alzheimer's
QUEENSLAND

Dementia and Aged Care Services (DACS)

CHCAGE005

Provide support to people living with dementia

Learner Guide

NATIONALLY RECOGNISED
TRAINING

RTO (30213)

Please Print Contact Details Below

First Name: ______________________ Surname: ______________________

Name of Workplace: ____________________________

Position: ____________________________

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Date: ________________

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Contents

Unit specifications

CHCAGE005 – Provide support to people living with dementia

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.

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.

1. Prepare to provide support to those affected by dementia
    - 1.1 Apply person-centred care approaches to all interactions with the person living with dementia
    - 1.2 Interpret individualised plan and familiarise self with the specific needs and wants of the person living with dementia
    - 1.3 Identify and address person's needs for a stable and familiar environment
    - 1.4 Recognise signs consistent with financial, physical or emotional abuse or neglect of the person and report to an appropriate person

2. Use appropriate communication strategies
    - 2.1 Use verbal and non-verbal communication strategies to maximise engagement of the person with dementia
    - 2.2 Gain cooperation and provide reassurance as appropriate by using reality orientation
    - 2.3 Use a range of validation strategies to relieve distress and agitation in the person

3. Provide activities for maintenance of dignity, skills and health
    - 3.1 Organise activities which aim to maintain independence, using familiar routines and existing skills
    - 3.2 Organise activities that are appropriate to the individual, reflecting their cultural likes and dislikes, in order to bring back pleasurable memories
    - 3.3 Ensure the safety and comfort of the person balanced with autonomy and risk taking
    - 3.4 Access information about the person's reminiscences and routines with family and carers
    - 3.5 Provide support and guidance to family, carers and/or significant others where appropriate

4. Implement strategies which minimise the impact of behaviours of concern
    - 4.1 Identify behaviours of concern and potential triggers
    - 4.2 Contribute to team discussions on support planning and review
    - 4.3 Take action to minimise the likelihood of and reduce the impact of behaviours on the person and others

4.4 Evaluate implemented strategies with support planning team to ensure effectiveness in minimising behaviours

5. Complete documentation
    5.1 Comply with the organisation's reporting requirements, including reporting observations to supervisor
    5.2 Complete, maintain and store documentation according to organisation policy and protocols

6. Implement self-care strategies
    6.1 Monitor own stress levels in relation to working with people with dementia
    6.2 Use appropriate self-care strategies and seek support as required

Performance Evidence
The candidate must show evidence of the ability to complete tasks outlined in elements and performance criteria of this unit, manage tasks and manage contingencies in the context of the job role.

There must be evidence that the candidate has:
S1. Provided support to 2 different people living with dementia:

a. using a person-centred approach to support
b. using appropriate communication strategies
c. assisting in implementing a range of suitable activities that meet the person's needs

Knowledge Evidence

The candidate must be able to demonstrate essential knowledge required to effectively complete tasks outlined in elements and performance criteria of this unit, manage tasks and manage contingencies in the context of the work role. This includes knowledge of:

K1. Up to date research on dementia and the different manifestations of dementia, including:
  a. Alzheimer’s disease
  b. vascular dementia or multi-infarct dementia
  c. Lewy bodies
  d. excessive alcohol intake or Korsakov Syndrome
  e. frontal-temporal lobe degeneration (FLTD) including Pick’s disease
  f. Huntington’s disease
  g. Parkinson’s disease
  h. younger onset dementia

K2. Dementia as a progressive neurological condition, including pathological features:
  a. amyloid plaques
  b. neurofibrillary tangles
  c. loss of connection between cells and cell death

K3. Common indicators and symptoms of dementia

K4. Behaviours of concern, needs driven behaviour model and de-escalation procedures

K5. Progression of dementia and potential impact on the person with dementia, their family and significant others, including:
  a. depression
  b. loss and grieving
  c. anger
  d. despair
  e. social embarrassment a family member might feel
  f. isolation
  g. financial burden on the family
  h. social devaluation

K6. Principles of person-centred approach to support

K7. Relevant activities which enhance self-esteem and pleasure in the person’s life, minimise boredom, and distract from or eliminate behavioural and psychological symptoms of dementia

K8. Competency and image enhancement as a means of addressing devaluation

K9. Verbal and non-verbal communication strategies including:

a. reality orientation
b. reminders of the day, the time, relationships, occasions
c. reassuring words, phrases and body language
d. validation
e. empathy
f. acceptance of the person’s reality
g. acknowledgement
h. allowing expressions of distress
i. providing verbal and physical reassurance
j. frequent reminiscence to connect with person

Dementia

Alzheimer's Queensland provides the following:

> "dementia is a collective name for progressive degenerative brain syndromes which affect memory, thinking, behaviour and emotion".

