CHCAGE005
Provide support to people living with dementia

Learner Guide

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How to study this unit

You will find review learning activities at the end of each section. The learning activities in this resource are designed to assist you to learn and successfully complete assessment tasks. If you are unsure of any of the information or activities, ask your trainer or workplace supervisor for help.

The participant will be required to demonstrate competence through the following means:

Methods of assessment

- Observation in the work place
- Written assignments/projects
- Case study and scenario analysis
- Questioning
- Role play simulation
- Learning activities
- Class discussion and group role-plays
- Assessment tasks

Consult your coach or trainer

Asking for help

If you have any difficulties with any part of this unit, contact your facilitator. It is important to ask for help if you need it. Discussing your work with your facilitator is considered an important part of the training process.

Name of facilitator: ____________________________ Phone number: ________________
Welcome to the unit CHCAGE005 Provide support to people living with dementia, which forms part of the 2015 Community services training package. This unit describes the skills and knowledge required to provide person-centred care and support to people living with dementia. It involves following and contributing to an established individual plan.

Application:
This unit applies to workers in a residential or community context, including family homes. Work performed requires some discretion and judgement and may be carried out under regular direct or indirect supervision. The skills in this unit must be applied in accordance with Commonwealth and State/Territory legislation, Australian/New Zealand standards and industry codes of practice.

WHAT YOU WILL LEARN

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Element 1: Prepare to provide support to those affected by dementia

Introduction

Demonstrating an understanding of dementia

Dementia is a growing health and social issue, with the number of people affected, directly and indirectly, projected to rise dramatically over the next fifty years. There is now a good understanding of the progression of dementia from early signs of memory loss and behavioural changes to high dependency on care, due to functional incapacity.

Dementia is not related to a single specific disease, therefore affects people differently and has varying impacts on their families and carers. Dementia is not a natural part of ageing although most people with dementia are older. After the age of 65, the likelihood of living with dementia doubles every five years and it affects almost 24% of those aged 85 years and over.

What is dementia?

Dementia is a general term used to describe the symptoms of a large group of illnesses. This leads to problems with memory and thinking, which leads to a decline, in social skills and behaviour and indicates that something is wrong with the brain. Dementia is not a disease but a specific set of symptoms, caused by a range of diseases. Apart from vascular dementia, most common types of dementias, including Alzheimer’s disease, are caused by the gradual abnormal accumulation of toxic proteins in the brain that results in Neuro-degeneration, in turn resulting in impaired brain function and brain cell death.

What happens when someone has dementia?

The brain controls all that a person does and says. When someone has dementia sections of the brain gradually become damaged and stop working properly, affecting what that person does and says. This means that a person with dementia will often have trouble speaking, understanding and remembering. It may also change their behaviour.

A person with dementia may:

- Be unable to do everyday tasks such as eating, dressing or driving
- Display strange or uncharacteristic behaviours
- Become easily upset or confused
- Be unusually aggressive or suspicious
- Jumble and confuse their words; and/or gradually lose their ability to communicate through written language
- May find it harder to do previously familiar tasks, such as, writing, reading, showering and using numbers.
Prevalence of dementia

Who develops Dementia?

Dementia can happen to anyone. One in four people over the age of 85 in Australia have the condition. Most people who develop dementia are over 65 years of age, but people in their 40’s and 50’s can also have dementia. At as at 2004 around 170,000 Australians over 65 years of age are living with a diagnosis of dementia. Many of these people live in the community, some independently.

According to the Australian Bureau of Statistics:

1. Dementia is most prevalent for people aged 65 and over. Of people aged 85 and over, one in four have dementia.
2. It is expected that as the population aged 65 and over increases, so too will the number of people with dementia.
3. In 2002 there were approximately 162,000 people in Australia with dementia.
4. By 2020, this figure is projected to increase by around 50% to 242,700 for people aged 65 and over. Just under half of these people (102,800) will be aged over 85.5
5. Within 40 years, the number of people with dementia is estimated to reach 500,000.
6. In Australia, dementia is the second largest cause of disability burden for all people but for older people causes the highest levels of severe or profound disability. By 2016 it will be the largest disability burden, surpassing depression and all other chronic illnesses.
7. Dementia is the 5th leading cause of death for people aged 65 and over.
8. Alzheimer’s disease is the most frequent cause of dementia in the aged population, with 3% of people aged 65-74, 19% of people aged 75-84 and 47% of individuals over 85 years having Alzheimer’s disease. In Western countries, Alzheimer’s is the fourth common cause of death.
9. Dementia was made a National Health Priority during the 2004 Federal Election Campaign.

Source:
Understanding the brain and its effect on dementia

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 (coloured below) follows:

**The Neuron:** Approximately 100 million brain cells or 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 under 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, this area is one of the first to be affected and short term memory loss results. 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 all 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, 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.
The Hippocampus

As mentioned earlier 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.

The main chemical conductor or neurotransmitter is acetylcholine, or ACH, a chemical that is released by the neuron and requires a particular enzyme called choline acetyltransferase (CAT) to be synthesized properly. Choline acetyltransferase controls acetylcholine production in synapses of the autonomic nervous system. The reduction in choline acetyltransferase results in less acetylcholine in the synaptic vessels to assist with neurotransmission. It is the lack of this enzyme that is thought to be the problem in AD.

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. Research is indicating AD may start in the hippocampus. 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.
Causes of dementia

Many dementias are due to the abnormal accumulation of proteins, such as tau, in the brain. These proteins are needed for brain cells to function normally. The proteins are manufactured, used and then broken down by processes within the brain cells. Malfunctions at any stage of this ‘production line’ lead to abnormal accumulations in and around the neurons of the brain.

The proteins clump together and interfere with brain cell function and connections, eventually leading to cell death. This cell death is evident as atrophy on structural scans of the brain. In addition to causing physical changes to brain cells these proteins also affect the neurotransmitters that neurons use to communicate.

Brain cells make a large number of proteins, such as amyloid or tau, by assembling them from raw materials (amino acids). These proteins are broken down again and the raw materials recycled for other proteins. If too much protein is made or not enough is broken down then protein can collect in the cell. This may block other functions of the cell or be toxic to the cell, eventually causing the brain cell to die. It is thought that many dementias are caused by abnormal collection of protein in this way. Although dementia is often associated with abnormal functioning of specific proteins, the same protein abnormality can cause a diverse range of symptoms in different people and at different ages.

Can dementia be inherited?

This will depend on the cause of the dementia, so it is important that the person is fully examined by a doctor as early as possible. If there are concerns about the risk of inheriting dementia, then the person should discuss it with their treating doctor.

Dementia is progressive in most cases, the speed with which dementia can progress varies, between individuals. Sometimes a massive decline can occur rapidly over a few months, in other cases, it may happen, over a number of years. Although the major signs and symptoms are the same, each person will have a unique and different way of expressing them. The dementing process is dynamic – it is always progressing and changing. It can vary from day to day but over longer periods it will progressively make the person more disabled.
The progressive stages of dementia

People with dementia differ in the patterns of problems they have, and the speed with which their abilities deteriorate. Their abilities may change from day to day, or even within the same day. What is certain though is that their abilities will deteriorate. Although the major signs and symptoms are the same, each person will have a unique and different, ways of expressing them. Although these features will not necessarily be present in every person, nor will everyone go through the same stage it remains a useful description of the general progression of dementia.

The three stages of dementia can be identified as follows:

Stage 1: Early dementia

The person has early difficulties, with subtle effects and changes often this phase is only apparent in hindsight. The onset of dementia is usually very gradual, and it is often impossible to identify the exact time it began. The onset of dementia is very gradual, and it is often impossible to identify the exact time it began. Alzheimer’s Australia has identified some signs of early dementia that may serve as prompts for carers to seek professional assessment.

The person may:

- Appear more apathetic, with less sparkle
- Lose interest in hobbies or activities
- Be unwilling to try new things
- Be unable to adapt to change
- Show poor judgement and make poor decisions
- Be slower to grasp complex ideas and take longer with routine jobs
- Blame others for ‘stealing’ lost items
- Become more self-centred and less concerned with others and their feelings
- Become more forgetful of details of recent events
- Be more likely to repeat themselves or lose the thread of their conversation
- Be more irritable or upset if they fail at something
- Have difficulty handling money.
Stage 2: Moderate dementia

At this stage the problems are more apparent and disabling. It is at this stage that services may be providing significant supports to the person with dementia and their carer.

- The person has increasing difficulty with daily living skills like handling money or driving
- Becoming repetitive in conversation
- Loses the thread of newspaper articles, TV programs, conversations
- Confuses time and place
- Neglects hygiene
- Has difficulty with everyday tasks
- Does not recognise family or friends
- Invents stories to fill-in blanks or have false memories
- Shows poor judgement or problem thinking
- Has reduced capacity for independence
- Displays behavioural outbursts
- Has mood swings
- May wander
- Gets upset with too many choices.

Stage 3: Advanced dementia

At the third and final stage, the person with dementia is severely disabled and needs total care. Immobility will become permanent and in the final weeks, or months, the person will be bedridden.

- Incontinent
- Immobile or has difficulty with mobility
- Confused as to who is who, and may not recognise family
- Less communicative – having difficulty understanding or using speech
- Confused – looking for people and place from the past.
One

Progressive stages of dementia

Read the following case study and answer the questions which follow.

Case study
Josie had cared for Mrs. Baker for just on four years. Lately she had noticed that Mrs. Baker had stopped speaking. Bathing and dressing had become increasingly difficult as Mrs. Baker ceased helping with any of the tasks. During the past week she had stopped feeding herself at meal times, even when prompted. Mrs. Baker seemed completely flat and withdrawn into a world where Josie couldn't make contact with her. Josie noticed differences in Mrs. Baker.

1. What differences or changes had Josie noticed?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

2. What do you think is happening to Mrs. Baker?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Two

Dementia Quiz

Decide whether these statements are: True or False. Tick the box.

1. People with dementia have problems with memory and thinking which can lead to a decline in their social skills and behaviour.
   - True  □ False

2. Everyone over the age of 85 has dementia.
   - True  □ False

3. Dementia describes a group of signs and symptoms and is not the name of a disease.
   - True  □ False

4. A sign or symptom of dementia is memory loss.
   - True  □ False

5. Vascular dementia is caused by many little strokes in the brain.
   - True  □ False

6. Alzheimer’s disease is the most common form of dementia.
   - True  □ False

7. Some conditions look like dementia but are reversible if treated, for example, depression.
   - True  □ False

8. Dementia is a progressive illness and goes through stages.
   - True  □ False

9. Dementia may change the way a person behaves and this can be challenging.
   - True  □ False

10. A person with dementia may forget how to do everyday living tasks and may need help.
    - True  □ False
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.

Aged Care Assessment Teams (ACAT)

Aged care assessment services include Aged Care Assessment Teams (ACAT) which can help people obtain a range of Commonwealth funded services to the elderly to help them to continue living in their homes or enter residential care facilities. A network of 125 regionally based multidisciplinary Aged Care Assessment Teams (ACATS) provide assessment services throughout Australia. An older person has to be assessed by an ACAT to be eligible to enter a residential aged care home, or to receive a Community Aged Care Package (CCAP). ACATS may also refer people to community based services. The ACAT comprises of a group of health professionals from various disciplines.

The ACAT team consists of:

- **Doctor or geriatrician:** specialising in common health problems of the elderly.
- **Psycho-geriatric Assessment Teams** (PGAT): can provide assessment and treatment.
- **Registered nurse:** to assess nursing care needs.
- **Social worker:** to assess welfare needs.
- **Occupational or physical therapist:** to assess physical function and mobility.
- **Speech therapist:** to assess speech therapy needs.

The assessment process and possible outcomes should be explained to all involved and time allow for clarification. A comprehensive assessment will involve questions and discussion about the aged person’s ability to manage activities of daily living, health problems, support from family and services currently utilised.

Depending on the outcome of the assessment, arrangements will be made to either assist the person to remain at home, if this is not a viable option, enter residential care. The person will be assessed as needing either low care (hostel level) or high care (nursing home level). If the person is assessed as not eligible for residential care then the ACAT would be able to inform the older person of the options regarding Home and community care, and with permission make referrals. Community aged care Packages and Community Options Packages (COP’s) or residential care. Other community-based services that are available include the HACC Program and Day Therapy Centres.
General Practitioners (GP): General Practitioners are often the first point of contact for families and people with dementia and may be responsible for initial identification of a problem and referral for specialist assessment. They may remain a significant primary contact point for medical support for the person and their family throughout the illness.

Neurologists/Geriatricians/Psychiatrists: Neurologists/Geriatricians/Psychiatrists specialise in neurological and/or psychiatric medical conditions and provide the primary source of specialist medical expertise for people with dementia, their families and GPs. They may be responsible for coordinating and/or referring other specialist services. Neuropsychologists specialise in brain-behaviour relationships. They integrate information from a range of validated, standardised tests with information on the person’s pre-illness intellectual functioning, developmental, medical, psychiatric and family history. They also include information about behaviour, mental state and personality.

(OTs) Occupational Therapists: Occupational therapists measure a person’s ability to function in their own environment. This functional assessment can take place in the person’s own home or workplace to assess levels of support and risk and plan strategies to help the person stay safely in their home as long as possible. Occupational therapists are also involved in driving assessments.

Social Workers: Social workers are primarily responsible for ensuring people and their families have access to the information and resources they need to support them during the illness. Social workers may also undertake a psychosocial assessment to identify areas of need and plan for change. Services and support vary but may include carer services, respite opportunities, recreational activities and accommodation options. Social workers may also be involved in arranging guardianship and administration orders.

Memory clinics and their use
Memory clinics are another option for assessing a person with dementia, used in many parts of Australia. These are mainly based in public hospitals and community centres. In Victoria they have been based in aged care services and called Cognitive dementia and Memory Services (CDAMS). Since 1997 they have been developed in a network throughout the state in order to improve dementia assessment and management.

The advantages of memory clinics are that they are thorough, specialise in dementia assessment and are usually multidisciplinary. This means they have on staff occupational therapists to determine the person’s level of function; Neuro- psychologist for a more detailed cognitive assessment; social workers to assess the family’s circumstances; community nurses and other medical specialist. The assessments are usually conducted over a number of sessions spread over a few weeks.

Current medications available for dementia
There are no current treatments that will halt, or reverse neither the 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 an enzyme from breaking down a chemical (acetylcholine) in the brain. This results in increased concentrations of the chemical, allowing healthy brain cells to function better. This results in 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, which causes the brain cells to be damaged further. Ebixa may help to protect brain cells by blocking this release of excess glutamate.
Policy framework for Dementia

The critical need to better support people who live with dementia and their carers has been acknowledged as a high priority within Australian and State Government strategic planning processes, as well as by peak provider and consumer associations.

