When caring for a person with dementia there needs to be a balance between meeting their physical, emotional and psychological needs. For example, a person may receive excellent physical care and nourishment but feel lonely, bored and helpless.

Physical Needs
The basic physical needs that must be met for a human being to survive are:
- Nutrition
- Hydration
- Shelter
- Safety

Emotional Needs
Meeting a person's emotional needs is as important as meeting their physical needs

Key Principles of Person-centred Care
Kitwood identified ten key principles that should be embraced in order to provide person-centred care:
- A non-judgemental acceptance of the uniqueness of each person.
- Respect for the past experiences and learning of each person.
- Recognising the whole person as having emotional, social, physical and spiritual needs.
- Staying in communication requires flexibility, lateral thinking, and acceptance of other viewpoints.
- Nourishing attachments means ensuring people feel welcome and included.
- Creating a feeling of community gives us a sense of belonging, of where we fit in and what is expected of us.
- Maximising freedom for people to contribute to their care and eliminating unnecessary controls.
- Allowing ourselves to receive from others and valuing what they give (in other words, allowing the person with dementia to contribute in some way to the care environment, as far as they are able).
- Building and maintaining an environment of trust - protect from bullying, exploitation and other abuses of power.

Focussing on positives - on people's abilities and what they can do.

The Eden Alternative
Dr. Bill Thomas, a medical doctor is the creator of the Eden Alternative – a philosophy developed to combat what he believes are the real killers in institutionalised care namely – loneliness, helplessness and boredom. When Dr. Thomas was invited to take over a facility he introduced cats, dogs and birds along with many indoor plants. Each resident was offered a bird, and two birds were offered if the resident could not speak. Where possible the resident assisted in the care of the animals and plants.

However, before the introduction of the animals and plants, staff had to be convinced that the sterile environment of the past was not the best they could offer. The Eden Alternative acknowledges the contribution made by the hands on staff and the knowledge they have about
their clients and encourages them to share this knowledge with other staff and contribute to reviews and meetings when care plans are updated. This move led to the removal of a layer of middle management! This model also appreciates how isolated many people were feeling and actively encourages outside organisations to visit often, especially children. Gardens also play a big part in the revitalisation of care. Dr Thomas is of the opinion that the life we offer our ‘elders’ should be as close to a ‘home’ life as possible, with people being encouraged to do ordinary everyday activities for most of the time, the same kind of things they would be doing in their own homes.

There are ten principles relative to the Eden Alternative:

**Principle One:** The three plagues of loneliness, helplessness and boredom account for the bulk of human suffering among our elders

**Principle Two:** An Elder-centred community commits to creating a human habitat where life revolves around close and continuing contact with plants, animals and children. It is these relationships that provide the young and old alike with a pathway to a life worth living.

**Principle Three:** Loving companionship is the antidote to loneliness. Elders deserve easy access to human and animal companionship.

**Principle Four:** An Elder-centred community creates opportunity to give as well as receive care. This is the antidote to helplessness.

**Principle Five:** An Elder-centred community imbues daily life with variety and spontaneity by creating an environment in which unexpected and unpredictable interactions and happenings can take place. This is the antidote to boredom.

**Principle Six:** Meaningless activity corrodes the human spirit. The opportunity to do things that we find meaningful is essential to human health.

**Principle Seven:** Medical treatment should be the servant of genuine human caring, never its master.

**Principle Eight:** An elder-centred community honours its Elders by de-emphasising top-down bureaucratic authority, seeking instead to place the maximum possible decision-making authority into the hands of the Elders or into the hands of those closest to them.

**Principle Nine:** Creating an elder-centred community is a never-ending process. Human growth must never be separated from human life.

**Principle Ten:** Wise leadership is the lifeblood of any struggle against the three plagues. For it, there can be no substitute.

Many people had their doubts about the Eden Alternative; however the need for medication was reduced, people were living longer and staff turnover and absenteeism were reduced. We now have several organisations in Australia that have adopted the Eden principles - Alzheimer’s Australia WA is one of them.

Importance of Environment

Physical Environment

It is good reflective practice to ask ourselves if we are encouraging people with dementia to do as much for themselves as possible. Is the physical environment offering clues to people who have trouble finding their way around? Are we catering well enough for people who may have poor hearing or vision problems?

As we get older it becomes more difficult to distinguish similar colours from one another, therefore, contrasting colours can be used for doors that we wish our clients to use, and we can paint doors we do not want our clients to use the same colour as the walls. A contrasting colour for skirting boards will assist a client who has perception problems to work out where the floor finishes and the walls begin. We should avoid heavily patterned floor coverings as these too can be misinterpreted – black and white squares on the floor can be interpreted as steps for instance. It will also be helpful if toilet seats contrast well with the toilet pedestal and surrounds as this may assist person to be able to toilet independently for longer.

Lighting is something else we have to consider. Older people will need more intense lighting to enable them to satisfactorily make their way around. Although bright lighting is good, glare is not, so this must be eliminated as much as possible. We also need to take into account that some sunlight is generally good for us. Encouraging people to spend some time out of doors when the weather is conducive is beneficial, and may assist in maintaining circadian rhythms.

Poor hearing can also be a problem for some people as they get older and unfortunately learning how to manage a new hearing aid is often beyond the capabilities of a person who also has dementia. Continual background noise such as television is not a good idea as most aids tend to pick up this kind of noise as well. Facing a person with hearing problems and talking clearly and not too fast is a better practice than raising your voice.

If we are working in a person’s home we will need to have an occupational safety and health check carried out, not only for the benefit of the client but also to make sure that our worker is working in a safe environment in the person’s home. This check may also reveal the need for such items as grab bars in the bathroom, or a ramp to allow wheelchair entry in a safe manner. Sometimes aids such as these are not needed when the service commences but may be needed as dementia progresses. It is then the responsibility of the care worker to feed this changed need back to their supervisor (coordinator) so that these matters can be discussed with the family. Families may need help with finding out how to gain access to these resources.

Further Reading:

Further reading:

Position Paper 3 Dementia Care and the Built Environment (2004)
Assistive Technology

Assistive technology and equipment can allow people with dementia to maximise their independence and minimise the care they require; and thus enhance their quality of life.

The range of equipment covers the following categories:

- Reminders and Prompts e.g. pill box alarms, clocks, fridge recorders
- Therapeutic Interventions e.g. sensory cushion, therapeutic doll, interactive wall boards
- Communication e.g., CommunicAid, talking photo album
- Safety e.g. door alert, key safe, flood alerts
- Monitoring Systems e.g. personal emergency monitoring system, Emergency ID Australia
- Every Day Living e.g. dinner sets, one touch radio, automatic safety iron.

For more information contact:
http://www.alzheimers.org.au

Social Environment

When a person begins to attend a day centre, or makes the transition from home into a residential facility there are ways in which this change can be made more acceptable. This is especially important when making the decision to place a family member in a residential facility.

In order to establish an organisation that offers social and emotional support we need to encourage a philosophy of open communication and good team work. People with dementia should be addressed by their preferred name and have their fears and anxieties managed with empathy. They should be encouraged to make decisions if they are able, in relation to their care and have an input into day to day activities. Personal items in residents’ rooms can reflect their interests and can be a good source of conversation. They should feel safe and able to express their feelings and opinions freely and family members and friends should be welcome at any time. It is also important that people with dementia are encouraged to maintain any skills that they have, even if these only apply to self care. Some may have other skills such as playing the piano or using a computer and these skills should also be encouraged and maintained.