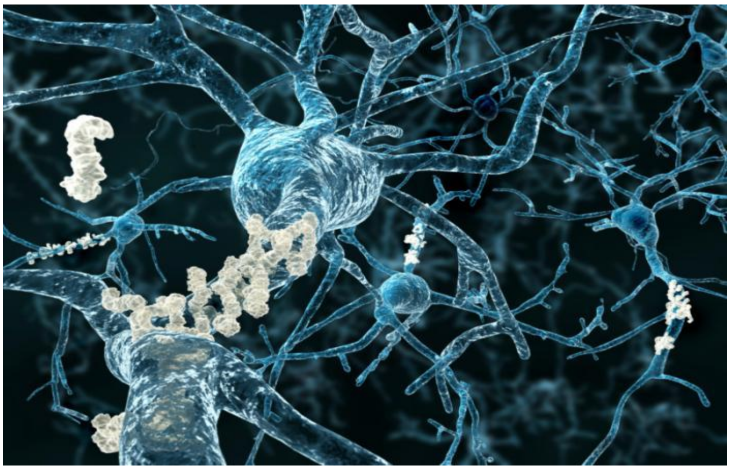
http://www.alzheimersonline.org

Though Alzheimer's disease is the most common form of dementia, the terms "dementia" and "Alzheimer's disease" are not the same thing. To give a similar example – we have the term "cars". The term "cars" describes vehicles we sit and drive around in. We also have "Holden Commodore" - a Holden Commodore is a type of vehicle which we can sit and drive around in. A Holden Commodore is a car but not all cars are Holden Commodores. In the same way, Alzheimer's disease is a form or type of dementia but not all forms of dementia are Alzheimer's disease.

Alzheimer's Disease

First described in 1906 by Dr. Alois Alzheimer, Alzheimer's disease is the most common form of dementia, accounting for around 60-80% of cases in the USA. It is characterized by problems with memory, thinking and behaviour. Onset is most common in individuals aged 65 and over, although people in their 40s and 50s can develop what is classed as younger or early onset Alzheimer's.

Alzheimer's is a progressive disease. It destroys brain cells and nerves disrupting the transmitters which carry messages in the brain, particularly those responsible for storing memories. German neurologist Dr Alzheimer wrote of a physical disease in which brain cells are destroyed. The appearance of this destruction is referred to as "plaques and tangles".



During the course of Alzheimer's disease nerve cells die in regions of the brain. The brain shrinks as gaps develop in the temporal lobe and hippocampus, which are responsible for storing and retrieving new information. This in turn affects a person’s ability to remember, speak, think and make decisions. The production of certain chemicals in the brain, such as acetylcholine is also affected. It is not known what causes nerve cells to die but there are characteristic appearances of the brain found after death during a post mortem. In particular, 'tangles' and 'plaques' made from protein fragments are observed under the microscope in damaged areas of brain. It is the finding of these ‘tangles’ and plaques’ that confirms the diagnosis of Alzheimer's disease.

The onset of the disease is usually quite gradual. Likewise, symptoms appear gradually, but progressively worsen as the disease spreads. Typically, Alzheimer's disease begins with lapses of memory, difficulty in finding the right words for everyday objects or mood swings.

As Alzheimer's progresses, the person may:

- Routinely forget recent events, names and faces and have difficulty in understanding what is being said
- Become confused when handling money or driving a car
- Undergo personality changes, appearing to no longer care about those around them
- Experience mood swings and burst into tears for no apparent reason, or become convinced that someone is trying to harm them

In advanced cases people may also:

- Adopt unsettling behaviour like getting up in the middle of the night or wander off and become lost

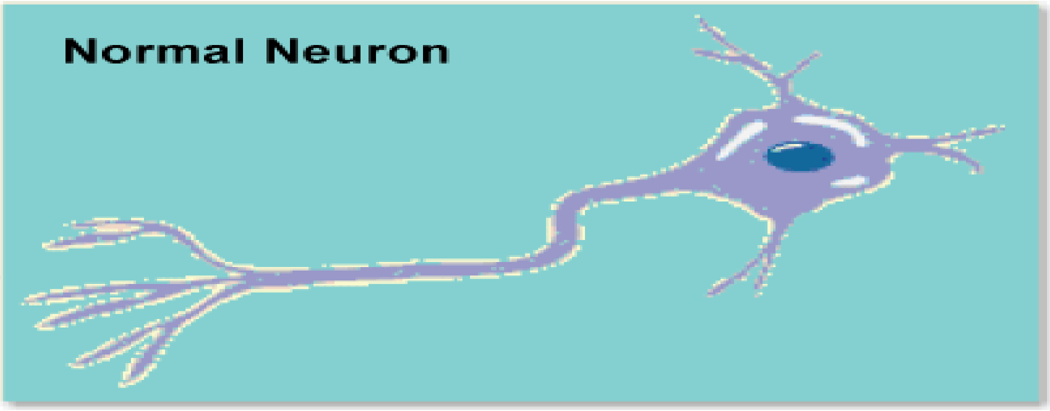
- Lose their inhibitions and sense of suitable behaviour, undress in public or make inappropriate sexual advances.