National Framework

At a National level, the Australian Health Ministers agreed in 2004 to develop a National Framework for Action on Dementia. The National Framework for Action on Dementia 2006 – 2010 was released in September 2005, which was endorsed by the Australian Health Ministers jointly in April 2006. The development of the Framework has provided an opportunity to create a strategic, collaborative and cost effective response to dementia across Australia.

The Framework was developed in consultation with people with dementia; their carers and families; the peak bodies that represent them; key stakeholders and service providers and represents a shared national vision for action on dementia.

The five key priority areas identified in the Framework are:-

1. Care and Support
2. Access and Equity
3. Information and Education
4. Research
5. Workforce development and training

State Framework

At a Queensland level, the Queensland Health’s Directions for Aged Care 2004-2011 was released in 2004 following extensive consultation. This document provides the strategic direction and framework for supporting older people of Queensland including those persons living with dementia and their carers.

A key feature of the Directions for Aged Care 2004-2011 is to support early diagnosis, assessment and a skilled workforce delivering a range of client-centred interventions for people living with dementia and their carers. People living with dementia and their carers should be able to access appropriate acute, community, palliative and residential aged care services. Those delivering services need to be aware of the special needs of people HACC Dementia Services Development Strategy - May 07 with dementia and must be trained to work confidently and supportively with them.

The Directions for Aged Care 2004-2011 also recognizes that carers play a vital role in supporting older people living with dementia to remain in the familiar environment of their own homes. Carers need appropriate support to sustain their caring role in the community. They need to be able to access respite and other support and care services in times of crisis; have access to education and training; and to be an active partner in service planning processes.
The Queensland Government has committed itself to recognising and supporting the valuable role of carers, including those of people with dementia, through the Carer Recognition Policy. The Directions for Aged Care 2004-2011 identifies five Action Areas related to the development of dementia services. These action areas are consistent with the suggested key priority areas for the National Framework for Action on Dementia.

**Action Area 1: Assessment**
Better targeted and more appropriate assessment of older people living with dementia

**Action Area 2: Access**
Improved access to a range of services for people living with dementia

**Action Area 3: Service Delivery**
Enhanced coordination and quality of care

**Action Area 4: Carers**
Carers able to access appropriate information, advice and support, to enable them to sustain their caring role.

**Action Area 5: Partnerships**
Partnerships strengthened between services/organisations associated with improving care to those living with dementia.

Adapted from: Queensland Health’s Directions for Aged Care 2004-2011

www.health.qld.gov.au
Types of dementia

Dementia describes a group of signs and symptoms and is not the name of the disease or illness that causes them. A collection of signs and symptoms is called a syndrome. Dementia is a syndrome that may be caused by a number of different illnesses. There are over 100 types of dementia, but most of them are extremely rare. In this section I will describe the some of the most common forms of dementia and those of which are rarer.

The most common types of dementia are:
- Alzheimer’s Disease – approximately 50-70%
- Vascular or multi-infarct dementia – approximately 20-30%

Other less common forms of dementia include:
- Neurological damage: Lewy Body Disease, Parkinson’s Disease
- Fronto-temporal lobe: dementia
- Alcohol-related - Korsakoff's Syndrome
- Genetic : Huntington’s Disease, Wilson's Disease, Pick’s Disease
- Infection: AIDS, CFJ, Syphilis.
Alzheimer’s disease

Alzheimer’s disease is the most common form of dementia and accounts for between 50% and 70% of all cases. It is a progressive and degenerative disease that attacks the brain. It is named after the German neurologist Alois Alzheimer, who first described the brain pathology in a famous lecture in 1906. Alois Alzheimer described the typical pathological brain changes associated with the disease. Alzheimer’s original description of the disease was based on a 51 year old woman who had developed memory problems as her first symptoms.

Alzheimer’s disease is a gradually progressive disease with a course of six to twelve years, although some people have been known to survive for up to twenty years. The Alzheimer’s disease process initially destroys nerve cells in parts of the brain that control memory, including the hippocampus. With damage to the hippocampus, short term memory fails.

Dementia, as well as Alzheimer’s disease occurs because the nerve cells in the brain begin to deconstruct instead of grows. This result, instead of naturally occurring, happens at a fast pace. It is also known to be a result of different genetic mutations that occur. These begin to take effect in ones older age, causing the nerve cells to break down faster.

The early symptoms of Alzheimer’s disease are:

- Memory loss
- Vagueness
- Taking longer to do routine tasks
- Losing the point of conversation
- Intellectual decline
- Impaired functional capacity
- Psychological depression, anxiety and psychosis
Not being able to swallow properly, for example, is one of the physical effects that take place. The later stages of dementia, or Alzheimer’s, will often cause the person to not be able to walk at all. The last type of symptoms that are developed with dementia involves speech and walking disorders. With speech, this will begin by one not being able to use simple words anymore, and will have a hard time finding the right words to use when communicating. The body will then begin to shut down and not be able to function properly.

**Vascular Dementia**: Vascular dementia is the broad term for dementia associated with problems of circulation of blood to the brain and is the second most common form of dementia. There are a number of different types of vascular dementia. Two of the most common are Multi-infarct dementia and Binswanger’s disease. Vascular dementia is the second most common form of dementia. It accounts for 15 to 20 percent of cases in Australia. Vascular Dementia occurs when blood clots block small blood vessels in the brain, ultimately destroying surrounding brain tissue. The disease can also trigger minor strokes.

**There are five subtypes of vascular dementia:**
1. Arteriosclerotic.
2. Acute onset.
3. Multi infarct.
4. Sub cortical or Binswanger’s disease.
5. Mixed cortical sub cortical.

**Symptoms of Vascular Dementia include:**
- Confusion
- Problems with recent memory
- Wandering or getting lost in familiar places
- Loss of bladder or bowel control
- Emotional problems such as laughing or crying inappropriately, difficulty following instructions, and problems handling money.

Usually the damage is so slight that the change is noticeable only as a series of small steps. However, over time, as more small vessels are blocked, there is a gradual mental decline.

**Medical management of vascular dementia involves:**
- Control of high blood pressure (hypertension)
- Low dose aspirin to reduce blood clotting
- Adequate exercise
- Moderate alcohol
- Low fat diet
- Stress management.

**Parkinson’s disease**: Parkinson’s disease is a progressive disorder of the central nervous system. It is characterised by tremors, stiffness in limbs and joints, speech impediments and difficulty with mobility. Some people develop dementia.

**Pick’s Disease/ Fronto-temporal lobe dementia (FTD)**: Fronto-temporal lobe dementia (FTD) is sometimes referred to as Pick’s disease and manifests at a younger age (30-40 years), has a familial history and lasts for 10 to 15 years. Pick’s disease, like Alzheimer’s disease, causes progressive and irreversible decline in a person’s abilities over a number of years. It is a rare disorder of the frontal lobe part of the brain.
People with Pick’s disease deteriorate quite rapidly with symptoms such as:

- Behaviour personality changes
- Irritability
- Apathy
- Loss of awareness.

**Huntington’s disease**: Huntington’s disease is an inherited, degenerative brain disease which affects the mind and body. It affects 7 in every 100,000 people in Australia. Its onset is usually between 30 and 50 years of age. Symptoms include personality changes, involuntary movement of the limbs, memory disturbance, and slurred speech. Medication can control movement disorders and psychiatric symptoms. Dementia occurs in most cases.

**Alcohol Related Dementia: Korsakoff’s syndrome**: Korsakoff’s syndrome is cause by too much alcohol and when the diet is deficient in Vitamin B1. This dementia is preventable, if people do not drink at a safe level. Affects include memory impairment, parts of the brain responsible for planning and organising and balance. If drinking stops the person the symptoms can improve. Taking thiamine appears to help prevent and improve the condition.

(CJD) **Creutzfeldt - Jacob Disease**: Creutzfeldt- Jacob Disease is also known as (Mad Cow Disease). It is extremely rare, fatal brain disorder. It occurs one in every million people per year. Early symptoms include changes in behaviour and memory loss, lack of coordination. As the disease progresses, usually rapidly, mental deterioration becomes pronounced, involuntary movements appear, and the person may become blind, develop weakness in the arms or legs and finally, lapse into a coma. Death from Creutzfeldt - Jacob Disease usually occurs within two years from onset of symptoms.

**Lewy Body Dementia (LBD)**: Lewy Body Dementia involves a special kind of brain cell death occurring in particular areas of the brain. Abnormal lumps called Lewy Bodies develop inside nerve cells in the brain. The name comes from the presence of abnormal spherical structures, called Lewy bodies, which develop inside nerve cells. It is thought these cause the degeneration and death of brain cells.

People with Lewy Body dementia often have:

- Visual hallucinations and delusions
- Tremors and stiffness like Parkinson’s disease
- Extreme variation in mood with periods of confusion
- Disturbed visual experiences.
- Clouding of consciousness
- Falls or collapses
- Depression.

Lewy Body dementia is often diagnosed as other forms of dementia and is only proven on autopsy.

**AIDS Complex Dementia**: Human immunodeficiency virus (HIV) is an infectious disease that suppresses the immune system and may cause cognitive impairment in its later stages. HIV causes acquired immunodeficiency syndrome (AIDS) in most infected individuals. About ten thousand Australians currently have AIDS, mostly men in their thirties and forties.

HIV dementia causes cognitive, behavioural and motor changes. Symptoms may be overlooked in early stages and many are not diagnosed until daily activities are impaired. Cognitive symptoms typical of HIV dementia include lack of concentration, forgetfulness, slowed information processing, impaired judgement and problem solving. Depression and apathy including reduced motivation and spontaneity are common as well as irritability and, more rarely, psychosis or mania.
Dementia after head injury: Dementia can be a long-term consequence of severe head injury, particularly repeated head injuries. Professional boxers are at an increased risk of cognitive impairment due to repeated head injury. Dementia may deplete a person’s cognitive reserve or the resting level at which a person’s mental resources ‘run out’, making impairments noticeable. People with this type of dementia tend to have a slower decline, than with other types of dementia.

Wilson’s disease: Wilson’s disease is an autosomal recessive disease which disrupts normal copper transport in the body. It occurs in approximately one in fifty. The diagnosis is made if increased levels of fatty acids are found in the blood or skin. MRI scans may also show white matter disease. Prognosis is generally poor due to progressive neurological deterioration although some people may survive up to ten years after diagnosis.

Treatable or reversal, causes of dementia

Some conditions present like signs and symptoms of dementia.

These may be reversible and include:

- **Infection**: bladder/urinary tract (UTI) infections are the most common (can cause “urinary psychosis”) but any infection can cause memory loss/confusion.
- **Medication Combinations/Interactions**: multiple prescribed and over the counter medications, especially from multiple physicians, can interact, increase side effects when taken together and/or become toxic when taken together. (Memory-enhancing drugs such as Aricept, Reminyl or Exelon are “cholenergic”; care should be taken if combining with “anti-cholenergic” drugs).
- **Medication Toxicity**: medications can build up in the body when the person can’t metabolize (digest) them due to frailty, health problems, etc.
- **Depression**: forgetfulness, lack of energy, confusion, and agitation (etc.) can occur. People diagnosed with depression usually admit to symptoms (compared to the tendency of people with Alzheimer’s disease to deny them). Estimates show as many as half of all people with Alzheimer’s disease may also suffer from depression, but are unlikely to recognize their depressive symptoms. Antidepressant medications can help restore vitality and function to people who are depressed and too many people with both dementia and depression.
- **Dehydration**: can cause confusion and “sundowning” (agitation & problems during the evening transition time). Assure good hydration in the afternoon and remember all fluids count (not just water) – but avoid beverages with caffeine.
- **Constipation**: can cause agitation in people with dementia, and can be caused or worsened by dehydration.
- **Chronic Pain**: is the most under-diagnosed problem for people with dementia, and can cause a wide-variety of agitated/confused responses, lack of initiative and depression on a bio-chemical level.
- **Poor Nutrition**: especially lack of the B Vitamins: Folic acid and Thiamin.
- **Sensory Losses**: hearing loss, vision problems, etc. - seem like dementia.
- **Tumors**: occurring anywhere in the body, especially in the brain.
- **Carbon Monoxide Poisoning**: is odorless. Install detectors in home.
- **Lyme disease**: (from ticks) diagnose by blood test. Treat with antibiotics.
- **Fluctuating Blood Sugar**: diabetes or hypoglycemic conditions.
- **Low Functioning or Hypo-Thyroid**: Deficiency in thyroid hormones.
Treatment

Currently there is no cure for either Alzheimer’s disease or Vascular Dementia that can reverse damage that has already occurred in the brain. Treatment for dementia generally focuses on controlling current symptoms (such as agitation or depression) and preventing additional brain damage (for example, by controlling high blood pressure). A number of psychological treatments and medications are useful in treating symptoms of dementia and enhancing the quality of life for all involved.

Delirium vs. Dementia

Delirium is often mistaken for dementia. However, delirium is treatable so it is really important to diagnose the difference.

What is delirium?

Delirium is an acute organic disturbance of brain function, which causes acute confusion that mimics dementia. The onset of delirium is very rapid.

Signs and symptoms of delirium

The signs and symptoms of delirium may include:

- Patchy memory
- Delusions and hallucinations
- Spatial disorientation
- Increased or decreased activity levels
- Disordered sleep/wake cycle
- Clouded consciousness
- Changed level of alertness.

Some common causes and contributing factors to delirium include:

- Dehydration
- Urinary tract infections
- Constipation
- Infections
- Pain
- Anxiety
- Tumours
- Vitamin deficiencies – electrolyte imbalance
- Physical stresses
- Altered environment
- Psychological stressors
- Drugs
- Malnourishment
- Impaired hearing and vision
- Depression
- Acute confusion.
Three

Dementia signs

Read the case study and answer the questions that follow.

Case study

Bill and Doug have been mates for more than thirty years and are in their early seventies. They regularly get together every fortnight for a yarn and a feed. Bill’s wife Geraldine passed away five years ago. Since his wife’s passing Bill has lived mainly with his daughter and, at times, his niece’s place.

One day Bill’s niece, Kayla drives him to Doug’s house. She hasn’t been there before and Bill gives her directions. “Just drive down Flinders Street and turn left at the end.” His directions seem to take them every which way and at one point Bill gets a bit stroppy, “Just go the way I’m telling ya!” he says. Eventually they get to Doug’s street and Kayla recognises his old car.