We also need make sure that we take into account the fact that some people we care for may be from other cultures. It is helpful if we find out some basic things about their culture so that we do not offend, and we are able to talk to them about things that are important to them. Finding out about their favourite foods and music for example and using this information when caring for a person is likely to be appreciated.

Nurturing a person’s spirituality is also important and for some people this will encompass religion. Finding out about a person’s previous habits, whether or not they attended church, whether this activity is still important to them and how to meet this and other spiritual needs will be another important aspect of care.
Emotional Environment

Person-centred care (PCC) is:
- A holistic approach to dementia care developed by Professor Tom Kitwood, focusing on the individual and utilising aspects such as the person’s past history, routines, personal preferences and needs.

Kitwood’s Model of Emotional Well-being

Attachment: A bond, a fundamental human desire for feelings of closeness that may be even stronger in people with dementia.
Inclusion: Belonging to a group and to have social interaction with others is a strong human characteristic.
Occupation: Some form of activity that draws on a person’s abilities and skills and results in a meaningful outcome for the individual.
Comfort: Tenderness, closeness, calming of anxiety, soothing of pain and sorrow, and the feeling of security created by empathy and support from another person.
Identity: Sense of self, of knowing who we are. We are defined by our past and the different roles we play in our lives.

If we strive to ensure the above are being experienced at some level then we are going some way to providing some quality of life for the person with dementia. It must be understood that as dementia progresses, verbal communication becomes more difficult. We have to make a greater effort to understand what the person with dementia is trying to tell us. Often this is manifested by way of a change in behaviour - a person looking for their mother may be expressing a need that they are feeling insecure or confused or they may just need some reassurance. Sometimes events from the past will influence behaviour as in the case of the lady who, upon admittance to a facility, began to crawl under the bed whenever she felt insecure. The staff reported this to the family who advised that the staff just blow a whistle and call, ‘All clear’ and the lady would come out from under the bed at her own volition. Apparently this lady often thought she was still living during the war years when bombs were dropping.

It is necessary to get to know the person with dementia as much as possible, including their past experiences in life and their preferences and dislikes. Knowing their past will often shed light on current behaviours and once we understand why certain behaviours occur we can take steps to either eliminate them or reduce their occurrence if they are of concern. If we cannot get to the bottom of concerning behaviours then we need to implement a monitoring process.

Further Reading:

THE EDEN ALTERNATIVE DOMAINS OF WELLBEING

(AI Power Hierarchy)

Identity – being known, having personhood, individuality, having a history, role, sense of self, familiar environment
Connectedness – belonging, engaged, involved, connections to past, present and future, companionship, connection to place and to nature, personal possessions, relationships, part of a community, supportive society
Security – freedom from doubt, fear and anxiety, safety, certainty, assuredness, privacy, dignity and respect, trusting relationships
Autonomy – liberty, self-determination, choice, freedom, empowerment, right to take risks
Meaning – significance, hope, heart, importance, value, purpose, reflection, sacred, spiritual, pertaining to you, beliefs
Growth - development, enrichment, unfolding, expanding, evolving, learning, exploring,
Joy – happiness, pleasure, delight, contentment, enjoyment
(Italic additional descriptors by J. Burton)
www.edeninoznz.com.au
Following are some more thoughts from Dr Al Power who gave us many things to think about when he visited us in 2015.

A new Model (Inspired by the True Experts ...people who are experiencing dementia!)

A new definition

“Dementia is a shift in the way a person experiences the world around him/her.”

- From fatal disease to changing abilities
- The subjective experience is critical
- From psychotropic medications to ‘ramps’
- A path to continued growth
- An acceptance of the ‘new normal’
- The end of trying to change a person back to who he/she was
- A directive to help fulfil universal human needs
- A challenge to our biomedical interpretations of distress
- A challenge to many of our long-accepted care practices

Autonomy and risk assessment

“The only risk-free human environment is a coffin.” Bill Thomas MD

Risk Taking – Two kinds of risk

Downside risk – The risk that things will turn out worse than anticipated

Upside risk – The risk that things will turn out better than expected

Long term care tends to focus almost exclusively on downside risk.

✓ We can reduce our downside risk by increasing safety, BUT
✓ As we increase safety, we also tend to reduce the potential for upside outcomes
✓ Therefore improving quality of life involves accepting some degree of risk
✓ Instead of trying to eliminate risk, we must negotiate risk

BY

- Discussion
- Exploration of values, tie-in to well-being
- Conditions of empowerment
- Continuum of empowerment
- Collaborative decision
- Documentation and monitoring of results
- Keeping other stakeholders abreast of the process

Re-frame ‘refusals’ and ‘resistance’ as exercising choice!!
Doing for versus doing with!!
Autonomy is often defined as the freedom to make your own choices, but people rarely make decisions in isolation. In addition to providing a safe physical environment we also need to balance freedom and risk. Taking risks is part of everyday life. A life without risk would be unimaginable. When caring for someone else, there is a natural desire to try to reduce risk as much as possible. However, this may mean missing out on benefits and restricting a person’s freedom. Risk assessment often focuses only on the possible risks, without considering what opportunities and benefits are being lost as a result. The goal is to take into account the wellbeing and autonomy of the person with dementia, as well as their need for protection from physical harm.

Further reading:
http://library.nhsggc.org.uk/mediaAssets/dementiasp/Nuffield_Dementia_short_guide_FINAL.pdf
Planning Support

Care Plans

Care workers should have access to a client’s care plan, as well as be able to work from the care plan. In order to do this they need to understand dementia and its effects on functioning, and they will need to be able to translate information in the care plan into practice.

Are they aware that dementia is a medical condition that affects the brain? We also need to determine their attitude to aging and older people in general.

The care plan needs to be designed around the care needed by a particular individual and not only will it prove to be a guide for the care worker, but the care worker will, as time goes by, be able to report on and contribute to the development of the care plan as the needs of the client change.

Each person who is involved in the care of a particular client should have the opportunity to feedback information in regard to changing needs, preferences and other information gained whilst providing care. This information should be used to modify the plan as the person’s needs change. Very often a particular care worker has worked out a good strategy to cope with a particular behaviour but this information is not shared and the behaviour remains a problem for other colleagues.

A good way to try to overcome this is to involve care workers in meetings when a care plan is reviewed. It also makes giving individual care to people with dementia easier if staff rosters are arranged so that a particular group of care staff regularly work with a particular group of clients. This arrangement enables staff to get to know their clients very well and become familiar with their interests, preferences and idiosyncrasies.

Duty of Care

Care workers who are responsible for the care of their client/s are expected in common law to extend a duty of care towards their client/s and to see that they come to no harm. They will be found to be negligent if they do not take into account industry standards and regulations, or do not give the kind of care that would normally be expected of someone with the same responsibilities.

Duty of Care - Responsibility of a person to avoid actions that can reasonably be foreseen to be likely to cause harm to others.
Ethical Requirements

Similarly there are certain ethical standards that must be met:

- Beneficence (providing benefit to others)
- Nonmaleficence (not harming others)
- Justice (providing services that are fair to all people)
- Autonomy (providing people with the opportunity to make choices about all aspects of their lives).