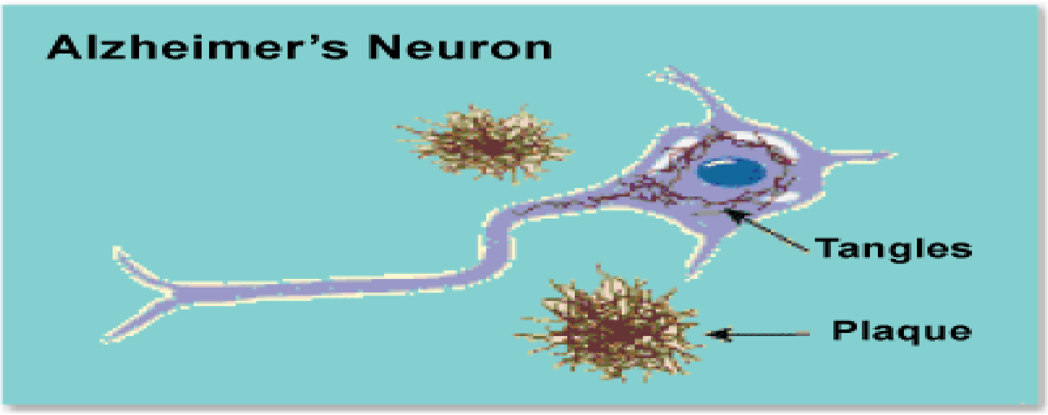
lzheimer's disease is a physical disease, not a mental disorder. The brain controls everything we think, say, feel and do. So when the brain becomes diseased, our thoughts, abilities and behaviours are all affected.

The symptoms of Alzheimer's disease are often mistaken as just a normal part of getting older. Many of us feel that as we age we forget things more easily. But the forgetfulness of old age is vastly different to the memory loss of Alzheimer's disease.

Although the jury is still out on the exact roles plaques and tangles play in the development of Alzheimer's, studies have suggested that build up of these proteins begins long before symptoms develop.

Dr Heather Snyder, Director of Medical and Scientific Operations at the Alzheimer’s Association in the United States says that “evidence suggests that the process of Alzheimer's disease begins more than a decade before clinical symptoms appear, suggesting we may need to intervene earlier to have a major impact on the course of the disease, particularly when using therapies designed to prevent the development of abnormal protein structures - plaques and tangles - that are abundant in the brains of people with Alzheimer's”.





Some research has proposed that targeting these abnormal structures could treat Alzheimer's disease. Researchers from the University of California-Irvine, have suggested that increasing brain cell connections could reduce plaque accumulation.

Some studies claim that lifestyle factors may be a driver of plaques and tangles typical of Alzheimer's. Research from Temple University in Philadelphia, PA, for example, suggests that chronic sleep deprivation may cause these abnormal brain structures. Another study suggests regular caffeine consumption could halt development of tangles, while research from the Icahn School of Medicine at Mount Sinai in New York, NY, claims eating grilled meat can increase the development of plaques.

As with all research, it is important to remember that research theories are not established until the results prove to be conclusive.

Vascular Dementia

Vascular dementia accounts for about 20% of all cases of dementia. Vascular disease occurs where blood vessels are damaged and the supply of oxygen is at risk. If oxygen supply fails in the brain, brain cells are likely to die leading to a series of mini strokes (infarcts) and possible vascular dementia.

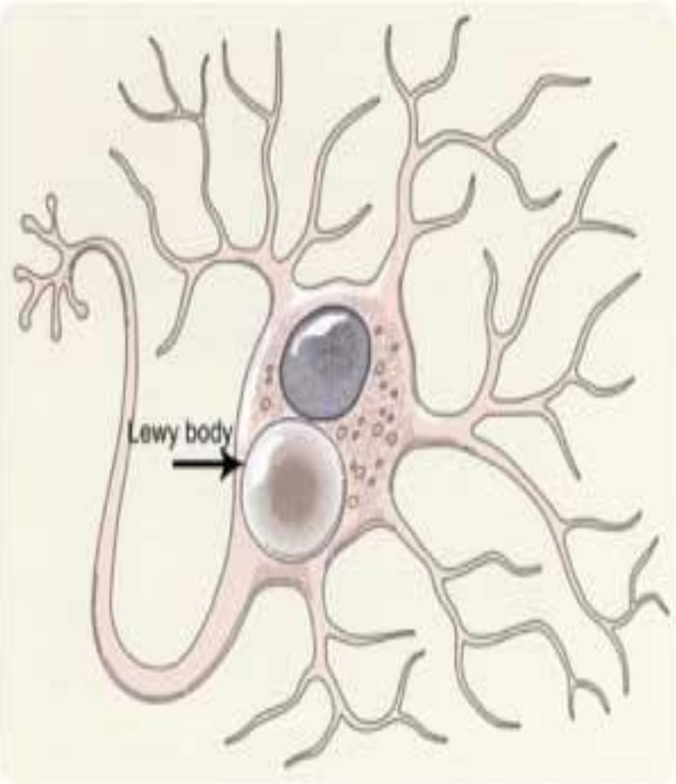
The mini strokes that cause vascular dementia are often so slight that they cause no immediate symptoms, or they may cause some temporary confusion. However, each stroke destroys a small area of cells in the brain by cutting off its blood supply and the cumulative effect of a number of mini strokes is often sufficient to cause vascular dementia. Vascular dementia and Alzheimer's disease frequently occur together and they may often act in combination to cause dementia.