Inside the house, Kayla and Maxine, Doug’s wife, start cutting up potatoes, cabbage and carrots for the meal. Maxine starts talking about old times. Meanwhile Doug and Bill play cards like they always do. Doug wins the first few hands easily and notices Bill is throwing out useful cards. “You should’ve hung onto that one, Bill,” states Doug. Bill loses his temper and yells, “Don’t tell me how to play! “I know more about cards more than you ever will.” Doug is a bit surprised by Bill’s show of temper. “Steady on mate, it’s only a game.”

Over dinner the conversation is easy and full of stories and laughter as some of the day’s earlier agitations are forgotten. “How come we took so long to get here today?” asks Bill. Kayla answers “Because you forgot which street was the right one. Your memory ain’t as good as it used to be Uncle Bill.” On the way back Bill says “How come it took us so long to get here today?” Kayla replies, “Uncle Bill, remember, I told you why it took us so long, “cos you forgot the way!”

1. How many signs and symptoms can you identify in this story of two old friends?

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2. What type of dementia do you think Bill has? Is there any way to tell?
Planning for support

Regardless of whether the services being provided are in a community of home environment it is best that people working in these situations have a range of skills, and who will 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. If you are going to be providing an evening and weekend service it is helpful to the client and employee if they are located within a reasonable proximity.

Planning for support in a facility is more complex as you have to look at covering a twenty-four hour period, seven days a week. There is plenty of 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 we get to know the people we care for really well and we 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 we 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 will be found in a clients care plan which all staff members should have access to.

Staff at all levels who have interaction with a particular client should have access to the client’s individualised care plan and be aware of how this relates to their role in the caring team. 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 in making meaningful interactions with the client.

Applying a person-centred care approaches to all interactions with the person living with dementia

Over the years the way we care for people with dementia has changed dramatically. We used to 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. 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.

Person-centred Care

The concept is based on meeting the needs of the whole person in order to create a feeling of wellbeing. 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. 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. This can be achieved by meeting the five areas of emotional need that the person experiences. 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 well-being. 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 are 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.
**Activity**

**Four**

**Applying a person-centred care approaches to all interactions with the person living with dementia**

Write down how you could use a person-centred approach to address each of the following scenarios.

1. A client has dementia, but is still physically able. He has always been a great bike rider, participating in marathon rides. The client and his wife would still like him to ride, but the client’s wife cannot let him ride alone, as he is likely to become lost or endanger himself.

   Write down your person-centred approach here...

   Write down your person-centred approach here...

   Write down your person-centred approach here...


2. A client cannot settle into a day program. The client has a history of volunteering and working with those in need.

   Write down your person-centred approach here...

   Write down your person-centred approach here...

   Write down your person-centred approach here...


3. A person with dementia has always had a glass of wine at dinner and a drink or two afterwards, but now forgets how much they have had, and may drink too much, putting themselves in danger.

   Write down your person-centred approach here...

   Write down your person-centred approach here...

   Write down your person-centred approach here...
Interpreting individualised plan and familiarise self with the specific needs and wants of the person living with dementia

To ensure that clients are provided with the specific care they need, an individual care plan will be developed. It is crucial that the care worker understands the purpose of the individual’s care plan and corresponding support services.

A care plan is a framework for individual client care. It is a legal document which must be followed. All staff will need to know the care requirements of each of their clients and any issues they may encounter when attending to that client. The care plan will also provide appropriate strategies to ensure that the appropriate care and support is given to the client. Any concerns relating to a client’s care plan must be discussed with a supervisor and documented in the client records.

Care workers need to be able to 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 fully understand about dementia and its effects on functioning, and they will need to be able to translate information in the care plan into practice.

The first thing we need to establish is how much a care worker knows about dementia and its effects. For instance are they aware that dementia is a medical condition where physical destruction of parts of the brain is taking place, thus rendering the person with dementia as being unable to respond to the environment in a normal manner? We also need to determine their attitude to aging and older people in general. The care plan needs to be introduced as a blueprint for 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.

In many cases more than one person will interact with a client and each person who is involved in the care of a particular client should have the opportunity to feed back information gained in regard to changing needs, preferences and other information gained whilst providing care. This information needs to be added to the care plan to ensure that everyone who interacts with the client has an up to date picture. 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. As mentioned earlier caring for a particular group of people, enables staff to get to know their clients very well and become aware of their interests, preferences and idiosyncrasies. Research is also showing that the best way to prevent falls is for staff to get to know their clients, and to be aware of their routines, habits and risk factors such as poor vision, medication or new environment.
Stages of the Individual care plan

Assessment

This is a gathering and analysis of as much information about the client as possible. The information required will not all be collected at once, but will require input from relevant health workers as well as the client and their family.

The initial assessment will collect information about the client’s health and their ability to attend to their ADLs. A risk assessment will also be conducted to identify if the client is at risk of harm, for example, if they are likely to fall and injure themselves, or if they present a risk to others. The client’s concerns, fears, cultural needs and preferences should also be considered in the assessment stage. It is important that those involved with the client when developing the care plan use effective communication skills and active listening to promote a feeling of security and comfort and to encourage the client to share the necessary information.

The assessment will depend on the organisation or facility and their policies and procedures but will cover areas such as:

- Physical and mental health – health conditions, allergies and any current medications, emotional status, medical history
- Cognitive status and any vision or hearing impairment
- Communication and any speech impairment
- Physical observations
- Alcohol and other drugs
- Personal care and toileting
- Eating and drinking
- Mobilising and risk of falls
- Domestic tasks
- Religious, spiritual, cultural, social and leisure activities
- Family and community support.

Planning

During the planning process, goals for the client are decided upon with input by the client and/or their family and the care team. The goals that are set should be prioritised within an appropriate timeframe. The goals also need to be realistic, achievable, observable and measurable. Strategies to achieve the goals should also be planned – this will include priorities and appropriate activities.

The plan will identify the appropriate support services and aids to assist to be used. The plan will also determine if any adaptations or modifications to equipment, services or the environment may be appropriate. A care plan for a client with dementia will include interventions to promote appropriate behaviour.
Implementation

During the implementation process the plan is put into action. The client is provided with the care and support identified in the care plan. Care staff must ensure that the care they provide is individual and reflects the needs of the client as identified by the care plan. Staff must ensure that they do not ‘take control’ but encourage the client to maintain as much independence as possible. This will assist the client to maintain their current abilities and a feeling of self-worth. Staff should always explain to the client what they are doing and should be respectful to ensure dignity and privacy is maintained. Each client is an individual and has different personal aptitudes, attitudes and abilities. Care must be provided in an appropriate manner that is not discriminating, stereotypical or judgmental.

Clients may simply require various levels of assistance. The various levels of assistance are often grouped as:

- No assistance: the client is able to attend to their own needs
- Verbal assistance: the client may need to be given instructions in a step by step process or be prompted as to what they are required to do next
- Setting-up assistance: the client may require assistance preparing, gathering and setting up the items they need
- Partial assistance: the client is able to meet part of their needs but may require assistance to complete some tasks, eg: assistance with socks/stockings and shoes, buttons or zippers
- Full assistance: the client is unable to complete any tasks safely or appropriately, without assistance.

The appropriate level of assistance should be provided; staff need to be aware of each client’s capacity and the appropriate procedures for giving assistance.

The care and support given to a client will include tasks relating to:

- Maintaining hygiene – personal care, bathing, toileting
- Eating and drinking
- Mobility
- Spiritual, social and emotional needs – socialising and leisure activities.

Staff should be trained to observe and report any physical changes, signs of pain, discomfort or illness, or emotional or mood changes. Consideration always should be given to maintaining the client’s privacy and dignity.

Evaluation

The evaluation process ensures the effectiveness of the care. Evaluation identifies if goals are being achieved and ensures updates and changes to the plan are implemented. This process must occur on a regular basis to ensure that the most appropriate care and support is being provided for the client. The carer has an important role in the evaluation of their client’s care plan. It is very important that they record and report any changes in client abilities, behaviour, health or assistance required as the changes occur, rather than waiting until a review date. The care plan is a dynamic document and should reflect the current needs of the client at any given time.
Activity

Five

Interpreting individualised plan and familiarise self with the specific needs and wants of the person living with dementia

Please use your own experiences and also refer to information in this workbook for more information. Think about the concept of care planning and then answer the following questions to the best of your ability.

1. In establishing a care plan what do you see as the most important issues?

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2. What are the benefits of care plans?

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3. What can go wrong with care plans?

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Identifying and addressing a person's needs for a stable and familiar environment

Importance of environment

Physical Environment

No matter what kind of environment you work in it will be important to find out as much about your clients as possible. Families should be regarded as an integral part of the team and a primary resource. We need to utilise the information they have and allow for the fact that family members will vary in the amount of contact and support they can give.

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 try and 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, for a time, 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 idea rather 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 back to their supervisor (coordinator) so that these matters can be discussed with the family. Often families have no idea how to gain access to these items.

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, communication in a verbal sense becomes more difficult. We have to make a greater effort to try to understand what the person with dementia is trying to tell us.

Often this is manifested by way of 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.

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 the occurrence. If we cannot get to the bottom of concerning behaviours then we need to implement a monitoring process.

**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 giant step of leaving home and going into a residential facility. This move generally occurs because the person is no longer capable of looking after themselves and either no family member is available or the job of caring has become too demanding for the family member.

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. New residents need to be welcomed and introduced to others in the care environment. They need to be addressed by their preferred name and have their fears and anxieties managed with empathy. Residents 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 the interests of the client and can be a good source of conversation.

Clients should feel safe and are able to express their feelings and opinions freely and family members and friends should be welcome at any time. It is also important that clients are encouraged to maintain any skills that they have, even if these only apply to self care. Some clients may have other skills such as playing the piano or using a computer and these skills should also be encouraged and maintained.

If we give care to people from other cultures do we make provision for this and research some of the things that may be important in that culture so that we do not offend? Are we aware of day to day customs that may be of considerable importance to a person from another culture? Can we access some music, DVDs and food that would be culturally appropriate?

Do we respect and nurture a person’s spirituality? 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.
Six

Identifying and addressing a person’s needs for a stable and familiar environment

1. When using a person centred approach what are the important things to assess in the client’s environment and when making changes that support the person?

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2. For what reasons would a client’s environment need to be modified to support their requirements.

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Recognising signs consistent with financial, physical or emotional abuse or neglect of the person and report to an appropriate person

Elder Abuse

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.*

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 then 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.

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 - 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 giving 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.

Possible 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

- 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
- Does not have money to pay bills
- Items are disappearing from home
- Money is not being spent to benefit the person with dementia
- Appears to be afraid of another person.

People working in the community who suspect abuse from a family member will need to be able to report this to their supervisor who will then investigate the matter. Visiting a family member who is suspected 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.

Very often, a visit from a supervisor to the family will 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
- Whistleblower 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.
Seven

Recognising signs consistent with financial, physical or emotional abuse or neglect of the person and report to an appropriate person

Read the following scenario and answer the questions.

Scenario
You work in a dementia specific unit in an aged care facility that has 20 beds. The unit has been short staffed due to winter illnesses with many staff having to take up the shortfall by working extra shifts. You have not had a day off for seven days. As you are working, you hear another care worker yelling at a dementia client then the sound of a punch and slap. You go to the area where the noise came from to find the staff member and resident, both distressed and crying. The client has a very obvious red mark on their cheek, and a bleeding lip.

1. What do you do? Consider all aspects, including duty of care and support services that may be available.

2. Identify the organisation’s policy approach in relation to risk of abuse, neglect or harm.
Element 2: Use appropriate communication strategies

Using verbal and non-verbal communication strategies to maximise engagement of the person with dementia

Communication

Communication is made up of three parts:

1. 55% body language.
2. 38% tone and pitch of voice.
3. 7% words we use.

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 problem 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 a change 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 really 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
- Unable to comprehend what is said
- May indulge in ‘confabulation’
- Unable to report abstract concepts such as ‘pain’
- Revert back to first language
Effective communication in the context of dementia

For a person with dementia, communication difficulties usually revolve around comprehension and expression. Equally, they may have impaired physical and/or neurological function, making it difficult for them to express themselves. There are however, a number of techniques and tools you can use to assist in communicating with a person with dementia.

Aiding comprehension

Verbal aids:

- Ensure eye contact (if culturally appropriate) and/or use face-to-face communication
- Use simple words and sentences
- Speak slowly and clearly
- Be calm; use a soothing tone of voice
- Raising your voice level slightly may assist
- Limit what you say to one question or statement at a time
- Don’t jump from topic to topic
- Ensure the person has their hearing aid fitted and/or their glasses on, if appropriate
- Make sure only one person speaks at a time
- If you need to repeat what you say, repeat it in the same way
- Don’t rush what you are saying. Try to give the person plenty of time – even when you are in a hurry
- Use people’s names repeatedly, rather than pronouns, to help the person follow what you are saying
- Use interpreters or family members if the person has a non-English speaking background
- Avoid using open-ended questions, eg: ‘What would you like to do?’ Provide specific choices instead, eg: ‘Would you like to watch television?’

Non-verbal aids:

- Use visual cues and prompts where appropriate (eg: if you are asking them if they want a drink, point to their cup, or demonstrate the action.
- If you are asking the person to do something, try to demonstrate what it is that you want
- Establish eye contact before you speak in order to gain the person’s attention
- Use body language that reflects empathy – sit close, maintain eye contact, touch the person (when this feels appropriate) and give them your full attention
- Gain their attention through touch, when appropriate (eg: a hand on their arm to draw their attention to you)
- Communication boards and picture cards may be used
- Use body language (ie: gestures, facial expression, actions).
Environmental aids:

- Minimise background noise and other distractions
- Try to limit what you need to communicate if the person is tired or upset
- Consider where the most appropriate place is to engage the person in this communication process

What not to do:

- Don’t argue with the person. It will only make the situation worse
- Don’t order the person around
- Don’t shout
- Don’t tell the person what they can and can’t do. Instead state what they can do
- Don’t be condescending. A condescending tone of voice may be picked up, even if the words are not understood
- Don’t ask a lot of direct questions that rely on a good memory
- Don’t talk about people in front of them as if they are not there.

(Adapted from Robinson, A, Spencer, B & Whites, L, 1991, Understanding difficult behaviours: some practical suggestions for coping with Alzheimer’s disease and related illnesses, Geriatric Centre of Michigan, Ypsilanti, Michigan.)

Aiding expression

It is also important to empower the person with dementia by encouraging them to express themselves. You can aid them in doing so by using the following guidelines.