Maintaining Independence

When caring for a person with dementia it is tempting for the care worker to do more than support and assist when necessary. Often a care worker will begin to shower or dress a person who is capable of doing these tasks unaided – they may just need a prompt or two. Their progress may be slow but to take over a task and deprive the person of the opportunity of carrying out a task themselves can be very detrimental for their self-esteem and may result in a loss of abilities.

Being able to manage our own self care is very important to most of us and we must strive to preserve a person’s self-esteem and dignity at all times. Tasks of self-care should be regarded as activities of daily living and allowing time for a person to undertake whatever they can achieve independently in this area should be factored in to their care plan.

Planning Support

Regardless of whether the services being provided are in the community or home environment, people working in these situations will need a range of skills, and be able to engage with clients in a stimulating and innovative way. This interaction is best if it is meaningful and relevant for the group or individual.

Planning for support in a facility is more complex as you have to look at consistency of care provision seven days a week. There is evidence to support the practice of utilising a particular group of staff to support a particular group of people with dementia. The advantage of this is you get to know the people you care for really well and you can gradually become attuned to their needs and habits. Also, it is much easier to research and remember the past history of a few clients rather than be rotated every couple of weeks and meeting the challenge of new clients all the time.

Staff rosters should be planned around the needs of the clients you are caring for, taking into account cultural aspects, preferences for showering or ‘washing’ times and whether or not clients sleep through the night. Some clients may get up during the night and want a snack or cup of tea for example. Personal routines also need to be observed. This kind of information should be documented in the care plan and all staff members should have access to it.

The information in the care plan should not only reflect the level of assistance and care required by the client, but should also contain family and other social information that will assist those offering care to interact in a meaningful way.
Elder Abuse

Older people have the right to live in safety, without being harmed or threatened. Unfortunately there are occasions when an older person is exploited and their best interests are not always taken into account. On some occasions the perpetrator may believe that they are acting for the good of the person, however; whether the harm sustained is intentional or non-intentional it is still considered to be abuse.

Older people generally have the right to make their own decisions about their welfare. If they are unable to do this, a person, preferably of their own choosing, can be asked to make decisions on their behalf.

People engaged in caring for older people are aware of the vulnerability of older people and need to make sure that their actions do not cause harm to an older person.

Definition of Elder Abuse:
Intentional or un-intentional action/s that cause/s harm to an older person that occurs within a relationship of trust.

Areas in which Elder Abuse can occur:

Physical Abuse – physical injury or coercion, poor living standards, lack of preferred food, inappropriate medication or lack of recommended medication.

Sexual Abuse - sexual assault, rape or sexual harassment – or not allowing person to express their sexuality

Psychological Abuse – threats and intimidation that lead to fear - disregard of a person’s customs and culture

Financial Abuse - improper use of an older person’s funds or possessions – not allowing a person access or control of affairs when a person is still capable – forcing changes to a will or other documents

Neglect – intentional or un-intentional failure to meet personal needs of an older person in regard to physical, mental, spiritual, social and cultural matters.

Risk Factors:
Sometimes there is conflict within families in regard to what is best for the older person. At times one family member will be expected to do all the caring and may eventually not be able to cope. This may result in the person who is providing the care lashing out in frustration. Often family members, who do not have extended periods of time with the person being cared for, do not realise how exhausting it can be.

If a person is being cared for in a residential facility then the facility should be able to offer a person with dementia the kind of special care this condition demands. Staff should be fully trained and knowledgeable about the effects of dementia and the kind of care and support that is required. Staff should also be well supported and feel able to express their concerns and ideas freely. Also a set of policies and procedures that have been put together with input from staff at all levels will assist in guidance when particular events arise.
Possble signs that may indicate abuse are physical injuries that appear on a regular basis with no satisfactory explanation for their appearance being forthcoming. Also a person being cared for may express concern in regard to their money or possessions being stolen.

Possible Signs of Abuse
- Physical injuries appearing without a satisfactory explanation
- Weight loss
- Withdrawal or depression
- Become fearful and distressed
- Rejects physical contact especially in regard to personal care
- Lack of money to pay bills
- Items are disappearing from home
- Money is not being spent for the benefit of the person with dementia
- Showing fear of another person

People working in the community who suspect abuse from a family member must report this to their supervisor who will then investigate the matter. Visiting a family member who is under suspicion of abuse requires great skill and it is good to express empathy with the family member and acknowledge what a difficult job they are doing at the outset. A visit from a supervisor to the family can be revealing, in that family members who are having difficulty coping, sometimes of their own volition, will admit that they sometimes take their frustrations out on the person they are caring for. This is a cry for help and should be treated as such. In some cases extra services may be required, or the person being cared for may require full-time care in a residential facility.

If abuse is definitely suspected then referral must be made to an appropriate agency – this could be police or an advocacy service – each case will be individual. Also the wishes of the person being abused must be observed as sometimes a person will choose to stay in an abusive relationship rather than look at an alternative. The rights of the person suspected of the abuse must also be maintained.

If you are working in a day centre or residential facility, procedures must be in place that allow for confidential reporting and protection of the person reporting the possible abuse. All evidence relating to the suspected abuse must be documented and the severity of the abuse should be determined. Policies and procedures should be in place that will support an investigation and a course of action should the abuse be confirmed.

Mandatory reporting
Recent legislative reforms (from The Aged Care Amendment Act 2008) regarding elder abuse include the following:
- Compulsory reporting of incidents of alleged sexual and serious physical assault in residential aged care
- Whistle-blower protection for approved providers and staff who report
- The appointment of a dedicated Aged Care Commissioner, who will have the capacity to initiate investigations into complaints
- Compulsory police checks of staff and community visitors
- Increased spot checks of aged care homes by the Aged Care Standards and Accreditation Agency
Documentation

Accurate documentation is essential in order that we can meet the requirements of our funding bodies and legal requirements, and be accountable in regard to the care we give to our clients.

Consideration will need to be given to:
- Compliance with organisational reporting requirements
- Completing documentation appropriately
- Maintaining documentation
- Filing documents

In order to meet the requirements of accurate and easily understood reporting we must be able to present reports and plans that make sense and are legible. Other people must be able to understand what has been written. Spelling can sometimes be an issue, especially in regard to people’s names and also medical information. Also we need to eliminate the use of acronyms. The information should be easily understood by all who read it.

In regard to the needs of our clients, we must be able to record their details and care needs in order that this information can be shared with all the professionals who interact with the client, and their family members. The people who have interactions with clients will also provide written reports which will add to the body of information on each client, recording changes in care and any other information which may assist in the care process.

Care workers will be expected to submit regular reports on their clients, recording day to day activities that monitor their wellbeing, or attend review meetings and contribute to them, depending on what setting they work in.

It is important to be aware of when you need to complete documentation, to whom the information should go, how the information is stored and who will be able to access the information.