With vascular dementia, a mental decline is likely to have a clear start date and symptoms tend to progress in a series of steps following each attack, suggesting that small strokes have been occurring. Symptoms may include severe depression, mood swings and epilepsy. Some areas of the brain may be more affected than others. Consequently, some mental abilities may be relatively unaffected.

Dementia with Lewy Bodies and Parkinson's Disease Dementia

Dementia with Lewy bodies is the third most common cause of dementia and may occur in up to 20% of cases confirmed at autopsy. Dementia with Lewy bodies is similar to Alzheimer's disease in that it is caused by the degeneration and death of nerve cells in the brain. It takes its name from the abnormal collections of protein, known as Lewy bodies, which occur in the nerve cells of the brain.

People with Lewy body disease are very sensitive to some tranquillisers known as antipsychotic or neuroleptic drugs and their use should be avoided if at all possible.



Dementia with Lewy body affects:

- Concentration and attention
- Memory
- Language
- The ability to judge distances
- The ability to reason
- People with Lewy body disease can experience visual hallucinations

Lewy bodies disease can take 2 forms – dementia with Lewy bodies or Parkinson's disease dementia. The difference between them lies mainly in how the disease starts. In dementia with Lewy bodies the person may have a memory disorder that looks like Alzheimer's disease but later on develops movement problems. In Parkinson's disease dementia they may have a movement disorder that looks like Parkinson's but later on they develop dementia symptoms.

Since Dementia with Lewy bodies is commonly misdiagnosed for both Parkinson's disease and Alzheimer's disease, it is helpful to understand how these diseases overlap.

Overlapping Symptoms of Parkinson’s, Alzheimer’s, and Lewy Body Dementia	
Parkinson’s and Lewy Body Dementia	**Alzheimer’s and Lewy Body Dementia**
Some of the **motor symptoms** found in both **Parkinson’s** and Lewy Body Disease's patients include: • tremors • muscle stiffness • difficulties with balance • shuffling gait • stooped posture • slow movements • restless leg syndrome	Some of the **cognitive symptoms** found in both **Alzheimer's** and Lewy Body's patients include: • behavioural changes • decreased judgment • confusion and temporal/spatial disorientation • difficulty following directions • decreased ability to communicate

Korsakov (Korsakoff’s) Syndrome

Wernicke-Korsakoff Syndrome (WKS) is a neurological disorder. Wernicke’s encephalopathy and Korsakoff’s psychosis are the acute and chronic phases, respectively, of the same disease.

WKS is caused by a deficiency in the B vitamin thiamine. Thiamine plays a role in metabolizing glucose to produce energy for the brain. An absence of thiamine therefore results in an inadequate supply of energy to the brain, particularly the hypothalamus. The hypothalamus regulates body temperature, growth and appetite and has a role in emotional response. It affects pituitary functions including metabolism and hormones. The disease is typically associated with chronic alcoholism, but may be associated with malnutrition or other conditions which cause nutritional deficiencies.

Frontotemporal Degeneration including Pick's disease

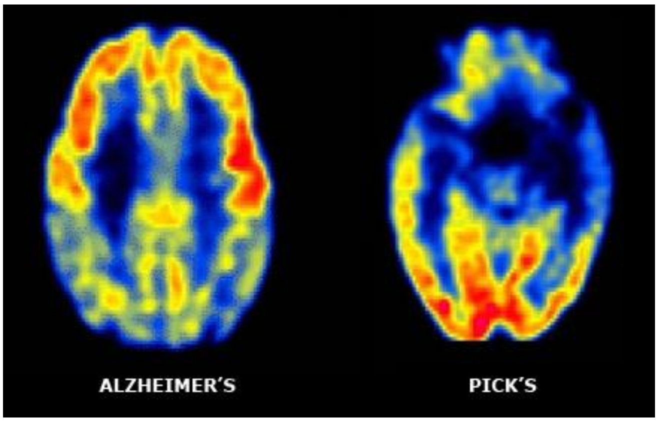
Frontotemporal degeneration is a disease process that results in progressive damage to the temporal and/or frontal lobes of the brain. It causes a group of brain disorders that share many clinical features. Frontotemporal degeneration is also commonly referred to as frontotemporal dementia, fronto-temporal lobar degeneration (FTLD), or Picks disease.