Verbal aids:

- Give the person plenty of time to formulate a response. If they are trying to say something, refrain from immediately stepping in and saying it for them
- Ask questions to help direct them, but make sure they are questions that give options for response rather than open-ended questions (eg: ‘Are you wanting to tell me about your daughter?’ rather than ‘Who did you want to tell me about?’)
- Don’t discourage the person from talking even if they are not making sense, unless they are becoming agitated or distressed
- Encourage them to stay calm by being calm yourself, by offering reassurance, by continuing to listen and by summarising what you think they are saying
- Use empathy in all communication.
- Try to leave the communication on a positive note.

Non-verbal aids:

- If they cannot respond verbally, encourage them to make a gesture (eg: thumbs up or down)
- Offer them reassurance such as a nod or a pat on the arm and a smile or friendly gesture, even if you are not sure what they are trying to say
- Watch the non-verbal language, eg: facial expressions, posture and body language
- This may communicate more than the person is able to verbally. Pick up whatever cues you can and feed back the information that you gain.
Environmental aids:

- Choose optimal times to communicate. For example, don’t try to talk with the person if they are tired, upset, hungry or ill
- Take the time to show that you are paying the person attention, that you are listening
- Encourage familiar routines and encourage them to talk about what they are doing
- Try to include the person in the conversation whenever possible. Don’t talk over them or about them without attempting to involve them
- Give them your full attention
- Remove distractions.
Eight

Using verbal and non-verbal communication strategies to maximise engagement of the person with dementia

What strategies can you use to improve communication with a person with dementia?

Communication quiz

Which of these communications are effective when communicating with a person with dementia? Mark them with a tick (for effective) or a cross (not effective).

Can you think of better ways of communicating the information in the statements you have placed a cross against?

- Would you like toast and honey, crumpets or chocolate biscuits Marion?
- Norm, come to the dining room now for tea (miming holding a cup and drinking)
- After lunch and when you have had your rest, if you’re really good at getting your best clothes on, your son will visit you.
- Mario, “do you want to come for a walk in the garden? (holding out your hand and pointing to the garden door)
- Oh my God Grace, where’s your hat? Have you lost it again? You’ll get terrible sunburn and that is bad for you!
- I’m really busy now but I’ll talk to you at dinner time
- Daniel you are such a naughty boy cutting up that magazine!
- Just say that again Mrs Peters, I couldn’t quite hear you!
- What do you want to wear today, your blue cardigan or the tweed jacket?
Communicating clearly with people with dementia

Case study
Jill is helping Mrs. O'Reilly to get dressed. 'Now Mrs. O'Reilly, here's a sock. Put it on this foot (waits while she does this). Now put this sock on the other foot (waits while she does this). Can you get your foot into this shoe? (Waits while she does this). That's right.'

1. How many ‘pieces’ of information did Jill give O'Reilly, at a time?

2. How would you describe her directions?
Gaining cooperation and providing reassurance as appropriate by using Reality Orientation

It is easy for a person with dementia to become confused. Confusion can lead to distress. If someone is distressed, upset or worried, it might be harder for them to cooperate with you. They may behave in a way that makes it hard to communicate with them. They may behave in a way that is dangerous for themselves or others. Reality orientation is one way to help ease confusion and distress.

**Reality Orientation**

Reality orientation means constantly reminding the person about the ‘here and now’ of their life and making it real for them. It does not mean correcting them when they make a mistake. It just means giving them important information about what is going on, who is involved, and when things are happening.

**Some useful Reality Orientation strategies or tips include reminders about:**

- The time of day
- The day of the week
- Relationships
- Events.

**Reminders about the time of day:** This might be a simple comment like 'Good evening, Mr Smith' or 'It's night time. You've had your dinner. Let's get you ready for bed now.'

**Reminders about the day of the week:** For people with mild dementia still living at home, the use of a calendar or a 'day of the week' sign on a noticeboard can be helpful. So can comments such as 'It's Thursday today. I'm here to help you with your shopping.' For a person with moderate to severe dementia, it is more useful to talk about what is happening now. Information about what day it is will become too difficult to understand. Information about activities or events is more useful. For example, 'Your daughter, Jane, is here to see you. I will take you to her now.'

**Reminders about relationships:** People with dementia can forget the names and faces of important people. They may not remember who someone is. They may confuse names. You can help by giving a reminder about the name of a person who is important to the older person. Photos are a useful way of reminding a person about relationships with other people. A photo album with labelled photos can help visitors as well as the person with dementia. Do not give the person with dementia many names at once. Suggest that people visit one at a time. Offer comfort to family members if they are distressed when the person with dementia forgets who they are.
Reminders about events: You could use a visual or verbal reminder. If something is visual, you can see it. If something is verbal, it is spoken. For example, showing an older person a Christmas tree is a visual reminder of Christmas time. Visual reminders often involve real objects that are linked with an event. Saying to the person ‘It is Christmas Day today’ is a verbal reminder. Verbal reminders always use words to give meaning. Verbal and visual reminders can work well when given together.

You can also give reminders about special events such as birthdays or holidays. It may be a reminder about a religious, spiritual or cultural event. It can also include reminders about daily or weekly events. These might be meal times, medication times, or showering or dressing times.

Giving reassurance: When older people with dementia become confused, they may not understand what is happening around them. They may become distressed. It is part of your role to relieve distress when you can. You can do this in three main ways: words, touch and body language.

Words: Try using calm, soothing words. Talk in a calm, friendly voice. Make sure you sound confident and in control of your emotions. Do not allow yourself to become distressed also.

Touch: For many people, touch is calming. Touch is a great way of connecting people. It is an action that does not need words to give it meaning. For this reason, touch may be understood more easily than words. Think about how it feels when someone places a hand on your shoulder. For some people, this is very calming.

Remember touch is very individual. Some people like a gentle touch. Others may pull away from you if you try to touch them. You need to understand what works for different people. Make a note in the care notes about any obvious reactions you see. Check the care plan to see if there is any information about using touch with a person. Remember that people from some cultural backgrounds may not like to be touched. But never assume that this is the case. Always treat people as individuals rather than as just a member of a cultural group.

Body language: Body language is part of how people communicate. It is using your body to send a message. Body language includes actions like smiling, nodding your head, holding out your hand or looking surprised. Think about your own body language when you are talking to someone with dementia. They may not understand what you tell them. They may have trouble explaining their needs or feelings. But it is possible they will read your body language quite well. If you are cross or impatient, you are likely to use different body language. This will also happen if you are feeling rushed or stressed. You may try to use calm words but if your body language tells the person you are feeling impatient and would like to be somewhere else, they are likely to sense this. Remember that your feelings often show in your body language. Practise managing your feelings and thinking about your body language when you are communicating.

Reality Orientation as part of daily life

The care environment is just as important as the care provided. The environment should be as comfortable and familiar as possible. Many aged care homes are set up to look like a regular home. They are designed to help calm and reassure older people with dementia. The design includes things such as the choice of furniture, colour of the walls and even the way the room is set up. Whether you are supporting a person in their own home or in residential care, try to include the person with dementia in everyday activities.

This could include things like:

- Peeling the vegetables for dinner
- Going to the shop for milk
- Watering the garden
- Hanging out the washing
- Setting the table.
All these tasks are part of daily life for many people. Joining in these tasks can help people with dementia feel more settled and calm. They may not be able to explain why they feel better for doing the tasks, but often it will be obvious that they do.

It is often better to show how to do a task than to explain it. People with dementia are often better at watching and copying than they are at listening and understanding language. If the person is still living in the family home, you could suggest some of these ideas to family members. This could help calm the older person with dementia and may also help them keep their skills longer.
Nine

Gaining cooperation and provide reassurance as appropriate by using reality orientation

Read the following two examples of reality orientation approaches. Discuss in groups and record your thoughts in the space provided.

**Scenario 1: 24 hour reality orientation technique (reassuring approach)**

**Personal Care worker/AIN:** “Good morning Mrs. Evans. What a beautiful spring day at Hope aged care Home, look at all the flowers.”

**Personal Care worker/AIN:** “Oh look at the time, it’s 5.30 in the afternoon already…nearby time for dinner. I can smell dinner cooking!”

Care worker: “Time goes by so quickly, I don’t know where the year has gone, its November 2008 already!”

**Scenario 2: Example of confronting approach.**

Mrs. Evans, who is 90, is at the front door of Hope aged care Home. She is asking everyone who passes by, ‘Have you seen my mother? I can’t find my mother. She said she would pick me up from school and she hasn’t come for me.’ Mrs. Evans is upset and agitated.

**Jacqui,** a Personal care worker/AIN, walks up and holds Mrs. Evans’s hand and listens to her.

**Jacqui:** ‘*How old are you Mrs. Evans?’*

**Mrs. Evans:** ‘I forget.’

**Jacqui (PCA):** ‘You’re 90! You’re all grown up and don’t have to go to school anymore. You left school a long time ago. You live at Hope aged care Home now, and your mother is dead.’

Mrs. Evans is totally confused, still agitated and now very upset.

1. Which of the two reality orientation therapy approaches used with Mrs. Evans do you think is more effective?
2. Why do you think the scenario (2) approach is not recommended? Do you agree with his opinion?
Using a range of validation strategies to relieve distress and agitation in the person

Validation therapy views old age as a natural part of the life process. In validation therapy, dysfunction is viewed as a way of dealing with a situation. In the case of a person with dementia, for example, distress and agitation might be viewed as a way of dealing with impaired intellectual functioning: feelings take the place of thinking. Validation strategies can be used to express empathy and understanding to the person with dementia.

These strategies advocate trying to appreciate the reality that the person with dementia is experiencing, rather than always insisting that they understand the actual reality. It is a way of acknowledging what the person with dementia believes to be happening. For example, if the person with dementia talks about their husband (deceased) as being away at war, the validation approach would advocate empathising with this belief in the current situation, in order to maintain the person’s dignity rather than arguing with them about the actual reality, which may cause them even further distress.

Through validation, you can empathise with the person’s grief and loneliness and the fact that they are missing their husband at this time, rather than focusing attention on the accuracy of factual information. Obviously, there are situations in which it is necessary for the person with dementia to be made aware of actual reality. There are other instances, such as the above example, when it may be possible to alleviate further distress by listening to the feeling behind what they are saying, rather than focusing on correcting them.

Distress and agitation are common and natural reactions to the experiences of not understanding a situation, of not remembering where you are, or who you are, or who everybody else is, or what is supposed to be happening. Carers of people with dementia become very familiar with such reactions.

Validation strategies include the following:

**Acknowledgement:** Validation involves acknowledging the importance of the person’s feelings, and of the belief that they are displaying, however far from reality, as something that is important to that person. Validation means responding to the person with care, empathy and warmth, which in turn encourages the person with dementia to feel safe to interact and respond to the carer and to others.

**Allowing expressions of distress:** Validation involves giving the person with dementia the opportunity to express their feelings. This requires patience and time on the part of the carer, and provision of support in the form of listening and attention.

**Reassurance:** Reassurance can be given verbally, by using a soothing tone of voice and by expressing your understanding of what the person is experiencing. Physical reassurance can also be provided, such as taking the person’s hand, touching their arm to let them know you are still there, maintaining eye contact while they speak, and so on.
**Reminiscing:** Allowing and encouraging people with dementia to reminisce about their past is a very valuable tool. Very often people with dementia feel much 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 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 very 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, getting married and having a family and any other meaningful events that colour our lives. One gentleman told us that the highlight of his life as a photographer was being engaged to take photos 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.
Ten

Using a range of validation strategies to relieve distress and agitation in the person

Read the case study and write down your response to the following tasks.

Case study
Hilda is 86 and has moderate dementia. She often looks for her father. She wanders the aged care home where she lives. She looks in rooms and asks workers where he is. She becomes upset when she is looking for him. Sometimes she sings songs in German. In Hilda’s care plan, there is information about her childhood. The information has been given by Hilda’s son and daughter. It says Ingrid lived with her father in a village in Germany. Together they used to go fishing and hunting. They would walk in the forest and camp overnight under the stars. They would sit by a camp fire and sing until late at night.

1. Highlight the key pieces of information in the case study.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

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________________________________________________________________________

2. Discuss with a partner how you could use validation to help Hilda?

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3. Would you tell Ingrid that her father is no longer alive?
Element 3: Provide activities for maintenance of dignity, skills and health

Organising activities which aim to maintain independence, using familiar routines and existing skills

Activities

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.

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 Inc.
- **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.

When the information for the care plan is gathered we need to make sure, if possible, that we not only record basic details and medical information, but that we also record the preferences and routines of a person. That is, when do they have their daily wash/shower, what kind of food do they like and dislike, what makes them laugh, and what particular interests do they have. 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 do not have fine motor skills and this indicates that complex craft activities may not be suitable.
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 client’s the individualised care that is best for them.

**Maintaining interest and enjoyment**

Maintain past interests and activities, where appropriate. For example, if the person with dementia has always loved reading, it may be possible to interest them in talking books if they are no longer able to read for themselves. If they have had a lifelong passion for football, encourage them to continue watching their team on television, or arrange a regular outing to a game.

If activities are not familiar, make sure that they are easily grasped and within their capabilities. Choose short activities that are appropriate for reduced concentration span, and use activities that draw on automatic responses, such as word games. Also consider choosing leisure activities that involve a variety of senses: taste, hearing, smell, touch, sight.

Fun is important. People with dementia may not necessarily remember what they have done over a day, but they do retain the mood or state of mind in which they performed it. Having fun – laughing – can lift their spirits, a good enough reason in its own right, but also helpful for maintaining cooperation with other more arduous tasks.

Where possible, choose activities that suit the person’s state of being. If they appear to be ‘wound up’ or are becoming agitated, choose a quiet, relaxing activity such as hand massage, listening to quiet music with a cup of tea, or reading together. If they are in good spirits, or seem a bit ‘flat’, choose something more stimulating, such as a walk, a craft or cooking activity, or a group activity where appropriate.

Music can be an important tool for lifting the spirits. Choose music that you know will be familiar. People with dementia often retain the words of songs and this may help to put them in touch with good memories.

Go on outings, particularly to places the person has previously enjoyed. Go shopping, visit galleries and museums and go for drives, particularly to familiar places. Remember that the person with dementia may be easily confused and subject to fears, particularly in unfamiliar places. Make sure they are well prepared for outings, that they are supervised at all times, and that they are with people with whom they are familiar and comfortable.

**Maintaining social contact**

Group activities in a residential care centre or a day centre can provide much stimulation and enjoyment. They also provide the person with dementia an opportunity to make a choice about their involvement – it should be something that they feel free to participate in or not, as they choose.