There are some laws and guidelines that assist:
- Privacy laws (these laws prohibit one from discussing personal information in relation to a client outside of your work role)
- Freedom of information legislation (if you had a complaint you would be compelled to supply any documentation in this regard to an authorised complainant or their representative)
- Regulations and codes of practice (regulations and recognised good practice guidelines)

Some forms that you may have to complete or contribute to:

Personal information forms (for clients and staff)
Care plans
Reviews/progress notes
Minutes of meetings
Accident and Incident forms
Service information
Staff records
When reporting on an accident or incident it is important to be objective, that is, not to put your own assumptions of what occurred in the report but to simply report what happened or what was said. These forms should then be filed in a designated place and then reviewed in a set time frame to make sure that particular situations are not occurring on a regular basis. If it should be the case that a particular event is occurring on a regular basis then strategies will need to be put into place to prevent the event re-occurring.

Re-write the following statements in an objective manner:

1. John blundered into the room of another person and proceeded to knock down their ornaments and in fact stole one or two items.
2. Jenny was in a bad mood today and refused to have her shower!

Legislation and Codes of Practice

There is legislation that requires aged care, including dementia and community care sectors, to comply with legal requirements.

Codes of practice or advisory standards provide practical guidance towards meeting legislative obligations. For example, the Occupational Health and Safety Act in each State and Territory places what is called general Duty of Care on employers and their employees. Employers are responsible not only for the safety of their employees, but also for the safety of other people in the workplace. In an aged care facility this would include residents, visitors, medical professionals and contractors who spend time in the workplace. There are a number of codes of practice in each state and territory covering injury, management, hazardous substances and manual handling for example. Australian standards also provide direction about a range of occupational health and safety measures. They must be followed if they are referenced in the Regulations.

There are many different pieces of State and Federal legislation. Some examples of this legislation applicable to the aged and community care industry are as follows:

**Commonwealth**

- Aged Care Act 1997

**State**

- Equal Opportunity Act 1984
- Consent to Medical Treatment and Palliative Care Act 1995
- Occupational Safety and Health Act 1984 (WA)
- Privacy Act 1988
- Food Act 1985 – Food Hygiene
- Guardianship and Administration Act 1993
- Health Records Act 2001

The Privacy Act states that people are entitled to have their personal information kept private and not shared with other people. Just as important is the Equal Opportunity Act which describes workplace rules, policies, practices and behaviours that are fair and do not disadvantage people because they belong to another ethnic group, for example.
Residential Aged Care Standards

Australia has a very comprehensive Commonwealth Aged Care Act, mainly for residential care, that was established in 1997. The Act includes legislation under the User Rights Principles, in which the Charter of Resident's Rights and Responsibilities is written. In residential aged care homes there is a set of quality standards relating to the care provided to residents. These are set by the Australian government through the Department of Health and Ageing. Auditing of care in residential facilities is conducted by The Accreditation Agency Ltd, according to a prescribed schedule of checks, including spot checks. The accreditation process is about making sure residential facilities meet all the 44 outcome standards. This guides the agreement, or contract that residents and providers must abide by and is signed by both parties on admission to care.

Aged care facilities need to comply with the accreditation process and be audited successfully to receive funding from the Australian Government (there are provisions for exceptional circumstances). There are four Accreditation Standards, and each standard has a number of expected outcomes, in all there are 44 expected outcomes. An overview of each Standard follows:

**Standard 1**  
Management systems, staffing and organisational development  
Principle: Within the philosophy and level of care offered in the residential care service, management systems are responsive to the needs of residents, their representatives, staff and stakeholders, and the changing environment in which the service operates.

**Standard 2**  
Health and personal care  
Principle: Residents’ physical and mental health will be promoted and achieved at the optimum level, in partnership between each resident (or his or her representative) and the health care team.

**Standard 3**  
Resident lifestyle  
Principle: Residents retain their personal, civic, legal and consumer rights, and are assisted to achieve active control of their own lives within the residential care service and in the community.

**Standard 4**  
Physical environment and safe systems  
Principle: Residents live in a safe and comfortable environment that ensures the quality of life and welfare of residents, staff and visitors.

For a complete list of all outcome standards please see the following website:  
Aged Care Standards and Accreditation Agency  
Community Care Standards
Community care programs are now audited against a revised set of national standards now known as the Community Care Common Standards. These standards are a revised and simplified version of the previous HACC National Service Standards and have been in place from 2010 onwards.

There are three standards, with each one having a number of performance criteria attached to them. The standards and their detail relate to the role and responsibilities of staff involved in care and services, including leisure and health programs for clients with dementia. The standards are as follows:

**Standard 1 – Effective management**
The service provider demonstrates effective management processes based on a continuous improvement approach to service management, planning and delivery.

**Standard 2 – Appropriate access and service delivery**
The client or prospective client has access to services and receives appropriate services that are planned, evaluated and delivered in partnership with themselves and/or their representative.

**Standard 3 – Service user rights and responsibilities**
The client, and/or their representative, is provided with information to assist them to make service choices and has the right (and responsibility) to be consulted and respected. They have access to complaints and advocacy information and processes and their privacy and confidentiality and right to independence is respected.

For a complete list of the standards and their performance criteria, please refer to the following website:

It must be clear that State and Territory laws may differ. There may be some similarities between each area but the student will need to be aware of the laws governing their particular work place.
Communication, Behaviour and Activity

Communication is made up of three parts:

- 55% body language
- 38% tone and pitch of voice
- 7% words we use

Source: Mehrabian (1967). UCLA

As you can see from this information, words are not the most important factor in regard to communication. We can inform people that it is lunch time in a friendly manner or an unfriendly manner by the tone and pitch of voice, plus our body language.

In dementia a person’s ability to communicate verbally will gradually become more difficult. For some, difficulty with words occurs very early and they will have great problems constructing a sentence, responding to a question and even concentrating on the subject being discussed. For some people comprehension is a difficulty. We may ask if they are ready for their shower but they might not be able to remember what a ‘shower’ entails and so reply with a ‘no’. We must remember that just because a person appears to handle social communication very well, it does not mean that they can necessarily understand everything we say to them. Similarly, a person who speaks very little may have a very good understanding of what we mean, but may be unable to give us a relevant verbal response.

When verbal communication is very scant or difficult to understand we will need to develop an understanding of the body language and the behaviour of the person with dementia. If a person develops a limp they may be in pain, or if their behaviour becomes very unsettled overnight they may have an infection. We must be aware that there will always be a reason for changes in behaviour and if we know our clients well, we will be able to follow up on the changes and investigate further.

As we get to know our clients well we develop an understanding of how dementia has affected each individual and their ability to communicate, and we apply individual techniques that meet the needs of the individual.

How dementia may affect communication

- Word finding difficulties may be apparent
- Difficulty concentrating on the subject matter
- Short term memory loss
- Difficulty comprehending what is said
- May indulge in ‘confabulation’
- Unable to report abstract concepts such as ‘pain’
- Reverts back to first language

Some helpful strategies

- Give short one sentence explanations
- Allow plenty of time for comprehension
- Repeat sentences in exactly the same way
- Agree with them or distract if necessary
- Accept blame when something is wrong
- Leave the room if necessary
- Respond to feelings rather than words
- Be patient, cheerful and reassuring
- Try to eliminate extraneous noise (TV)
• Introduce yourself
• Establish eye contact (if appropriate)
• Use their name often
• Do not talk about a person in front of them
• Try not to interrupt and never argue
• Prompt and reflect back if necessary
• Look out for symbolic language
• Avoid questions and
• Do not remind them that they have forgotten

### Communication Approaches:

#### Reality Orientation
Reality orientation places the person with dementia in the here and now. We can use clocks, calendars and notice boards that reflect what is going on around us, the time of day, the season, whether or not it is meal time, or time to go to bed. Sometimes, in a day centre for instance, a person may arrive and at that point in time have no idea where they are, even though they may be a regular visitor. The staff introduce themselves and welcome the person, maybe sit them next to someone they have a special relationship with, or tell them that they are needed to assist in a special task for the day. Reality orientation is particularly useful in early dementia and for prompting people in regard to the time of day.