Frontotemporal degeneration is distinct from other forms of dementia in two important ways:

- The hallmark of frontotemporal degeneration is a gradual, progressive decline in behaviour and/or language (with memory usually relatively preserved). As the disease progresses, it becomes increasingly difficult for people to plan or organize activities, behave appropriately in social or work settings, interact with others, and care for oneself, resulting in increasing dependency on caregivers.

- Onset of frontotemporal degeneration often occurs in a person's 50s and 60s but has been seen as early as 21 and as late as 80 years. Roughly 60% of cases occur in people 45-64 years old (Knopman, 2011), therefore frontotemporal degeneration can affect work and family in a way dementia in older patients does not.

The length of progression varies, from 2 to over 20 years with a mean course of 7-13 years from the onset of symptoms.



Huntington’s Disease

Huntington’s disease is a neurological (nervous system) condition caused by the inheritance of an altered gene. In Huntington’s disease the death of brain cells in certain areas of the brain results in a gradual loss of cognitive (thinking), physical and emotional function. Huntington's disease is a complex and severely debilitating disease, for which there is no cure.

Huntington’s disease symptoms fall into three types:

Physical symptoms include:

- Mild twitching of the fingers and toes
- Lack of coordination and a tendency to knock things over
- Walking difficulties
- Dance-like or jerky movements of the arms or legs (chorea)
- Speech and swallowing difficulties

Cognitive symptoms include:

- Short-term memory loss
- Difficulties in concentrating and making plans

Emotional symptoms include:

- Depression (around one third of people with Huntington's disease experience depression)
- Behavioural problems
- Mood swings, apathy and aggression

A person with Huntington's disease may live for 15 to 25 years after developing the first symptoms.

Younger Onset Dementia

Dementia takes many forms, such as Alzheimer’s disease, Vascular dementia, Fronto-temporal, Lewy Body etc. Many people assume that Alzheimer's disease and other causes of dementia only affect older people. In fact about 1 person in every 1000 with dementia is below the age of 65. While rare, it can affect people in their 40's and 50's. Younger people tend to be affected by the less common forms of dementia, which often present with more challenging behaviours and progress at a faster rate.

Any dementia beginning before the age of 65 is known as younger onset, even if the correct diagnosis is not received by the person until a later age. There are estimated to be approximately 22 000 Australians currently living with younger onset dementia but there are very few services to cater for their specific needs. Through targeted promotion and advocacy, it is hoped to raise the profile of the illness and the impact it has on those affected by it.

Symptoms of younger onset dementia

The symptoms of dementia are similar whatever the person's age. Dementia affects the brain in many ways and may cause:

- Memory loss
- Mood changes and inappropriate interactions
- Disorientation in time, day and place
- Difficulties in communication
- Inability to concentrate
- Personality changes
- Difficulties in recognition, understanding and comprehension
- Behavioural changes

Although the symptoms of dementia are similar whatever a person's age, younger people with dementia have additional issues.

They may:

- Be in work at the time of diagnosis
- Have dependent children still living at home
- Have significant financial commitments
- Be physically fit and behave in ways that other people find challenging
- Be more aware of their disease in the early stages
- Find it hard to accept and cope with losing skills at such a young age
- Find it difficult to access information, support and services for younger people with dementia
- Have a carer who is still in fulltime employment
- Often have the rarer types of dementia (such as frontal-temporal and Lewy body) which present with more challenging behaviours.

Progression of dementia

Researchers are now saying that the disease itself may be occurring in the brain up to 20 years before the first symptom might be noticed. The way in which a person will be affected by dementia varies. Individuals will not follow a set pattern of functional loss nor will dementia spread and progress at the same speed from person to person. In some instances, the deterioration will be slower than in others. Unfortunately, there is one certainty, the disease will progress, and the person will lose skills and abilities.

There are three (3) common stages of dementia:

- Early
- Moderate
- Advanced

Early dementia – This stage may be hard to identify, though when looking back, the stage appears clearer.

- At first, family and friends may notice quieter periods
- They may resist having to make decisions or make poor decisions
- They may appear to have lost their inner sparkle
- They may get forgetful
- They may have periods of irritability, especially if in a stressful situation
- They may avoid complex tasks and hobbies
- They may lose the thread of their conversation and go off on tangents
- They may "lose" things

Moderate dementia – The symptoms are more apparent in this stage.