Here are some points to consider in planning and carrying out group activities:

- Choose a quiet, warm space, free from distractions and background noise
- Make sure the group is not too large for you and other carers to support individual members.
- Make sure that participants know each other, or make familiarisation part of the group activity
- Prepare yourself ahead of time. Have all your materials ready and on hand. Be clear about the process and how you are going to demonstrate and explain each step
- Make sure the purpose of the group is clear to all participants
- Build in some flexibility to ensure that all group members are able to participate and achieve some level of success with the activity
- Remember that all group members have the right not to participate
- Make sure that you have enough helpers
- Choose activities that are culturally appropriate for the group. Contact cultural groups and associations if you are not sure how to gather information about relevant activities and ideas
• Be aware of the skill levels of group participants. Think ahead of time where possible, about what each participant is likely to be able to contribute

• Be aware of other impairments that may impact on group members' abilities to participate. For instance, be aware of group members who have visual or hearing impairments and how you might compensate for these in the group setting

• Make sure your instructions are clear and simple. Demonstrate where possible

• Work alongside group participants rather than leaning over them or standing out the front like a schoolteacher

• Make it fun! Enjoy yourself and encourage other group participants to enjoy themselves. Employ your sense of humour; don’t take the outcome too seriously; be prepared to laugh at yourself

• Be aware of what group participants are experiencing. If they are not joining in, try to work out why. Try to accommodate individual experiences

• Encourage conversation by encouraging participants to talk about what they are doing and to recall other events that it brings to mind

• Choose age appropriate activities that maintain the dignity of group participants.

**Reminiscing**

Family members can be invaluable in providing the background information necessary for reminiscence.

They can inform you as to aspects of the person’s history, such as:

• Chronological history
• Family history
• Stories about childhood
• School days
• Young adulthood
• Working life
• Information about where the person has lived
• What their interests and skills have been
• Their favourite music.

Family members can also provide photographs, which may be a valuable prompt for the person with dementia. They can bring in favourite objects such as ornaments, books, diaries, journals and so on, which might also help to prompt the person.

**Making a ‘This is your Life’ album**

A useful tool for reminiscence is a book comprising information, stories, letters, special greeting cards, newspaper clippings and photographs – anything that describes the person’s history. A large photo album is probably the most practical way of gathering this information. Photos should be labelled so that anybody going through the book with the person can prompt them.
Types of activities

Many activities that help maintain independence centre around daily living skills. These are the skills that help people stay in control of the most basic areas of their lives.

Here are suggested activities for nine of the most common areas.

1. Personal safety

   Where possible people with dementia should be involved in making choices about how to stay safe in the home, in the community or in an aged care home. Activities might include:
   - Understanding how to recognise dangers
   - Learning what to do if danger is present
   - Learning cooking safety
   - Learning fire safety
   - Understanding household security
   - Reading evacuation plans
   - Practising safe travel on public transport
   - Understanding what to do if lost.

2. Communication

   People with dementia should be encouraged to communicate for themselves using spoken words, writing and body language. Activities might include:
   - Learning to make reminder notes about important activities or dates
   - Reading name tags of workers
   - Using photos to help with choices about daily activities
   - Listening to taped stories or music
   - Singing familiar songs
   - Going to activities run in their first language, if they have learnt English later in life.

   If the person with dementia uses body language or signs to communicate, support workers should write notes about the possible meanings in the person’s care notes.

3. Eating and drinking

   People with dementia should be able to make choices about the food and drink they would like to have. Their likes and dislikes should be respected. Activities might include:
   - Offering a limited number of choices based on your knowledge of their likes and dislikes
   - Encouraging them to make choices
   - Preparing special meals for special occasions
   - Planning family focused meal times or morning teas
   - Using familiar settings for food and drink, such as the same cup and plate offered in the same place
   - Involving them in setting the table, getting plates and cups ready, pouring drinks, making conversation at the table and clearing up after a meal.
4. **Moving and transferring (from place to place, or changing position)**

When you are moving a person from one place to another, such as bed to shower chair, wheelchair to regular chair, toilet seat to wheelchair, wheelchair to bus seat, they should be involved in the move.

**Activities might include:**

- Using verbal and physical prompts to encourage the person to help with a transfer or movement
- Explaining why the person is being moved before the transfer or movement starts
- Explaining what is happening using simple words and phrases
- Encouraging physical strength and balance skills through exercise or physiotherapy programs
- Using photos to prompt understanding of where the person is moving to
- Planning for a gradual loss of physical skills over time.

5. **Personal hygiene**

The person with dementia should be encouraged to maintain personal hygiene tasks such as bathing, toileting, brushing teeth or caring for personal linen.

**Activities might include:**

- Completing a task together with the person
- Using visual prompts, such as a toothbrush, to remind a person about the task
- Doing the first part of the task for the person and then encouraging them to take over
- Providing only the support that is needed
- Planning for a gradual loss of skills.

6. **Dressing and undressing**

You can help a person with dementia make choices about the right clothing for the day according to weather, occasion, personal likes and dislikes and cultural background.

**Activities might include:**

- Reminding the person about special occasions such as visitors, birthdays or outings
- Doing the first part of the task for the person and encouraging them to do the rest
- Giving a choice of two items of clothing
- Giving information about the weather through conversation, such as 'It’s a hot day today – we need summer clothes'.

7. **Spiritual needs**

The person with dementia can be encouraged to stay involved in religious or spiritual activities based on their individual likes and dislikes and background.

**Activities might include:**

- Taking the person to a religious festival or regular religious event
- Reminding the person about religious activities that occur on particular days of the week; for example, church on Sunday
- Being aware of the spiritual needs of people – you can find this information in care plans
- Having religious visitors or volunteers attend an aged care setting
- Providing a chapel or place of worship within an aged care setting.
8. Grooming

You can help the person with dementia make independent choices about hair care, shaving, make-up and nail care.

**Activities might include:**

- Starting a task yourself, but encouraging the person to finish it
- Organising a hairdresser to visit an aged care setting
- Offering to paint nails or having a podiatrist visit Planning a make-up day
- Making sure people with dementia are always well groomed according to personal likes and dislikes.

9. Expressing sexuality

Being able to express sexual needs and feelings in a socially acceptable way is an important part of being an independent adult.

**Options might include:**

- Providing private places for couples
- Including photos of a person’s partner, whether living or dead, in an album or book
- Respecting privacy when needed.

Maintaining predictable daily routines

Predictable daily routines are important for minimising confusion and providing a sense of certainty, for the person with dementia. Daily routines may be recorded in the care plan. Records should be as specific as possible to minimise the confusion which might be caused by change of staff. As much as possible, tasks should be performed in the same way each time.

The person with dementia should be considered in planning daily routines. How do they like to do things? What routines have been important to them in the past? For instance, if they have always risen early and listened to a specific radio program with their morning coffee, it would be beneficial to maintain this routine. None of us likes to have our habitual routines interrupted, however insignificant they may seem.

The person’s habitual ways of showering, dressing, eating and so on should also be taken into account. We all have idiosyncratic ways of performing habitual tasks and would find it difficult to think about doing them differently. (Think how you would feel if you were forced to hold your fork differently, or to tie your shoe laces in a different way.) Habitual routines should be given precedence over the perceived ‘correct’ way of performing these tasks to minimise confusion and disruption for the person with dementia.

**Guidelines for maintaining independence**

Encourage the person with dementia to perform as much of a task as they can independently, to support them to maintain their confidence and motivation. Focus on strengths, on what the person can do rather than what they are not doing correctly. For instance, you might focus on the fact that they can set the table, and encourage them to do so even if they don’t put all the forks in the right place.

- Praise and encouragement should be offered for successful completion of tasks, but not in a manner that could be perceived as patronising or condescending.
- Break tasks into small achievable steps whenever possible.
- It may be helpful to rehearse the steps involved in a task.
- Frequent practice of skills may prolong their maintenance. Verbalise the steps as they are performed.
Eleven

**Organising activities which aim to maintain independence, using familiar routines and existing skills**

This can be completed as a group activity, or completed individually. THINK specifically about a person with dementia that you have been caring for, so you can begin to build up a file of activities that are purposeful and enjoyable.

**Some examples include:** ADLs such as: getting dressed, singing, dancing, art, painting, craft activities, cards, walking, cooking, quizzes, crossword puzzles, photo albums, favourite videos, bus trips, creating sensory environments.

<table>
<thead>
<tr>
<th>FEATURES OF SUCCESSFUL ACTIVITIES</th>
<th>EXAMPLES OF ACTIVITIES</th>
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<tbody>
<tr>
<td>Have a purpose but also give the person pleasure in doing.</td>
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<tr>
<td>Fulfil a need for self expression.</td>
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<tr>
<td>Take into account lifestyle and old routines, activities and interests, boosting self esteem, confidence and safety.</td>
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<tr>
<td>Allow opportunities for repetition, which often helps people with dementia, feel comfortable.</td>
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<tr>
<td>Tap into some of the five senses.</td>
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<tr>
<td>Take advantage of old skills and thereby comfort the person with dementia by helping to reinforce their identity.</td>
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<tr>
<td>Include some physical activity where appropriate, so mobility can be improved. This may also improve sleep patterns.</td>
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Organising activities that are appropriate to the individual, reflecting their cultural likes and dislikes, in order to bring back pleasurable memories

Identifying individual needs

When you are working with people with dementia, you need to think about their individual needs. Although some activities may be offered as part of a group, it is still important that the activities have been planned to meet the needs of individuals. There will be information in care plans that explains what the goals, needs and interests are of each person. Some of this information may also be included in other documents, such as a social profile, which list the dislikes, likes, work and social history of the person.

Often, much of the information you will have about a person with dementia will have been put together with the help of family members. Families can help with information about the past. They can explain who was important in the person’s life. They can fill in details about places they have lived and things they have done.

Cultural background

You will need to think about the background of each person you support. They may have been born in another country. Understanding cultural background will help you plan for activities. You cannot assume that all people from the one culture will like and dislike the same things. But there may be things you should know about their background that will tell you what activities might suit them. Taking part in cultural activities they enjoy can bring back many pleasurable memories for the person.

Language: Some of the people with dementia that you support may have spoken another language before they learnt English. This is important to know because as people lose their language skills, they may be able to express their needs better in their first language.

Language skills tend to be lost backwards, with the most recently learnt skills lost before earlier skills. If you hear a person with dementia talking in another language, this may be the reason. It may be important to plan for this need in people who have learnt English as a second language. An interpreter may be needed (someone who can translate from one language to another). You may need to learn a few words of another language so you can communicate with the person.

Cultural likes and dislikes: Many of the likes and dislikes of the people you support will be recorded in the care plan. Take the time to read the care plan. Make sure you understand the likes and dislikes of the person. Plan activities to cater for the things they enjoy and try to avoid activities that you know they do not like. For example, people from some cultures enjoy large gatherings while others prefer small groups or activities they can participate in on their own. As people age, they may enjoy being with people who share their culture.

Notice what happens each time you do something with a person with dementia. Learn about what they seem to enjoy. Notice the things that are not enjoyed. Make notes in the care notes about any important reactions to activities. For example, if you find an activity that works very well for the person, you might write this in the care notes. That way, other workers can use the information to plan similar activities.
**Steps to Providing Culturally Sensitive Dementia Care**

- Consider each person as an individual, as well as a product of their country, religion, ethnic background, language, and family system

- Understand the linguistic, economic and social barriers that individuals from different cultures face, preventing access to healthcare and social services. Try to provide services in a family’s native language

- Understand that families from different cultures consider and use alternatives to Western healthcare philosophy and practice

- Do not place everyone in a particular ethnic group into the same category, assuming that there is one approach for every person in the group

- Respect cultural differences regarding physical distance and contact, appropriate eye contact, and rate and volume of voice

- Cultivate relationships with families over time, not expecting immediate trust in and understanding of the Alzheimer’s Association

- Consider the family’s background and experience in determining what services are appropriate

- Consider the culture’s typical perception of aging, caring for elderly family members and memory impairment

- Regard the faith community for various cultures as a critical support system.
Ensuring the safety and comfort of the person balanced with autonomy and risk taking

Maintaining safety

People with dementia are less able to take responsibility for their own safety. Everyday activities can be hazardous because of their forgetfulness and lack of sound judgment. The person may forget that they are no longer able to perform certain tasks (eg: chopping vegetables), which may lead to accidents. As the disease progresses, more supervision is required to ensure the person’s safety when performing everyday tasks. Safety issues can also present if the person with dementia is inclined to wandering and then forgetting where they are.

Look for safety hazards in every environment you go with the person:

- Remove loose rugs and mats that might be easy to trip on
- Observe the environment from the point of view of safety – are there any likely hazards? In a hospital or residential care setting, safety hazards are regularly assessed by safety experts. If the person is in the home environment, it is also sound practice to regularly review the environment for possible hazards
- Whatever the situation, make sure that the environment is free of clutter
- Make sure furniture is stable
- Ensure lighting is adequate
- Make sure there are no hazardous or poisonous materials in reaching distance
- Make sure that medications are kept out of reach
- Make sure that hot drinks are not left and forgotten
- Minimise the likelihood of confusion and distress, and minimise the amount of stimuli – accidents are much more likely to occur under these circumstances
- Have an emergency plan in place. What will you do if an accident does occur?
- What will you do if the person becomes distressed and resists your efforts to help them?
- If outside, check for uneven pavement, wet or slippery surfaces, etc; ensure safe and secure area to wander.
- Cooking – what are the possible hazards if this is a chosen activity?
- Appliances may need to be used in some instances to assist the person with dementia to continue to perform certain tasks safely, but with a degree of independence. Examples include:
  - Building prostheses (such as rails) to aid the person standing, sitting and climbing stairs
  - Bright lighting to ensure that the person can see clearly
  - Heating that turns itself on and off automatically.

You may not need to assess what is required, but you will be in a position to observe whether the person’s environment is suitable, or whether it poses undue risks to their safety.
Other safety concerns include:

- Inability to find their own way
- Inability to negotiate traffic
- Wandering or other behaviours relating to agitation
- Behaviours relating to psychotic experiences or mood disorders
- Inability to safely prepare, cook and store food and drink
- Inability to control temperature of water
- Inability to use home appliances
- Inability to maintain personal and home security
- Inability to manage own finances
- Inability to recognise dangers in their environment
- Inability to recognise the safety needs of others.

Autonomy and risk assessment

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.

For example: it may seem safer not to allow a person with early stage dementia to go walking, however, with the security of the “Safe2Walk” device the risk can be minimised. If they gain pleasure from walking, and at the same time physical and social benefits are achieved, these may outweigh the risks. Risk assessment often focuses only on the possible risks, without considering what opportunities and benefits are being lost as a result. The consideration is to take into account the wellbeing and autonomy of the person with dementia, as well as their need for protection from physical harm.