#### Validation
‘Validation therapy’ is attributed to Naomi Feil who recognised that reality orientation is not always appropriate, especially for people with more advanced dementia. When a person has dementia it is not unusual for their memories to become confused and often they go back into their past and for them this becomes their reality. When this occurs, rather than bringing them back to our reality we can ‘step into their world’ and respond to the feelings and anxieties they may be expressing. Sometimes they may be looking for their mother who will have passed away many years ago. We can respond to this by engaging them in conversation about their mother, and when the time is right distracting them on to another subject. We do not need to explain that their mother is no longer alive, as this is likely to cause much upset and on occasions they may recall this fact themselves whilst talking about their mother.

#### Reminiscing
Allowing and encouraging people with dementia to reminisce about their past is a valuable tool. Often people with dementia feel more confident when talking about past events and sometimes their verbal skills will even improve. We can reminisce as a pleasurable activity or in a game and we can also employ reminiscing when we wish to distract a client from the task at hand, for example, if appropriate when showering a person we may talk about some places they have lived or visited, their former job, or a significant event that occurred in their life that has great meaning for them.

#### Life Stories
A good activity related to reminiscing is to complete a ‘Life Story’ with a client and their family. It will depend on the capabilities of the person with dementia as to just how much information they can contribute, and the family should be encouraged to help if possible. The aim is not to write a novel but to concentrate on the milestones in life such as being born, starting school, going to university or getting that first job, and any other meaningful events that colour our lives. For one gentleman the highlight of his life as a photographer was being engaged to take photo’s of Prince Charles! Sometimes when a person becomes upset, we can remind them of a meaningful event in their lives and this may assist in calming them.
Behaviour

One of the most challenging aspects of dementia care is dealing with some of the behaviours of concern that may arise such as:

- Delusions
- Hallucinations
- Misidentifications
- Depression
- Personality change
- Behavioural patterns
- Aggression
- Hostility

Systems will need to be in place for an assessment to be carried out. This should involve the gathering of objective information in relation to the behaviour that is being exhibited. If a number of concerning behaviours are present it is best to deal with them one at a time. However, we do need to enable staff to understand that although some behaviours may seem odd at times, if they are not harmful, and fulfill a need for the person, then there is probably no need to try to change them.

Once information has been gathered then it is time for a case conference which should include direct care worker/s, nurses/supervisors, family members, person’s doctor (if available) and any other relevant people. If the person with dementia is competent it may also be pertinent to have them attend the meeting. However, this may not be the case if dementia is involved. The information already gathered should be presented to the group and ideas in regard to possible causes, or triggers for the behaviour are to be discussed.

A holistic approach is best and we should consider the following areas for possible triggers:

- Physical and emotional health - e.g. is the person sick or in pain, are they upset or anxious?
- Environment – e.g. is the person too warm or too cold, is there too much noise, too many people?
- Tasks – e.g. is the task too difficult, too many steps?
- Communication – e.g. is the person able to make their needs known? - can they hear us?
- Past history – e.g. are past memories influencing the behaviour?

When we know the person and their history we can analyse these points in more depth. Other tools that can assist involve collecting accurate information on exactly what is happening at the time a particular behaviour occurs. It is important to be objective when making these observations.
The ABC approach looks at:

A - antecedents (what was happening before the behaviour occurred)
B - behaviour (an objective description of the behaviour that ensued – what, when, where, who and why)
C – consequences (the results of the behaviour, including the responses of others to the person and what happened to the person displaying the behaviour – were they ignored, told off, sedated etc.)

We can also look at the STEP approach:

Step One – the person
Gather up all the information you have on the person and write down any new information available. Involve everyone – family, friends, direct care staff, auxiliary staff. Look at the person’s life history, previous lifestyle, personality, routines, significant events and significant people in their life.

Step Two – The behaviour
Describe the behaviour of concern (what, when, where, who, why). Use behaviour charts and documentation when available.

Step Three – The reasons
Based on what you know about the person and the behaviour, look for reasons, triggers, factors that may have been a probable cause.

Step Four – The strategies
Decide on a course of action to respond to the behaviour. Be flexible and creative and focus on the individual and their needs. In this step it will be wise to consider if the complete needs of the person is being met – if not then this will influence the strategies that you may like to trial. Decide who will do what and be consistent.

Step Five – The results
Implement your strategy and then monitor over a reasonable period of time. Evaluate the effectiveness of the strategy and if necessary change the strategy. Learn from the results so that you can apply this knowledge in other similar situations.

The next step will be to come up with strategies that may lesson the behaviour or even eliminate it altogether. Very often it will be best to start with a full medical review, including medications being taken. The results from this exercise may very well make a difference to behaviour. However if there are no medical complications then we can look at the other information we have gathered. Lateral thinking is to be encouraged and the input of direct care staff can be of great value. Once the group has identified some strategies then it is imperative that everyone who comes into contact with that person is aware of them and that a consistent approach is maintained. In most circumstances it will take a little time for changes to be noted and the client should be closely monitored during a specific time frame after which a review can take place and strategies are evaluated.

Be proud of successes and make sure others are aware of why the change has occurred.
Case Study

Mr. C had recently entered the Greensleeves Aged Care Facility. Mr. C appeared non-communicative and would walk away when anyone attempted to approach him. He would spend the day wandering around aimlessly, or so it appeared. After a few days he began pulling up a chair next to the kitchen island and tried to use the chair to climb over to access the kitchen, or to escape. Staff were not sure which!

The support staff took a look at his information regarding his background. This revealed that he had experienced a troubled personal life, was estranged from his family and that he had also been a baker!!

Will this information assist in explaining the actions of the client? Explain why?

Will this information make devising a suitable strategy easier? Why?

Can you think of any strategies that may suit the client?

When a strategy has been agreed upon it is important that this information is shared with all team members and that a review date is set so that the team can meet and discuss the success or otherwise of the strategy.

Further reading:


Activity

When we think of activities we need to encompass activities of daily living as well as activities that may keep us fit, provide us with pleasure or have a tangible outcome. Activities are what we fill our day with – from the moment we get out of bed until we return in the evening. Washing, eating, drinking, chatting, reading and working are all activities.

A person with dementia should be given the opportunity to carry out all personal activities for as long as they are able, with care staff only providing prompts, and then assistance, when it becomes necessary. We need to remind staff not to take over tasks that a person can do for themselves even though it may be much quicker for them to take over. Allowing people with dementia ‘time’ is a great skill and a very necessary one.