- Their forgetfulness increases
- They may lose track of what day or time it is
- They could experience panic if they can't find their way around
- They could experience difficulty with names
- They may repeat things several times
- They may act in an un-social manner or be uninhibited in their actions
- They may wander aimlessly around the house, the garden or even around the streets

Advanced dementia – The person is affected severely by the disease.

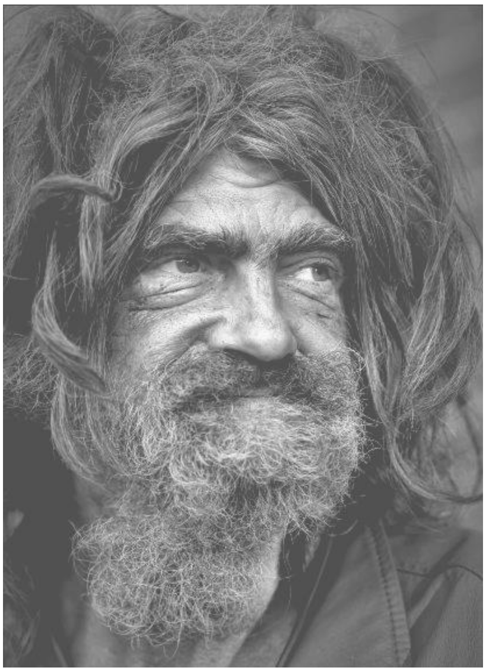
- Their short term memory may fail them completely. Things that occurred 5 minutes before may be forgotten
- They may not be able to communicate
- They may need to be supported to eat, shower and dress
- They may be incontinent
- They may not be able to walk independently
- They may no longer remember what common articles, such as a brush, are used for
- They may no longer recognise family members

Even in the advanced stage of dementia people may be reached emotionally through their sense of smell, touch and, at times, their hearing**.**

Social devaluation

According to "Choosing Values; The Consequences For People's Lives" (Kendrick and Hartnett, 2005) it is important to understand that what people say and do has the potential to hurt others. Even the slightest negative comment can wound a person just as much as a physical wound. Anything that lowers our social value can injure a person. Whether we think that a "loss of face" may not really matter is irrelevant to the pain it may cause.

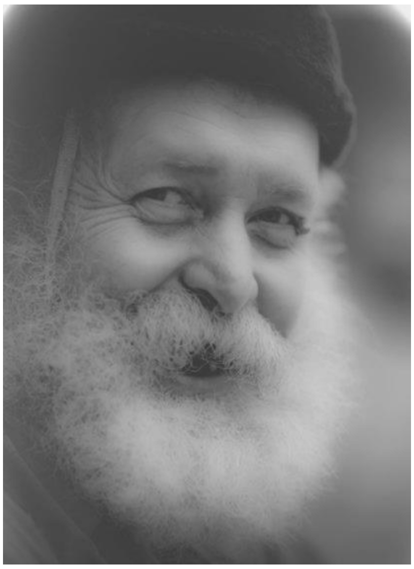
Another point to consider is that hurtful thoughts and words can quickly lead to hurtful deeds, especially once it becomes acceptable to treat others as "outsiders", "sub-human" or simply as "different".



Human beings are deeply attuned to being valued as persons. Prolonged instances of being devalued by others may leave scars on our life experiences. If someone sees a group of people devalue a person, they may automatically consider that person as a person of lower value, as someone to be looked down upon. It may also cause the person to consider themselves to be of less worth than others. Our fate, both psychological and social, will follow from the way we are perceived by others. Though some people are resilient and are able to rise above the often brutal misjudgements and mistreatments associated with being socially devalued, most are more vulnerable than they might care to admit.

Social devaluation is no trivial matter. It becomes clear that the social devaluation of people may lead to their rejection by their social circle, their communities, and may lead to becoming isolated. When we, as valued citizens, do not intervene the problem will continue to grow in strength and spread.

Professor Wolfensberger, the father of “Normalisation” and “Social Role Valorisation” argues that evaluation is an intrinsic (basic) part of each human being's perceptual processes. Humans are 'hardwired' to notice differences in each other and to evaluate these differences. Some differences are perceived as positive, others are perceived as negative. Usually, humans value those whom they perceive positively and devalue those whom they perceive negatively. The real risk of social devaluation arises when a majority in a culture perceives particular characteristics of a group as negative.



Professor Wolfensberger proposes that a method to counteract social devaluation is for individuals, or groups at risk of devaluation, be supported to achieve valued social roles. Wolfensberger argues that the social roles filled by a person will determine how a person will be perceived, valued and treated; in fact, they can be 'life defining'. Wolfensberger argues that holding valued social roles is so important because ‘the good things in life’ will then most likely be accorded to that person or group.