To achieve a balance between ensuring safety and comfort, and maintaining autonomy, you might wish to consider the following:

- Be aware of the person’s skills and strengths. What can you do to promote autonomy and risk taking through these?
- Be aware of the severity of the dementia. To what extent is memory impaired? To what extent is ability to see consequences and make judgments impaired? How does this impact on planning suitable activities?
- Plan thoroughly. Think through what is involved in the activity. Assess the possible risks against the person’s strengths and weaknesses. How can you provide optimum enjoyment and independence while considering risks and ways of avoiding them?
Your duty of care

The relationship between you and the person with dementia is that you are a worker and the person is your client. This means you are responsible for what happens to a person while they are in your care.

You are not responsible for:

- People who are not in your care
- People who have been in your care but have become the responsibility of someone else
- People with whom you do not have a working relationship as worker and client
- Situations that are not in your control or in your job role description.

Your duty of care to your clients means you must think about how to keep them safe.

Two things that affect safety are the:

- Person with dementia
- Environment or situation.

As a dementia support worker, you need to think about both the person and the environment. For example, if they can’t see well, or if they are in the later stages of dementia, it might be safe for them to walk around their own room but unsafe for them to cross a road without help.

Negligence

- If you do not pay attention to duty of care, you may be negligent. Negligent means you have not provided duty of care to a person, and as a result they have been hurt in some way.
- If someone wants to prove you have been negligent, they would usually need to prove that:
  - You owed a duty of care to the person at the time
  - You breached (stopped or broke) your duty of care
  - The injury or accident was a direct result of you not providing a duty of care.
Twelve

Ensuring the safety and comfort of the person balanced with autonomy and risk taking

Safety and comfort

Balancing safety and independence is about minimising the risk and coming up with clever solutions. Read the case study and come up with the solutions.

Scenario

Bryce had been a carpenter in his younger years. He still loves woodwork activities, but power tools and sharp implements have become a safety risk, to him, as he finds it difficult to remember any instructions given to him. Bryce has been given an opportunity to make wooden toys for a local children’s charity, and asks you if this is possible, considering his dementia.

1. How could you ensure Bryce can continue making the wooden toys for the local charity and still ensure his safety?
Accessing information about the person’s reminiscences and routines with family and carers

Reminiscing

Families and friends are an invaluable source of information about the resident’s life and routines. The information they can provide is really important in helping staff develop appropriate activities for the person who has dementia. Remember every family is different. Some families may not know much about the relative or friend as others.

Relatives can provide the personal carer and other members of the care team, with information regarding the client/resident’s life experience, family background (family of origin), likes and dislikes, previous routines etc. This information will be invaluable for reminiscence with the client and will also be of great benefit when determining the most appropriate activities. Family members can be invaluable in providing the background information necessary for reminiscence.

They can inform you as to aspects of the person’s history, such as:

- Chronological history
- Family history
- Stories about childhood
- School days
- Young adulthood
- Working life
- Information about where the person has lived
- What their interests and skills have been
- Their favourite music.

Family members can also provide photographs, which may be a valuable prompt for the person with dementia. They can bring in favourite objects such as ornaments, books, diaries, journals and so on, which might also help to prompt the person. Reminiscence can involve much more than conversation. Reminiscence can be undertaken as a group activity, or it can be a valuable tool for working with individuals.

A range of activities can be based on reminiscence, including opportunities to listen to (and dance to) music of a particular era, watch films from a particular era, even dramatise well-known and important events.

You may find that some of the materials you use, prompt less than happy memories and are disturbing for the person with dementia. If this is the case, you may need to distract the person with other materials and activities. Try to find out from family members what might have distressed them and whether there could be other triggers for this response. If reminiscence continues to be disturbing, the person may benefit from referral to someone more capable of addressing the underlying issues, such as a counsellor, diversional therapist or social worker. As a ground rule, if it distresses the person, discontinue the activity, however positive you might have thought it could be.

It is also important to keep family members informed about how activities have gone (whether they were successful, or what went wrong) and to get their input into what you might do to ensure optimum enjoyment of activities by the person with dementia.
Thirteen

Accessing information about the person’s reminiscences and routines with family and carers

1. How might you work with a client on reminiscences and connecting with them?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

2. How can you use families as a resource to assist in caring?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Providing support and guidance to family, carers and/or significant others where appropriate

The impact of dementia on family, carers and significant others

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 attack the brain do shorten life span, a person is 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 in fact 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 sympathetic towards the person supporting a person with dementia.

In the initial stages of the disease a person is likely to be able to care for themselves in the normal way but will generally be developing memory problems, appearing to change personality, or becoming illogical, depending on what type of dementia they may have. As time goes on a person with dementia will need increasing amounts of support and will eventually not be able to even 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 job – support person giving up job 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.

Accordingly, the person with dementia may need considerable emotional and social support from carers, family and friends. It is important to be sensitive to the emotional needs of the person, and to provide emotional support where appropriate, or arrange for this from others.

Encouraging the person to maintain involvement in social activities will add to the person’s wellbeing and sense of self-worth. Be aware of the person’s family situation. A person living alone will need different support to that of someone living with their family. In either case, the involvement of family members where possible can be beneficial, particularly in the early stages of the condition and at review points. A decline in a client’s emotional health can have a negative impact on other areas of their wellbeing.

**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, that the person really cannot remember how to do a task even though you may have just taken them through it. They are 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 for most be most helpful, and will assist them in understanding the mysteries of dementia and how it affects functioning.

If we are providing services in the home then 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. Having this helps us be aware of what may well 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 cope with any changed behaviours.
Moving into Permanent Care

When a person is placed in permanent care this is an extremely distressing time for family members. Often the primary carer is feeling very guilty and asking themselves if perhaps they could have coped for longer, or they could or should have done a better job whilst caring. Family members need due acknowledgement that the job they were doing was very challenging and becomes a twenty-four hour a day job which then makes it an impossibility for one person to undertake for long. It must also be acknowledged that all families are different and whatever kind of care was given, the situation would have proved challenging.

Many carers will 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 and Ledesert (1992) Woods and 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 need to be involved in the making of 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 dependent 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 barriers may be that the visitor is 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 to 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 in regard to 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 dementia journey it is imperative that family members are 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 will 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.

Using respite care

Respite care is an opportunity for families and carers to have a break from the responsibilities and demands of looking after someone with dementia. It also gives people with dementia the opportunity to socialise. It is not uncommon for problems to arise when using respite care, particularly for the first time. Families may find the person with dementia doesn’t want to leave home, or they may be worried about the effects of respite care. There are many ways these problems can be managed so that people can make the most of respite care.

It may be necessary to start with short breaks and build up to longer ones, and to provide reassurance to both the person and their family. It is important that communication is clear between the family and the respite provider. The needs and background of the person with dementia should be clearly explained so that they can be best taken care of, and families should understand exactly what will be provided and what will happen.

Family members may feel a sense of guilt if they cannot look after their loved one, or need a break, and may become protective and demanding. It is important to be sensitive and understanding of these responses. Families are encouraged to think of respite as a partnership between themselves and the respite provider, working together to make the most of respite. Discussion should be had regarding the type of respite that is available and what will work best for the person with dementia and others surrounding them.
Support services available to people with dementia and their carers

Aged Care Assessment Team (ACAT) – ACAT teams provide assessments to help a person obtain a range of Commonwealth 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 doctor refers the person to the ACAT team and the doctor 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 Home and Community Care (HACC) programme 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
- Community Aged Care Package (CACP) - Cover a range of services
- Extended Aged Care in the Home (E.A.C.H) - Designed for higher care service
- Extended Aged Care in the Home-Dementia (E.A.C.H-D) - Designed for higher care service for people with dementia

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, such as nursing homes or hostels. A nursing home provides ongoing nursing care. In a hostel a person can 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).
Fourteen

Providing support and guidance to family, carers and/or significant others where appropriate

What information would you provide for families and carers to:

a. Assist their understanding of dementia
b. Help them understand the impact of the disease on the client/family
c. Suitable approaches to providing care
d. Support services available.

Provide examples, eg: in a booklet format, or power point presentation.
Element 4: Implement strategies which minimise the impact of behaviours of concern

Identifying behaviours of concern and potential triggers

Identifying behaviours of concern
Behaviours of concern as it is also known as is, a catch-all term that, in the context of dementia.

It includes one or combinations of:
- Shouting
- Wandering
- Biting
- Throwing objects
- Repetitive talking
- Destroying personal possessions and other objects
- Agitation and general anger
- Physical attacks on others
- And waking others at night.

In short, this term describes any behaviour by people with dementia that is deemed to be dangerous to themselves, their fellow residents, and staff, or is considered antisocial within environments where those people have to coexist with others on a long term basis. It is important to identify any changes in a person’s behaviour. You can then monitor and respond to the situation before it gets out of control.

For example:
- The client is threatening, invading the space of others
- The client is displaying distressed, agitated behaviour
- The client and others are in obvious danger or already hurt
- The client is avoided by others
- Objects in the environment have been, or are in danger of being, damaged
- A client is masturbating in front of other residents
- A client with dementia is screaming and shouting.

Behaviours of concern may lead to difficult, even risky situations for the aged client and others in their environment. In Dementia, aggressive and other difficult behaviours are frequently triggered by feelings of fear, anxiety and misinterpretation of the environment.
Reasons behind the behaviour: There are many reasons why a person’s behaviour may change. Dementia is a result of changes that have taken place in the brain. It affects the person’s memory, mood and behaviour. Dementia can cause people to act in different ways that don’t necessarily fit into ‘normal behaviour’ patterns.

This sort of behaviour can be a challenge to the person with dementia and the carer themselves. However it is important to remember that people with dementia do not behave badly on purpose. You need to constantly see the person behind the behaviour. Imagine yourself in their shoes. Avoid arguments and accept whatever compromise will work. It is helpful to understand why the person may be reacting or behaving in a certain way. If you can discover the cause that influences the behaviour then you can try and prevent or respond to the situation in the future.

Types of behaviours of concern/challenging behaviour: The following section describes some of the commonly used terms to describe behaviors of concern/challenging behaviours and the possible reasons for these behaviours. Some of these terms have negative connotations and can be discriminatory and judgmental. There is the potential to label people.

Taking people’s possessions and hiding them: A person who is going through the dementing process often has the sense that things are being taken away from them. In response they may take, hide or hoard things as a way of ‘keeping things safe’. This problem becomes worse when people forget where they have ‘hidden’ their things. It is usually an expression that they feel unsafe and insecure.

Verbal outbursts/verbal disruption: A person who has lost the skill to communicate clearly may have verbal outbursts as a means of expression, protest, attention or self-stimulation. Verbal disruption is where a person makes sounds or noises that continually invade other people’s environments. Verbal disruption can be in the form of a person’s persistent interruption of another person’s conversation. It can be a person continually crying out, moaning or making high pitched screams. The person suffering a dementia type problem may also have other contributing factors that create vocal disruption and verbal abuse.

These include:
- Pain - the person may not be able to verbalise that they’re feeling pain, or cold or heat
- Over-tiredness from poor sleeping patterns
- Depression - the person may be depressed and grieving but unable to say what they want to say
- Sensory deprivation
- Frustration at inability to perform activities of daily living
- Undiagnosed infections or illnesses.

Abusive Language: People with dementia often lose their inhibitions or learned social graces. People who have never used obscene language may start to use obscene language. It is usually an expression of anger, fear or frustration. Verbal abuse is using language and/or sound to threaten or intimidate another person. It can be an angry, spontaneous outburst that occurs rarely or it can be in the form of continuous abuse and threats. The words used during verbal abuse may have sexual overtones, and be offensive to you. You should remain objective when receiving this abusive language.

Agitated and repetitive acts: Sometimes a person with dementia seems to be ‘stuck’ in the same activity or task. The message in their brain gets stuck like a needle on a record and they can’t move on.

Shadowing: There may be times when a person with dementia follows their carer around like a shadow. This is usually because they are insecure and need reassurance.

Sexual Behaviour: People with dementia still have sexual needs and desires. Loss of inhibitions may mean they make advances to others, or fondle themselves in public.
**Catastrophic Reactions:** This describes an overreaction to a situation by the person with dementia. They may be unreasonable, very agitated or stubborn. They may also scream, shout, cry, or laugh uncontrollably and inappropriately. It is usually caused by stress or frustration.

**Suspicion and accusations:** People who are confused, deluded or hallucinating can make wild accusations. They are probably feeling very insecure.

**Wandering:** A person may feel uncertain and disorientated in a new environment, such as a new house or residential facility. Wandering may be also due to a loss in short-term memory. A person with dementia may also wander just to use up excess energy, indicating they need more regular exercise. They may also be bored, agitated or even in pain.

**Evening agitation or ‘Sundowning’ Syndrome:** People with Dementia often become confused or agitated in the early evening. It can be worse after a move or change in the person’s routine. They may become more demanding, restless, upset, suspicious, or disorientated. Their attention span becomes even more limited. No-one is sure what causes ‘Sundowning syndrome’; however it is thought to result from brain disease. Look for causes in the person- e.g. - tiredness, onset of darkness, visit from relative or friend, pain or hunger. Many carers say that the person becomes more anxious late in the day and wants to pack their things and go home.

*‘Sundowning syndrome’ may elicit the following responses in those suffering it:*

- Motor activity such as wandering and rocking.
- Tapping feet and scratching
- Security seeking behaviour such as hoarding and kicking
- Escape behaviour - moving restraints, dressing and undressing inappropriately
- Sense of urgency
- Mumbling and moaning.

**Incontinence in dementia**

People with dementia often lose the control of their bladder or bowel. This may be because they have forgotten where the toilet is, they couldn’t undo their clothing in time, or they have forgotten how to go to the toilet. Sometimes a person may deliberately smear their faeces over the floor or furniture. It is thought this may be a desperate bid for attention by someone who has lost hope in life.

**The changes in a person’s brain with dementia interfere in their ability to:**

- Recognise the need to go to the toilet
- To be able to hold on until it is appropriate to do so
- Find the toilet
- Use the toilet properly
- Identify and deal with treatable causes such as urinary tract infections etc.

**Incontinence may also be caused by:**

- Infection
- Constipation
- Medication
- Hormonal changes
- Prostate enlargement.
Potential triggers for behaviours of concern

A trigger is something that influences or starts the behaviour. It could be anything. Some triggers may be obvious and the solution is therefore simple. Other triggers may be a combination of things and the solution is complicated. You will need your problem-solving skills to discover a possible solution. Almost anything can trigger or influence behaviour.