Many people with dementia prefer to stay with familiar tasks, for instance ladies may feel quite at home working in the kitchen washing dishes whereas men might enjoy sitting in a shed knocking a nail into a piece of wood, or even just sitting and chatting with some mates!! Other people may have particular interests that still remain – someone who had an interest in stamp collecting for instance may still enjoy activities related to this hobby, or a person who had been a keen knitter may still like to touch and feel different wools. Similarly, a person who used particular tools relating to a hobby or occupation may like to handle these old tools even though they may no longer be able to use them.
Varied Activities allow us to:
- Socialise – e.g. be with others, talk and share
- Contribute – e.g. to assist in setting the table
- Achieve success – e.g. arrange some flowers
- Retain skills – e.g. a carpenter assists in hanging pictures
- Have a sense of control – e.g. be allowed to water the garden
- Fulfill a religious or spiritual need – e.g. attend a church service
- Grow and learn – e.g. trying something new

Adapted from

When the information for the care plan is gathered it should also include information in regard to a person’s social interests, spiritual interests and the kinds of activities they may like to be involved in. This information will then be a guide for staff in that they will be able to plan an individualised routine for the client according to their preferences. They will have a good idea about the subjects that particularly interest the client and this information will enable them to successfully engage the client in conversation or interaction. Whilst group activities and entertainment have a place, we must cater for the individual and their needs and interests.

When we consider activities we must relate these to real life as much as possible and make sure that activities are purposeful for the individual. Activities can give people the chance to socialise, to be productive or to contribute (assisting with table setting for example). They can assist in the retaining of skills, and can give a person some sense of control as well as meeting religious or spiritual needs.

Whilst craft activities have their place it must be remembered that many people with dementia have difficulty with tasks requiring fine motor skills and this indicates that complex craft activities may not be suitable. However, there are many craft activities that are simple and where success is likely, for example finger painting.

Many organisations are now realising the value of having resident pets, whether it be birds, dogs or cats. Animals can provide us with unconditional love and be a joy. Animals are also a responsibility and people with dementia can also play a part in their care by assisting with walking the dog or feeding the cat, bird or fish.

Another activity area can be the garden and again assisting people with dementia to have some responsibility in regard to selecting plants, planting them and caring for them can be very rewarding, even more so if vegetables are grown for eating.

Another idea from ‘The Best Friends Staff’ is to encourage staff to bring their interests and ideas into the workplace. This can stimulate a whole new range of activities and help to create a sense of community.

Gaining intimate knowledge of your client is the key and when armed with knowledge from information gathered at the beginning of the service, plus information gained during the caring experience, it is possible to offer clients the individualised care that is most appropriate for them. This in turn will provide staff at all levels with greater job satisfaction.
Restraints

<table>
<thead>
<tr>
<th>Types of Restraint</th>
<th>Description</th>
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<tbody>
<tr>
<td>Physical Restraint</td>
<td>Any action that prevents a person moving freely. Example: tying them to a chair or locking doors.</td>
</tr>
<tr>
<td>Chemical Restraint</td>
<td>When medication is used to control a person’s behaviour rather than for a therapeutic reason. Example: to calm them or put them to sleep.</td>
</tr>
<tr>
<td>Psychological Restraints</td>
<td>Usually verbal threats. Example: “If you don’t behave I will put you in a home.”</td>
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Justification for Restraints

Reasons for using restraints are often cited as being used to keep the client safe. People may be restrained if they begin to be unsteady on their feet for example. If a client is restrained and in fact discouraged from walking then this may contribute to a decline in their walking ability. The use of restraints does not appear to have an impact on the lessening of falls. The best way to reduce falls is for care staff to assist clients to walk according to their individual needs, and to make sure that a client is not overmedicated to a degree when falls are likely.

Rather than applying physical or medical restrictions at the outset we need to try and analyse what may be causing a particular behaviour:

- Is the client restless because of some possible physical discomfort?
- Is the client disorientated due to over medication?
- Are the clients needs not being met therefore they are reacting with anxiety or aggression?

Sometimes de-escalation techniques such as reacting in a calm way, with a calm voice are employed successfully. A care worker spoke in a whisper to a client who was upset and shouting and the client responded by whispering back! Therapeutic approaches may also assist such as massages or relaxation sessions.

Older people must be treated with respect and dignity and have the right to make their own decisions in regard to how they live their life if they have the capacity to do so. If a person is deemed not have the capacity to make decisions in regard to how they live their life then generally a relative will be called upon to make decisions that are in the best interests of the person. This means that a restraint may only be used with a person’s consent, or that of a relative who is representing a person who has not got capacity, or in an emergency when it is being used to prevent harm.

People most likely to be restrained are generally looked upon as 'difficult', 'noncompliant' or are less physically able.

Generally staff are confused in regard to what constitutes a physical restraint and would like some guidance in the form of a policy and procedure being in place covering such items as:

- Definition of restraint
- When it is appropriate to use a restraint
Staff will need to be educated in regard to alternatives to restraint as well as when their use may be the last resort.

Understanding the ‘duty of care’ of the care provider distinguishes between putting people at risk and enabling them to choose to take reasonable risks. It does not mean that we have to keep someone safe from every eventual risk. No environment is entirely risk free. Removing risk is impossible and an attempt to do so may diminish the quality of life for our clients.

The above material is CSCI copyright – Rights, risks and restraints, November 2007

Assault and battery
Assault and battery are two terms which can be related. Assault refers to threatening to harm another person; battery refers to an instance where the person has been touched without their consent. Consent is the key issue. Consent must be gained from the older person, or their guardian for any treatment, procedure and indeed the application of a restraint.

The common law doctrine of assault and battery can be leveled against the person responsible for excessive, inappropriate or non-consensual restraint. Facilities often misplace their interpretation of duty of care in favour of the use of restraints, when equally the older person’s rights are infringed when excessive, inappropriate and/or non consensual restraint is applied.

More information about assault and battery in reference to restraint is available from:

Further reading

Dilemmas in Dementia Care:
http://www.nuffieldbioethics.org/dementia/dementia-dilemmas-care


More information about the reporting of elder abuse is available from:
Supporting and Guiding of Care workers

It is the responsibility of a team leader to ensure that their care staff have a good understanding of dementia and that the care they are providing meets with regulatory requirements, as well as the requirements of the organisation they are working for.

It is important for care workers to know of the relevant legislation and industry regulations that govern care practices and are enshrined in ‘Acts’ which have been passed either by commonwealth or state governments. Whilst it is not necessary for them to be conversant with all of these ‘Acts’ the policies and procedures of their organisation will reflect these requirements, therefore it is important that they are aware of, and understand these.

An induction program for new staff is a good way to assist them to become aware of the requirements relative to their role, and also to be introduced to the philosophy of care that is practised within the organisation.

Once a care worker has undergone an induction process and has been familiarised with the organisation’s policies and procedures they normally commence work. At the commencement of their employment it may be necessary for them to undertake additional courses as part of their ongoing development. A trial period may take place during which the worker will be given assistance, and possibly teamed up with an experienced worker. During this time (usually about three months) the worker should be given regular feedback on their performance and be encouraged to ask any questions they may have.

Annual performance appraisals should be carried out in which the supervisor and the worker discuss current work performance, any further training that may be required and any particular goals the worker may wish to aspire to, or be required to achieve.

Support workers employed to go into people’s homes and give care are in a different position to people working in a care team. They work in isolation; therefore support from their supervisor is essential. It is also beneficial to team them with a more experienced worker initially. Community workers often share clients with another worker, therefore it is good practice to have regular meetings that also allow carers who share a client to learn from one another, or carers that have had particular success in an area to share this with the group.