SRV in Aged Care

A socially valued role is when a person does something regularly that is important to other people. To be socially valued, the role must be perceived by others as being important. The most valued roles are those that society views as 'productive'.

In contrast, devalued roles are occupied by people with a 'handicap' or are too old for the workforce. These people are stigmatised because they are seen as different and unproductive.

As Shultz (2004) states, "The challenge comes when frailty or cognitive impairment means that older people are no longer able to be involved in those roles that society views as 'productive'. There is a need to support older people to have valued roles that involve 'being' as well as 'doing'".

There are 3 steps to help achieve value in 'being' as well as 'doing':

Step 1: Enhancing a person's image to address devaluation

One of the ways you can enhance a person's image in a positive manner is to make sure they are dressed appropriately. This means that when you take clients on outings they should "look" like everyone else. There shouldn't be anything about them or yourself that stands out and makes you noticeable in a negative manner. Clients should not be underdressed or overdressed for an occasion. If they are attending a casual event and the dress code is casual, then they should be dressed as such. If they are attending a formal occasion, then they should be dressed formally. The same positive image message is given by the way clients are groomed. Clients should be groomed in an age appropriate manner. Hair styles, lipstick and nail polish colours should be appropriate.

Step 2: Enabling the older person to experience increased social interactions.

The following real-life examples demonstrate how SRV principles can be applied in dementia care to increase socialisation and participation in valued social roles.

a. With the help of the local priest, it was organised for a lady with dementia to arrange the flowers for her church. This lady had maintained a valued role working in the church all her life, but due to dementia, she had lost this role. The fact that she was invited to arrange the flowers returned her to her past role of involvement with the church which gave her great satisfaction, especially when she was thanked for her work.
b. Another lady with dementia participates in a family day care centre. She enjoys the interaction with the children and they have accepted and feel comfortable with her. The centre has included intergenerational activities because of this lady's involvement. Initially she visited the centre with a member of (respite centre) staff, but has now become independent of this support and accomplishes her work on her own.
c. A man with dementia regularly enjoys a pool game at the local Italian club where he can socialise with people of his own culture.

Step 3: Provide opportunities for meaningful activities, with a focus on engagement and enjoyment, rather than achievement. (see Activities section)

Supporting People with Dementia

Person-centred Care

Person-centred care is another way you can address social devaluation.

Person-centred care is treatment and care provided by health services that places the person at the centre of their own care and considers the needs of the older person's cares. Person-centred practice is treating clients as they want to be treated.

It makes sense that:

- When you get to know the person well, you can provide care that is more specific to their needs and therefore provide better care.
- By promoting and facilitating greater personal responsibility, clients are more likely to engage in treatment decisions, feel supported to make behavioural changes and feel empowered to self-manage.

A recent literature review found that person-centred practice can make a positive difference to health outcomes and client satisfaction and can improve health care workers' sense of professional worth. The National Health and Hospitals Reform Commission recommended "people and family centred care' as the first principle for guiding the delivery of health care".

It describes this as health care that is:

- Responsive to individual differences, cultural diversity and preferences of the people receiving care.
- Easy to navigate.
- Provided in the most favourable environment.

We "are human beings, our patients or clients are human beings, and it is shared humanity that should be the basis of the relationship between us".

What are the principles of person-centred practice?

1. Getting to know the client as a person – You need to get to know the person beyond the diagnosis and build relationships with them.
2. Sharing of power and responsibility – Respecting preferences and treating clients as partners in setting goals, planning care and making decisions about care, treatment or outcomes.
3. Accessibility and flexibility – Meeting clients' individual needs by being sensitive to values, preference and expressed needs. It also focuses on giving the patient / client choice by giving timely, complete and accurate information in a manner they can understand so they can make choices about their care.
4. Co Cordination and integration – Working as a team to minimise duplication and provide each client with a key contact. Teamwork allows service providers, and systems working behind the scenes, to maximise client outcomes and provide positive experiences.
5. Environments – Physical and organisational or cultural environments are important, enabling you to be person-centred in the way you work.

What can I do to become more person-centred in my practice?

Culture change requires a long-term effort. It starts with analysing individual, team or organisational practices to identify areas requiring development. It is important for the team and organisation to identify and improve in areas that are uniquely important.

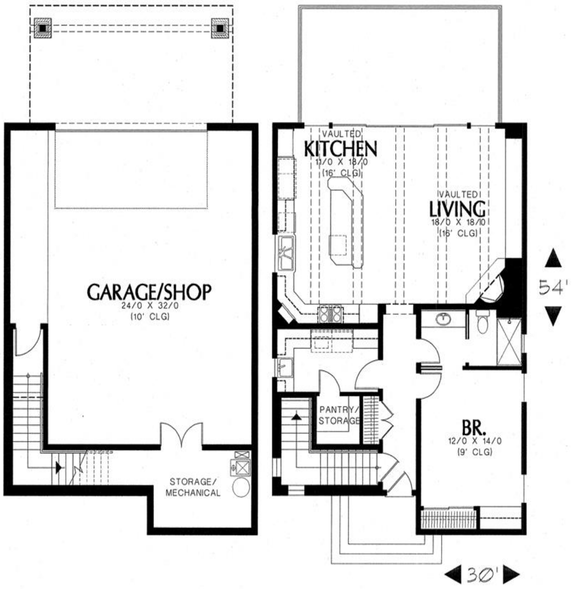
The health care decision-making process can be a positive example of promoting truly person-centred care.