Factors that influence the behaviour of residents/clients may include:

- Adverse reactions to their medications
- They may have a urinary tract infection
- Cognitive problems e.g. dementia
- They may be afraid, stressed or suffering from anxiety
- In unfamiliar surroundings
- Physical condition
- Their emotional state
- Depression
- Quality of lifestyle
- Relations between other residents/clients and others
- Feedback and interaction.

Communication:

- Is the patient/client able to make and communicate their choices?

Environment:

- Are there constant changes in noise levels, temperature, staff, and procedures/equipment?

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.
Identifying behaviours of concern and potential triggers

Read the following case study and write your response to the questions below

Case study
Gerard’s only hobby was gardening and his son and daughter encourages him to potter around, digging up the soil in the veggie patch and pulling up weeds. He has to be shown which are the weeds and will repeatedly ask if he is doing the right thing. Gerard’s wife recently started to take him to the local day care centre so she can have some respite time.

On this day he was given some cane to weave baskets. He refuses and becomes abusive and trying to leave the centre. The activity worker tries to pacify him by holding onto his arm and saying that he has to stay and do the activity. Gerard becomes upset and continues to walk down the corridor muttering: “I can’t find it” and he wets his trousers.

1. What behaviours did you identify in the case study that is classed as behaviours of concern? List these in the space provided.

________________________________________

________________________________________

________________________________________

________________________________________

2. Give an example of when a person with dementia has become hostile and angry in your workplace and explain what contributed or triggered their behaviour?

________________________________________

________________________________________

________________________________________

________________________________________

________________________________________

________________________________________
3. What do you believe were Gerard’s behaviours of concern in this case study?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

4. How could the activity worker have handled Gerard’s behaviour in a more constructive way?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Assessing behaviour

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.
## People with dementia and behaviours of concern – assessment form

**Patient’s name:** ___________________________  **Date of birth:** ___________________________

### Presenting behaviour and characteristics
(include duration, frequency, antecedents, consequences)

__________________________  ____________________________

__________________________  ____________________________

__________________________  ____________________________

### Physical/psychological health status

<table>
<thead>
<tr>
<th>Exclusion of delirium</th>
<th>Considered</th>
<th>Systems review</th>
<th>Reviewed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infections</td>
<td></td>
<td>Eyes (spectacles, reduced acuity)</td>
<td></td>
</tr>
<tr>
<td>Respiratory</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urinary</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neurological</td>
<td></td>
<td>Ears (hearing aid, wax, audiology)</td>
<td></td>
</tr>
<tr>
<td>Metabolic disorders</td>
<td></td>
<td>Nutrition (vitamin deficiency, dentity, oral hygiene, swallowing, appetite, hydration, diet, aspiration)</td>
<td></td>
</tr>
<tr>
<td>Electrolyte disturbance</td>
<td></td>
<td>Continence (bladder distension, faecal impaction)</td>
<td></td>
</tr>
<tr>
<td>Mental failure</td>
<td></td>
<td>Mobility</td>
<td></td>
</tr>
<tr>
<td>Vascular disease</td>
<td></td>
<td>Level of functioning</td>
<td></td>
</tr>
<tr>
<td>Hypertensive encephalopathy</td>
<td></td>
<td>Pain</td>
<td></td>
</tr>
<tr>
<td>Shock</td>
<td></td>
<td>Sleep patterns</td>
<td></td>
</tr>
</tbody>
</table>

**Medication review**
(drug interactions, compliance, usage or non prescription medication medicines)

__________________________  ____________________________

__________________________  ____________________________

__________________________  ____________________________

### Mental state

**Appearance (stance, facial expression, dishevelled)**

__________________________

**Behaviour (general behaviour apart from local problem eg early morning awakening)**

__________________________

**Form of speech (thoughts slowed)**

__________________________

**Content of speech (hallucinations sad and hopeless thoughts)**

__________________________

**Mood (anxious, agitated, depressed, unresponsive)**

__________________________

**Diurnal variation in mood**

__________________________

**Awareness**

__________________________

### Pre dementia personality, hobbies, occupation, education

__________________________  ____________________________

__________________________  ____________________________

__________________________  ____________________________

### Social assessment
(support network, physical supports, financial support, lifestyle/cultural issues, social activities)

__________________________  ____________________________

__________________________  ____________________________

__________________________  ____________________________

### Carer assessment
(dementia knowledge, coping skills, stress levels, physical, social supports; including Alzheimer’s Association)

__________________________  ____________________________

__________________________  ____________________________

__________________________  ____________________________

### Physical environment

**Safety considerations (restraints, wandering, smoking, night, time lighting)**

__________________________

**Environmental stimulation (level of interest orienting cues mouse level individual alternation)**

__________________________

**Reviewed**  **Comment**
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.

**ABC Approach**

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

The next step will be to come up with strategies that may lessen 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.
Contributing to team discussions on support planning and review

Reviewing behaviour management strategies

All care plans must be reviewed often. A care plan review involves consultation with the person with dementia (when they are able to contribute), family members, carers and significant others, health professionals and workers involved in providing support to the person. The frequency of a review depends on the support service and the needs of the person with dementia. If the needs of the person change suddenly, their care plan must be reviewed. If their needs remain the same over several months, the plan may only be reviewed a few times a year. Part of any review process will be to look at what has been done. This includes strategies to manage challenging behaviour.

A good review will look at:

- What the behaviour/s is/are
- How the behaviour/s affects the person and others
- What strategies have been tried and for how long
- What happened with each strategy
- Whether a behaviour increased, decreased or stayed the same
- Whether there were any special triggers for the behaviour
- The least restrictive strategy for dealing with a behaviour
- Which strategies should be continued and which should be changed.

This review might happen as part of a team meeting. You might get together with your supervisor to talk about strategies. You might meet with family members or advocates for the person with dementia. You might talk to the person themselves as part of the review process. Even if the person with dementia is not able to join in a review process, you should think about their needs. Consider how they would feel. Think about what they would say if they could express their feelings.
Sixteen

Contributing to team discussions on support planning and review

Explain why Care plans and behaviour management strategies should be regularly reviewed to check on their effectiveness and improve or change the strategies to meet needs.
Taking action to minimise the likelihood of and reduce the impact of behaviours on the person and others

The possible impact of challenging behaviours

The ultimate consideration in dealing with challenging behaviours is the safety of the person with dementia, and of others. Whether the person lives at home or in a residential setting, the environment must be adjusted to provide safety, while promoting optimal independence and stimulation. Not handling challenging behaviours can result in increased distress of the person and of others, as well as threatening the safety and wellbeing of those concerned. You need to be aware of strategies for dealing with the various challenging behaviours that you might encounter when working with people with dementia.

Options for working with challenging behaviour should be discussed with all who are involved with the ongoing care of the person. Options should be analysed in view of collective knowledge about the person's probable response to determine the degree of likely effectiveness. Family members and other long-term carers should be able to provide valuable insight into likely triggers and the strategies that have worked previously to deal with challenging behaviours.

Strategies

Modifying the environment

Environmental factors can significantly impact on the behaviour of the person with dementia. A well-designed physical environment can serve to enhance independence and the person’s sense of control and self-sufficiency.

Some factors to consider with respect to the physical environment include the following:

- Ensure that there are cues in the environment that provide the person with dementia with information about their whereabouts, or give directions to other frequently used locations.
- The environment should provide adequate options for maintaining privacy, but also for facilitating social contact.
- Ensure that the person with dementia is given a sense of autonomy and control in arranging their personal environment (eg: where their personal things are placed).
- The environment should be viewed and designed with reference to accident prevention.
- The environment should facilitate maximum independence in carrying out daily activities.

Responding to physiological/medical needs

- Make sure medications are clearly labelled.
- Establish routines for taking medications that take into account the level of dementia and the likelihood of success with proceeding independently with these routines.
- Medication routines will no doubt be clearly documented in residential care settings – ensure that they are in home settings as well.
Responding to communication difficulties

If the person has difficulty communicating, try to guess what they are trying to say and repeat it for them. Reassure them that you are trying to understand what they are saying. Encourage them to use gestures, or to point to something that might give you an idea of what they are talking about.

If the person says the same thing repeatedly (perseveration), or repeats what you are saying (echolalia), try to respond as if it is the first time the person has said something. Use distraction – change the topic; offer reassurance. Provide a safe, regular routine. Perseveration might occur more frequently in situations in which the person with dementia feels anxious or threatened. Talk in a calm and reassuring manner. Use conversation as a soothing device, even if you are not sure how much of what you say will be understood.

Dealing with wandering

- Try to ascertain why the person is wandering. Are they bored? Distressed?
- Wanting to escape, or searching for something (which may not be attainable)? Or is the wandering without purpose – the result of aimless ambulation, random distraction, or imitation of others departing?
- Eliminate any factors that contribute to the tendency to wander.
- Alert others of the person’s tendency to wander.
- Provide opportunities for ‘safe’ wandering, such as going for walks, visiting other residents, or providing distraction by moving to another space (eg: going to the dayroom).
- Provide opportunities for supervised outings (eg: with family members), which provide stimulation and a change of environment.
- Look at the pattern of wandering behaviour. How does it relate to other factors such as meal times, medication, weather, bath-time, social activities, and so on?
- Make sure that the person is comfortable in their environment. Do they have a comfortable place to sit?
- Approach the person who is wandering in a non-threatening way. Talk calmly and lead them back to where they should be.
- Provide distractions and activities of interest.
- Make sure the person’s clothing is labelled so that their name and address are easily identified.

Dealing with aggressive behaviour

Aggression as a term refers to the following types of acts:

- Verbal abuse
- Hitting
- Kicking
- Spitting
- Spitting
- Scratching
- Biting
- Pinching
- Pulling hair
- Threats of violence
- Throwing objects, or threatening to.
While aggressive behaviour towards staff or carers of others is unacceptable, the emphasis in terms of behaviour management remains preventative. Where possible, the situation should be resolved before it escalates to the point of aggression. How?

- Allow the person to express their feelings.
- If there is a history of aggressive behaviour, work in pairs and be aware of what might trigger the aggressive response.
- Ensure that the person's personal space is maintained.
- Provide distractions.
- Ensure time-out for staff and carers who may carry the stress of being alert to aggressive behaviour.
- Review care plans on a regular basis and ensure that necessary adjustments are made (e.g., to medication, pain management, physical environment).
- Your place of work will have policies regarding responding to aggressive behaviour.
- They may also provide training to staff to ensure that due care is taken to prevent the risk of harm or injury from people displaying aggressive behaviour.
- Many workplaces screen clients for risk of aggressive behaviour and record their strategies for dealing with such an event in the care plan.

Remember, if you experience an act of aggression from someone you are working with, report the incident so that the necessary precautions can be taken to guard against future incidents. Don’t try to handle a situation that is beyond your training and experience. Seek help from supervisors or more experienced staff.
The need for restraint

The use of restraint is a complex and contentious issue and it is not within the bounds of this publication to discuss it in any depth. The key factor to remember is that the use of restraint is an infringement of personal liberty and should only be used as a last resort measure to protect the person or others from harm or injury. What is strongly promoted as an alternative to restraint or seclusion (restraining the person by isolating them in a space that they cannot leave) is positive procedures which prevent situations escalating to a point where restraint may be required.

We have discussed all of these strategies, but in summary, consider the following points:

- Altering the physical environment to accommodate the person’s needs.
- Avoiding situations or activities that might provoke anxiety or distress.
- Avoiding socialisations that have previously proved disturbing or disruptive.
- Providing enjoyable and meaningful activities.
- Allowing opportunities for the person to wander safely.
- Workplaces have policies regarding use of restraint. Always seek assistance when possible. Do not try to handle a situation on your own which is beyond the scope of your experience or training.

Some further general strategies for responding to challenging behaviour:

- Offer distraction – conversation, a change of activity, a change of environment.
- Talk about what is currently happening to re-orient the person and minimise confusion.
- Activities such as reminiscence, music, dancing and walking can be soothing and minimise the likelihood of challenging behaviour.
- Talk reassuringly about familiar and favourite topics.
- Use behaviour modification strategies, which may be outlined in the person’s care plan (eg: offering positive reinforcement and incentives for completion of routine tasks such as bathing).
- Address physical triggers to behaviour (eg: re-evaluating pain management).
- If the person with dementia exhibits agitation, distress or restlessness, try to distract them by changing the topic, using reminiscence or handing them an object which might be of interest.
- If they are uncooperative, try to break the task into smaller, more easily managed steps. Try not to exhibit irritation or argue with them. Try to pinpoint where their understanding is breaking down and find ways of communicating and demonstrating.
- If they respond in a catastrophic manner, remain calm. Use distraction, provide reassurance and try not to argue with them because this may escalate the situation. Move the person somewhere quiet and focus on calming them. Talk about something different; use reminiscence.
- If the person becomes disoriented or confused, provide information regarding time, whereabouts, date, etc. Use ‘Reality Orientation’ techniques. Be reassuring.
- Use validation techniques.
- Consider the use of complementary therapies (eg: diversional therapy, massage, aromatherapy, doll therapy, music, pet therapy) to soothe and calm the person with dementia.
Seventeen

Taking action to minimise the likelihood of and reduce the impact of behaviours on the person and others

Identify and describe the impact of three situations where it may be challenging for you to ensure duty of care is maintained.

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

Case study:

Mrs. Fuller, who is 65-years old, is about to move into the high care aged care facility in which you are employed. She has severe dementia, and has recently begun to ‘wander’, often being found several blocks from where she was living with her daughter.

What strategies might you put in place to minimise the possibility of Mrs. Fuller wandering, and therefore putting her own safety at risk?

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________
Evaluating implemented strategies with support planning team to ensure effectiveness in minimising behaviours

Reviewing behaviour management strategies

All care plans must be reviewed often. A care plan review involves consultation with the person with dementia (when they are able to contribute), family members, carers and significant others, health professionals and workers involved in providing support to the person. The frequency of a review depends on the support service and the needs of the person with dementia. If the needs of the person change suddenly, their care plan must be reviewed. If their needs remain the same over several months, the plan may only be reviewed a few times a year. Part of any review process will be to look at what has been done. This includes strategies to manage challenging behaviour.

A good review will look at:

- What the behaviour/s is/are
- How the behaviour/s affects the person and others
- What strategies have been tried and for how long
- What happened with each strategy
- Whether a behaviour increased, decreased or stayed the same
- Whether there were any special triggers for the behaviour
- The least restrictive strategy for dealing with a behaviour
- Which strategies should be continued and which should be changed.

This review might happen as part of a team meeting. You might get together with your supervisor to talk about strategies. You might meet with family members or advocates for the person with dementia. You might talk to the person themselves as part of the review process.
Element 5: Complete documentation

Complying with the organisation’s reporting requirements, including reporting observations to supervisor

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. 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.