Caring for people in general used to be perceived as an unskilled task. We now recognise that it requires a number of skills and this is especially so when caring for people with dementia.

Skills required for a Support Worker

- A good knowledge of the effects of dementia and its progression
- Knowledge of best practice principles
- Empathy for people with dementia
- A clear understanding of the role
- Ability to read and put care plans into action and to reflect on the results
- Ability to work as part of a team
- Effective communication skills

Many support workers who are currently employed are from different countries and may have a different cultural view of older people and people with dementia. If this is the case it is helpful if
we spend time finding out their views regarding older people as we can learn from them and they can learn from us. In some cultures older people are valued, however this may not be the case when a person develops dementia.

Another large group in this particular workforce are more mature people, with some having worked in the industry for many years. For some in this cohort, it may be difficult for them to adapt to changes in approaches to care. For this group, often the ‘medical’ model is the most familiar approach to care. Considering the needs of the client, other than medical needs, was not contemplated. Staff in this group may need to be reminded that the human spirit does not thrive without a purpose in life. We all need to feel that we can contribute, to laugh, to play, to stay connected with life as in gardens, animals and other people. People with dementia still have the need to experience quality of life and best practice guidelines and new models of care are all designed to meet this goal.

It must be acknowledged that caring for people with dementia is a demanding task that can be stressful at times. In order to give our very best in the workplace we need to ensure that we balance our life with work and pleasure. We also need to monitor self-care abilities in ourselves and co-workers and be there to offer guidance and support whenever necessary. If a co-worker has had a particularly demanding day, we need to make time listen to their account of the day. Often this is all that is needed. However, on other occasions it will be necessary to advise the person to contact a professional agency that can assist. Some organisations have an arrangement with a support agency and it is important to stress to workers that this assistance is available to them, normally free of charge and confidential.

Person-centred care should not just be limited to persons with dementia. If staff are not valued, and treated with respect it is unlikely they will provide a good level of care to the people in their care.

We must also consider the needs of auxiliary staff and volunteers who may have interactions with people with dementia. As a general guide it will be appropriate for them to attend courses and gain knowledge of how dementia affects a person, and how to communicate with a person with dementia. Volunteers who may have considerable interaction with people with dementia will definitely need to undergo some form of training and mentoring just as new care staff do.
References/Further Reading


Alzheimer’s Australia Fact Sheets and Updates, Papers on website www.alzheimers.org.au

Alzheimer’s Australia, February 2003: Philosophy of Care described in Alzheimer’s Australia Quality Dementia Care Position Paper http://www.alzheimers.org.au/content.cfm?infopageid=3612


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Dementia care Essentials 2010, Alzheimers Australia WA Ltd
Dementia Care Essentials CHCAC416A

Dilemmas in Dementia Care:
http://www.nuffieldbioethics.org/dementia/dementia-dilemmas-care

Exploring the needs of younger people with dementia in Australia
http://www.dadhc.nsw.gov.au


For further information on Vascular dementia visit:
http://www.alzheimers.org.au

For further information on Parkinson’s Disease visit:
Parkinson’s Australia Inc. - http://www.parkinsons.org.au

For further information on Lewy Body Disease visit:
http://www.alzheimers.org.au

For further information on Frontotemporal Disease visit:
http://www.alzheimers.org.au

For further information on Alcohol Related Dementia visit:
Health A to Z: Your Family Health Site
http://www.healthatoz.com/healthatoz/Atoz/ency/korsakoffssyndrome.isp

For further information on AIDS related dementia visit:
The Australian Federation of AIDS Organisations: http://www.afao.org.au

For further information on Dementia Risk Reduction visit:
Alzheimer’s Australia - http://www.alzheimers.org.au

For further information on Huntington’s Disease visit:
National Institute of Neurological Disorders and Stroke
http://www.ninds.nih.gov/disorders/hintington/hintington/htm

For further information on AIDS related dementia visit:
The Australian Federation of AIDS Organisations: http://www.afao.org.au


More information about assault and battery in reference to restraint is available from:

More information about the reporting of elder abuse is available from:


Glossary of Terms

The following resources were used in generating this glossary:
At your fingertips - Dementia Alzheimer’s and other dementias, H. Cayton, Dr. N. Graham, Dr. J. Warner
The Australian Oxford Paperback Dictionary, F. Ludowyk, B. Moore

Acetylcholine
One of a group of chemicals known as neurotransmitters. Found throughout the brain, acetylcholine enables nerve cells to communicate with each other. In Alzheimer’s disease, the levels of acetylcholine are lower than usual.

Agnosia
Inability to recognise familiar objects, people, sounds, shapes or smells.

Apraxia
Inability to make familiar movements despite having muscular strength and co-ordination.

Aphasia
Impaired ability to produce, comprehend or use language.

AIDS
Abbreviation for Acquired Immune Deficiency Syndrome.

Alzheimer’s disease
The commonest cause of dementia. It usually begins after the age of 65 and results in gradual, progressive loss of memory and other functions of the brain.

Amyloid
A protein that is found in the brains of people with Alzheimer’s disease. It is deposited throughout the brain in microscopic clumps known as plaques. Its function is unknown and it may be the cause of the deterioration of brain function.

Anticholinesterase drugs
Also known as cholinesterase inhibitors, these dementia drugs, stop the breakdown of acetylcholine. Aricept and Exelon are examples.

Antipsychotic drugs
A range of tranquillisers, also known as neuroleptic drugs, that help to reduce symptoms of aggression.

Aricept
The brand name for donepezil, a dementia drug.

Blood pressure
The amount of stress placed on the walls of the arteries, veins and heart chambers by the flow of blood.

Brain scan
A general term to mean any investigation that produces pictures of the brain. A CT scan or MRI scan shows slices through the brain. A SPECT scan shows the brain’s blood supply.

Bradykinesia
An abnormal condition that features slowness of speech and movements.

Cerebral cortex
The outer layers of the brain, involved in thinking, memory and the interpretation of perception or the senses.

Cholesterol
Substance found in animal fats and oils, and is also made in the...
body. It is necessary for the making of vitamin D in the skin and for making various hormones. Too much cholesterol can be responsible for deposits in blood vessels and eventual restriction of blood flow.

**Cholinergic**
Referring to acetylcholine. For example, a cholinergic neurone is a brain cell that contains the chemical acetylcholine.

**Cholinesterase inhibitor**
An alternative name for anti-cholinesterase drug.

**Chromosomes**
Microscopic thread-like structures that are present in all cells. They are collections of genes, which contain the genetic information that is transmitted from generation to generation.

**CJD (Creutzfeldt Jakob disease)**
A very rare form of dementia caused by an infectious agent called a prion. As well as loss of memory, CJD commonly causes muscle jerking, blindness and problems with walking. Death occurs within a year or so.

**Cognition**
The faculty of knowing or perceiving things.

**Cognitive tests**
Tests that assess how well a person can think and how well his or her memory is working.

**Community care**
A term covering health and social care services delivered to people in the community, usually in their own home.

**Complementary medicine**
An approach to health care that explores alternatives to conventional treatments. Acupuncture, homeopathy, aromatherapy and spiritual healing are examples of complementary therapies.