Consideration will need to be given to:

- Compliance with organisational reporting requirements
- Completing documentation appropriately
- Maintaining documentation
- Filing documents.

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 or to attend review meetings and contribute, as well as recording day to day activities that monitor the wellbeing of the client. 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.
Complying with the organisation’s reporting requirements, including reporting observations to supervisor

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!

Finally: When you have finished your writing always re-read and make sure everything makes sense and then sign and date the work.
Types of issues to report

As a care worker you are often the one person who deals with your client on a regular and ongoing basis. It is therefore possible for you to get to know your client well and easily observe any changes in appearance, behaviour or mood. The more you get to know your client the more efficient you will be at being able to judge the significance of these changes. If the person with dementia is acting differently to their normal routine or pattern it is important that you pay attention and observe.

You may notice that your client:

- Is behaving in an unusual or different manner
- Has changed their daily routine in a way that may concern you
- Is concerned or upset about an issue
- Is exhibiting a change to their physical or mental condition
- Is making unusual changes to their environment or in relation to their belongings.

All of these issues should be noted and recorded. Any changes that appear to be significant should be reported immediately. Changes may require an investigation or alteration to the support provided.

The people you may need to report to

Organisations have specific policies and procedures in place to direct your reporting methods. These guidelines advise who you should report any significant changes to. The people you may need to report to include:

Your supervisor:

The most important person you need to report information back to is your supervisor. They need to be informed at all times of any significant changes in appearance or behaviour of your client in order for them to take the appropriate action. When you report any changes to your supervisor they will then direct you on any further action you may need to take.

Colleagues and other support workers: It is important that any changes in behaviour or appearance of your client are documented in their care plan so that other support workers have access to this information. The sharing of information about your client is often essential in ensuring that the needs of your client are being fulfilled.

Healthcare professionals or the person’s medical practitioner: You will need to report any change of condition, especially those related to a medical issue to other health workers and the medical practitioner of your client. These people are responsible for the health and safety of your client and therefore need to be aware of any information that may affect your client’s health and well-being.

Health care services and other health professionals: There may be times when an organisation or worker from outside your organisation can assist your client with a problem. If this is the case then information needs to be reported to them so that they may be of assistance. The types of people you may need to report this information to include podiatrists, dentists or occupational therapists, who may be able to assist with a specific problem.

Home and Community care: Changes in behaviour or appearance of your client may need to be reported to organisations that provide your client with other types of community care. They will need to know this information in order to assist your client effectively and make any alterations to the types and kind of care that they provide.

Emergency services: There may be times when you need to report a change in your client’s condition or behaviour directly to emergency services. Emergency services need to be contacted if you consider the situation to be critical and requiring immediate attention, eg: delirium, a heart attack, severe injury or acute psychosis.
Administrators: Some clients will have administrators responsible for their health and well-being or responsible for other matters such as financial issues. Any changes related to these areas may need to be reported directly to the administrators in order for them to be aware of the change and respond accordingly.

Human services: There may be times when you need to consult social services to report changes in the behaviour or appearance of your client. This may be in situations of abuse or matters of security that social security can offer assistance with.

Relatives or next of kin: Some changes in behaviour or appearance of your client, such as increased aggressive behaviour, should be reported to the next of kin or family members of the client. This is sometimes important to ensure that you have legally informed your concerns to the family. A family member may be able to counsel the client or help you with strategies that can assist in working with the person with dementia.
Completing, maintain and store documentation according to organisation policy and protocols

Securing client records

Access to records should be limited to those with a justifiable “need to know”. Safeguards should be in-built to maintain confidentiality – especially if computer based documentation systems are being utilised. All dementia residents/client information must be securely stored and should never be left lying around in view of family members, the general public or anyone who is not authorised to access them. If written confidential information is passed to anyone other than the person concerned, it must be sealed in an addressed envelope.

Records may be kept in locked filing cabinets or in password protected computers. From time to time old documents need to be taken to a secondary storage area. All documents required by legislation to be stored for certain periods of time are clearly labeled and stored securely according to organisational policies and procedures. When it comes time to dispose of these records they should be destroyed and not merely thrown out. Drugs, equipment and other materials requiring secure storage and potentially posing an OHS threat to others, should be stored securely at all times.

What information is considered as confidential?

Confidential information is any information that your client may prefer that other people did not know.

This could include the following information:

- Identifying data like given name, family name and address
- Personal information like age and religion
- Medical or health information
- Financial matters
- Family situation
- Legal issues
- Personal history
- Living arrangements
- Sexuality
- Social life
- Personal habits
- Services being used
- Political views
- Criminal history
- Employment history.

Staff must follow confidentiality policy and practices when carrying out their duties. It is the responsibility of their supervisors to ensure this happens. Any breaches of confidentiality practices can lead to disciplinary action by your organisation.
Record keeping and filing systems

Each organisation will maintain manual and electronic filing systems based on specific needs. The records are like a memory of an organisation. Vital information needs to be maintained about clients and staff in an organisation, and those records must be filed appropriately to ensure simplicity when retrieving records, as well as security and confidentiality.

Effective and efficient record keeping are essential to:

- Reduce liability
- Ensure office productivity
- Eliminate potential errors and ensure efficient service delivery
- Provide information to funding bodies and government on how services are delivered
- Facilitate information exchange between staff and boards of management and funding bodies.

What are essentials of a good filing system?

A good filing system should have the following characteristics:

- **Simplicity:** It should be easy to understand and use, allowing quick and accurate retrieval of documents.
- **Security:** The documents need to be stored in a secure manner with controlled access to ensure they are not read or taken by unauthorized people.
- **Compact yet comprehensive:** A good filing system will retain only those records that are required to be filed. You will need to learn how to identify the different categories of documents that must be filed according to the organization’s policies and procedures, and those documents that are not filed. If in doubt, ask!
- **Follow-up procedures:** When a file, report or document is removed from its normal storage place, there needs to be a procedure in place, in order to show who borrowed that client's file and when it is due to be returned. This will help reduce the number of files or documents that go missing from the filing system.
- **Economical:** The filing system needs to be economical to set up, use and maintain
- **Classification systems:** Records can be filed in different ways depending on the needs of the organisation.
Nineteen

Completing, maintaining and store documentation according to organisation policy and protocols

1. Describe the reporting processes of your organisation.

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2. Why is it important to attend to reporting?

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3. What is your organisational process for access to and storing client reports?

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Element 6: Implement self care strategies

Monitoring own stress level in relation to working with people with dementia

The challenges of working with a person with dementia in a residential care facility are many and difficult. Caring for someone who has dementia can be physically and emotionally demanding on Personal carer workers, nurse and other members of the care team. Care workers may be employed to assist the care workers are givers- they give of their time, their energy and their affection. They are often so involved in caring for other that they forget to care about their own needs. Although it may sound very generous, in reality it is not wise. If you do not take of yourself, you will not be able to care affectively for people with dementia.

A care worker assists a resident with dementia and their family with a variety of tasks including showering toileting, meals. All of these tasks require the care worker to utilise skills such as problem solving, patience, time management, counselling and humour. Aged care facilities and community care providers may find they are constantly adapting their own practices to meet the changing physical and emotional needs of the person with dementia and their family and carers.

In the process of caring for a client with Dementia, a number of situations or problems can arise which are frustrating and stressful for both the client with Dementia and for those who are providing care for them. These difficult situations and the resulting behaviour can occur during times when close and often intimate care is being given, or at the busiest time of day.

Sometimes the behaviour occurs because the person feels suddenly overwhelmed by a task or the situation and reacts disproportionately (a catastrophic reaction). Some behaviour can be a direct result of loss of function, for example: Incontinence, where the client has lost muscle control, but more often than not, the immediate cause is something else.
Stress management

The term ‘burn out’ has been introduced into workplace studies on stress over a decade or more. It implies that the caring person has lost ability to care in the way that they used to due to excessive work pressures. Within a work situation there are some stressors which are known to impact on a care worker’s performance:

Research has shown that stress-related illness in support workers is linked to:

- Poor management practices
- Poor relationships with supervisors and colleagues
- Resident aggression
- Burn out.

Causes of burnout

These are the following:

- An inability to say no
- Pushing yourself past limitations
- Having no control or ability to make decisions about your job and how to do it
- Being unsure of your role
- Resident aggression
- A lack of positive feedback in aged care
- Experiencing grief due to resident illness and death
- Having poor relationships with supervisors or other staff
- A feeling that you have no sense of accomplishment
- Sexual harassment in the workplace
- Workplace bullying or workplace violence

The most significant cause of burnout is the sense of overload that you cannot do everything you want to do for your clients/residents that needs to be done. However it is important to remember that ultimately a worker can only do their reasonable best. There are limits to the care that a care worker can provide. Few people are in the position to devote themselves entirely to work. This is because our family, social life etc must have equal value. Hence it is important to strike a healthy balance. We must nurture ourselves if we want to continue nurturing others.

Warning signs of excessive stress at work

When people feel overwhelmed, they lose confidence and become irritable or withdrawn, making them less productive and effective and their work less rewarding. If the warning signs of work stress go unattended, they can lead to bigger problems. Beyond interfering with job performance and satisfaction, chronic or intense stress can also lead to physical and emotional health problems.

How do I know if someone is (or if I am) having trouble coping with stress?

There are many different signs and symptoms that can indicate when someone is having difficulty coping with the amount of stress they are experiencing:

Physical: headaches, grinding teeth, clenched jaws, chest pain, shortness of breath, pounding heart, high blood pressure, muscle aches, indigestion, constipation or diarrhoea, increased perspiration, fatigue, insomnia, frequent illness

Psychosocial: anxiety, irritability, sadness, defensiveness, anger, mood swings, hypersensitivity, apathy, depression, slowed thinking or racing thoughts; feelings of helplessness, hopelessness, or of being trapped
**Behavioural:** overeating or loss of appetite, impatience, quickness to argue, procrastination, increased use of alcohol or drugs, increased smoking, withdrawal or isolation from others, neglect of responsibility, poor job performance, poor personal hygiene, change in religious practices, change in close family relationships.

**Using appropriate self care strategies and seek support if required**

When stress on the job is interfering with your ability to work, care for yourself, or manage your personal life, it’s time to take action. Start by paying attention to your physical and emotional health. When your own needs are taken care of, you’re stronger and more resilient to stress. The better you feel, the better equipped you’ll be to manage work stress without becoming overwhelmed.

Taking care of yourself doesn’t require a total lifestyle overhaul. Even small things can lift your mood, increase your energy, and make you feel like you’re back in the driver’s seat. Take things one step at a time, and as you make more positive lifestyle choices, you’ll soon notice a noticeable difference in your stress level, both at home at work.

In many cases, the origin of the stress is something that cannot be changed immediately. Therefore, finding ways to help maintain good mental health is essential. There are many ways to be proactive in dealing with stress. In the workplace, you might try some of the following as suggested by the Australian Mental Health Association:

- **Laughing:** is one of the easiest and best ways to reduce stress. Share a joke with a co-worker, watch a funny movie at home with some friends, read the comics, and try to see the humour in the situation

- **Learn to relax:** take several deep breaths throughout the day, or have regular stretch breaks. Stretching is simple enough to do anywhere and only takes a few seconds

- **Take charge of your situation:** by taking 10 minutes at the beginning of each day to prioritise and organise your day. Be honest with your colleagues, but be constructive and make practical suggestions. Be realistic about what you can change

- **Exercise:** Aerobic exercise –perspiring –is an effective anti-anxiety treatment lifting mood, increasing energy, sharpening focus and relaxing mind and body. For maximum stress relief, try to get at least 30 minutes of heart pounding activity on most days but activity can be broken up into two or three short segments.
Here are just some ways exercise helps with stress:

**Exercise may help to cause positive changes in the brain by:**

- Releasing serotonin contributing to feeling relaxed and satisfied and increase alpha-wave activity in the brain producing a calming effect
- Exercise can help to get your mind off negative, stressful thoughts. Most forms of physical activity and exercise in general require good concentration helping respect
- Exercising at a gym, at home or doing activities outside will present an opportunity to work out any negative feelings that cause you stress or simply clear your mind and think about nothing at all
- Working out with someone helps to provide you with the pleasure of companionship and prevents you from feeling lonely
- Exercise helps you feel vigilant and invigorated helping to dramatically reduce your feelings of stress
- Exercise is a stress relief. It can help to ease nagging muscle and emotional tension and helps you to have a deeper and more relaxing sleep.

**Practice Relaxation methods:** In addition, there are certain relaxation methods that can help you relieve the effects of stress:

- Meditation, tightening and loosening each muscle group in your body one after another
- Closing your eyes and visualizing a soothing scene, and listening to peaceful music
- Sit quietly and breathe slowly and uniformly. Close your eyes and inhale and exhale slowly through your nose. Pause for 2 seconds after you exhale and repeat until you feel the stress has lessened.

**Nutrition:**

- **Make food choices that keep you going and make you feel good:** Eating small but frequent meals throughout the day maintains an even level of blood sugar in your body. Low blood sugar makes you feel anxious and irritable. On the other hand, eating too much can make you lethargic.
- **Drink alcohol in moderation and avoid nicotine:** Alcohol temporarily reduces anxiety and worry, but too much can cause anxiety as it wears off. Drinking to relieve job stress can also start you on a path to alcohol abuse and dependence. Similarly, smoking when you're feeling stressed and overwhelmed may seem calming, but nicotine is a powerful stimulant – leading to higher, not lower, levels of anxiety.

**Seeking extra support and debriefing**

It is vital for workers who care for people with dementia, to ask for support and guidance from their supervisor or other colleagues when they feel they need support.

**If you decide to choose someone to confide in, or seek support remember to:**

- Choose someone you have a rapport with
- Can clearly explain your problem or feelings
- Explain anything you don’t understand about your job role.

Some situations can be quite distressing for workers and it may be advisable for them to seek a formal debriefing after involvement in any disturbing event. Debriefing can play an important part of keeping workers effective, creative, inspired, and above all sane, in their role as a support worker. Debriefing is a process which allows workers to discuss their feelings which occur after an incident or issue in the workplace. De-briefing sessions will help alleviate any stress they are experiencing.
Activity

Twenty

Using appropriate self care strategies and seek support if required

Complete the following questions.

1. State some self-care practices which you could use to combat the stress associated with aged care work.

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2. Why can people with dementia be emotionally and physically demanding for care staff?

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3. Explain who you go to for support in your workplace when you are feeling the effects of stress or burnout.

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4. Share with your classmates the situations which push your buttons and how that makes you feel.

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Bibliography