**Confabulation**
Producing false memories to replace memories that are no longer capable of being stored. A person may guess an answer or imagine an event and then mistake it for an actual memory. Although it may be seen by others as lying, the person is unaware that their memories are false or inaccurate.

**Confusion**
A state in which problems with memory and concentration impair the function of the mind.

**Dehydration**
A state in which there is insufficient water in the body. It occurs when a person's fluid intake fails to balance fluid loss through sweating, vomiting or diarrhoea.

**Delirium**
Features confusion, speech disorders, anxiety and sometimes hallucinations. Often has a rapid onset and lasts from hours to weeks. Fluctuations in conscious state.

**Dementia**
A term used to describe impairment of brain function, involving
memory, thinking and concentration. Dementia usually becomes progressively worse, eventually making it impossible for someone to cope with living without help. There are many causes of dementia, including Alzheimer's disease, vascular dementia, Lewy body dementia and Pick's disease.

**Depression**  
An illness in which the main symptoms are feeling low, tearfulness and loss of enjoyment. Depression can affect sleep, appetite, motivation and concentration. It is treatable.

**Diabetes**  
Occurs when the amount of sugar in the blood cannot be regulated. There are several types of diabetes.

**Diagnosis**  
The process of identifying and naming a disease from a person's symptoms and signs. Getting a diagnosis may only involve talking with the doctor and having a physical examination. In other cases, special investigations may need to be done as well.

**Disinhibition**  
Loss of feelings of shame or embarrassment that normally help control a person's actions. Disinhibition results in inappropriate or improper behaviour.

**Disorientation**  
A state in which someone loses their awareness of time and place. For example, they may fail to recall the date or even the year, and may not be able to say where they are.

**Donepezil**  
The generic name of Aricept, a dementia drug.

**Down syndrome**  
A genetic condition caused by an extra copy of chromosome 21 that results in slowed growth, abnormal facial features and intellectual disabilities.

**Enduring Power of Attorney (EPA)**  
A legal document in which one person gives another the power to handle his or her financial affairs. An EPA can only be drawn up if the person handing over this power can understand what he or she is doing. The EPA comes into force only after it has been officially registered.

**Epileptic seizures**  
Caused by a group of nervous system disorders that produce an uncontrolled electrical discharge in the brain.

**Exelon**  
The brand name for rivastigmine, a dementia drug.

**Frontal lobe dementia**  
A dementia in which the disease process mainly affects the frontal lobes of the brain. Memory is affected less than in other dementias, but there may be major problems with loss of motivation and disinhibition.

**Frontal lobes**  
Parts of the cerebral cortex situated at the front of the brain.
This is the area of the brain that controls movement of the body. It is also involved in ‘higher functions’, such as planning ahead, problem-solving and initiative.

Galantamine

The generic name of Reminyl, a type of dementia drug.

Genes

Material contained within the chromosomes. Genes carry the blueprint for the body; information that dictates how our bodies are built up, including the colour of our eyes and skin, how tall we are, our gender and many other details. Some genes have defects, or mutations, that cause disease.

Hallucination

A perception (hearing, seeing, smelling or feeling something) without appropriate stimulus. For example, hearing voices when there is no-one there. Hallucinations are quite common in people with dementia.

Huntington’s disease

Also sometimes called Huntington’s chorea, a disease in which mental deterioration is accompanied by involuntary twitching and muscle spasms.

Incontinence

Involuntary or inappropriate passing of urine or faeces. Help is available from continence advisors.

Korsakoff’s syndrome

A memory disorder caused by lack of vitamin B1 (thiamine) sometimes caused by alcoholism.

Lewy body dementia

A type of dementia in which abnormal collections of protein called Lewy bodies, occur in the brain. People with Lewy body dementia typically show more variation in their mental abilities from day-to-day than is usual with other dementias.

Memantine

A dementia drug, which works by altering chemicals called NMDA receptors in the brain. It may slow the progression of dementia in some people. (Ebixa)

Memory

The retention in the mind of information that may be recalled later.

MRI scan

Abbreviation for Magnetic Resonance Imaging scan. A type of brain scan that creates pictures using a powerful magnetic field rather than X-rays.

Neuroleptic drugs

Another name for antipsychotic drugs.

Neurologist

A doctor who specialises in the diagnosis, treatment and management of diseases of the nervous system.

Neurone

A nerve cell.
Neurotransmitters  A group of chemicals in the brain that enables nerve cells to communicate with each other. Groups of adjacent nerve cells tend to use the same neurotransmitter. Examples include acetylcholine, serotonin and dopamine.

Limbic region  Situated deep inside the brain, this region is responsible for functions such as eating, sleeping, consciousness and emotions.

Occipital lobe  Part of the cerebral cortex situated at the back of the brain, responsible for interpreting what is seen.

Parietal Lobes  Part of the cerebral cortex situated on either side, above the ears. Responsible for anything to do with order and structure.

Parkinson’s disease  A chronic disease of the nervous system that is characterised by slowness of movements, a tremor and an expressionless face. Some affected people also develop dementia.

Person-centred Care  A holistic approach to dementia care focusing on the individual and utilising aspects such as the person’s past history, routines, personal preferences and needs.

PET scan  Abbreviation for Positron Emission Tomography scan. A sophisticated brain scan which is able to look at the brain in great detail. It is not generally available in clinical practice.

Pick’s disease  A rare dementia which commonly affects younger people than Alzheimer’s disease. It affects language and personality before there is any significant change in memory.

Prevalence  Rate of occurrence.

Reality orientation  A psychological treatment in which every opportunity is taken to make people with dementia aware of the time, where they are and the world around them.

Reminiscence therapy  A treatment that aims to stimulate people’s memories by means of old films, pictures, music, etc.

Reminyl  The brand name for galantamine, a dual-action dementia drug. It is anticholinesterase drug and also works by stimulating areas of the brain called nicotinic receptors.

Rivastigmine  The generic name for Exelon, a dementia drug.

Temporal lobes  Parts of the cerebral cortex situated behind the temples, and responsible for our memory.

Sedative drugs  Drugs used to reduce symptoms of anxiety and agitation and to
help people sleep. Sedative drugs increase confusion in people with dementia.

**Side effects**

The unwanted ‘extra’ effects that occur in addition to the desired therapeutic effects of a drug. Most drugs have some side effects. These will vary from person to person and commonly disappear when the body becomes used to a particular drug.

**Stroke**

A result of a haemorrhage in the brain, or of a blood clot in an artery of the brain, leading to paralysis of part or all of one side of the body, or loss of speech, or loss of consciousness or death. The paralysis may be sudden or gradual in onset.

**Syndrome**

A group of signs and symptoms that occur together and are typical of a particular disorder or disease.

**Thyroid**

A gland in the neck that produces a chemical known as thyroid hormone. This hormone is essential to the workings of the body. Thyroid hormone deficiency is a rare cause of dementia.

**Tranquillisers**

Drugs used to help people who are very anxious. These drugs can cause increased confusion in people with dementia.

**Validation**

A technique used in caring for people with dementia that focuses on feelings rather than confusion.

**Vascular dementia**

A type of dementia associated with problems affecting the circulation of blood to the brain, such as may result from a series of small strokes.