For example, person-centred treatment decision making, and care planning helps ensure that people:

- Are able to express their wishes, including consent or refusal of treatment, even in advance, if they want to.
- Can participate in the decision-making process to the extent they wish to and are able to include whoever is important to them in this process.
- Can appoint a substitute decision maker if they wish to.
- Receive treatment that accords with their values, goals and beliefs.
- Do not receive unwanted treatment.
- Have their wishes for future treatment known across the health and broader community sectors.

Individualised plans for people with dementia

Just like house plans provide details to the various tradespeople involved in building a house, care plans provide different levels of information to the various roles of workers involved in meeting their care needs.



The purpose of an individualised plan is to capture information about a client, their needs, wants, routines and to assemble this information in a manner that doesn't breach confidentiality but still provides appropriate "chunks" of information to those that provide direct care.

Originally the information contained in a client's care plan was solely about their clinical care needs however, with the introduction of the person-centred care approach far more than a client's clinical care needs are now recorded.

The reason for capturing more information is so that you "learn" more about clients. As you learn more about clients you will see them as people, as individuals, coming from different backgrounds from different cultures and different occupations. They each have individual skills and abilities. Using the person-centred approach, you can support those residual or remaining abilities and "tap into" a range of abilities that are part of their long term memory. The most important item you need to support is a person's ability. To do this you need to know as much about them as possible. It is their social history that will provide you with an insight into the types of skills and abilities they had previously.

The following is "My Story", a tool designed to assist you to capture information regarding the social history of clients. The information can be gathered from the client, their family and their friends over a period of time. This information is then used in conjunction with the client's clinical assessment to form an individualised care plan to meet the client's needs.

As I was before

My Story – Daisy Test

As I am now

All About Me

My Full Name: *Daisy Patricia Test (Nee Wilson)*

However, I like to be called *Daisy*

My nickname *They used to call me "Carrot top" at school*

My date of birth *27th February 1930*

My place of birth *Logan, Brisbane, Queensland*

My date of arrival in Australia (*if born overseas)*

I have been an Australian citizen since *Since birth*

My religion *Catholic*

My place of worship *St Paul's Catholic Church, Logan*

My height *5' 2"* My eye colour *Blue*

They say I take after *My Grandmother Edith*

I grew up in (*where*) *On a dairy farm in Logan*

I lived with (*parents, siblings, others*)

My parents Mary and Albert Test and my brother John and sisters Tess and Judith. My other brother Edward was still born

I was the (first, second, etc) *1st* child in a family of *5* children.

Special childhood memories

Milking the cows, bringing them up from the paddock, going to John's school dances (used to have a dance before Christmas break), Christmas Dinner – Mum and I would cook and bake to prepare everything

Major events and upheavals

My brother John going to war – Men coming around to the farm asking for work and Mum giving them chores to do and then giving them some milk to drink

My School Days

My primary schools

It wasn't a real school, the priest at St Paul's Church taught the local children to read and write and about God. I only went to school for 2 years. Mum would sometimes make me practice my writing. She said it would come in handy

My favourite subjects

Learning about God

My favourite teachers

Father Mulchany would give pictures of the Virgin Mary to the best students at the end of the year

My best friends I had a friend at school,

her name was Margaret Brown but I didn't see her much after I left school, only at Church on Sundays

My secondary schools

I didn't go because girls didn't really need an education unless they wanted to be school teachers. If I got too much book learning my Dad said that no one would want to marry me.

My favourite subjects *N/A*

My favourite teachers *N/A*

My school achievements

I learnt to read and write – I learnt about the Virgin Mary and the saints

I received my tertiary education at *N/A*

Degrees/diplomas/courses *N/A*

Special memories

I loved being with the other children

My Working Life

My first job was with (*organisation*)

I only worked on our dairy farm

My age when I started work

When I finished school, I was 8 years old

My first weekly pay was

After I turned 15 *Dad gave me 2/6d a week*

I spent it on

Material for a dress that Mum helped me make

I worked there from *8 years of age to*

until I got married at 17

My position was

I suppose you could say general farm hand

My major jobs/appointments (*organisations, positions and dates*)

After I got married to George I worked on his farm, it was a market garden It was much harder work

The work that gave me the greatest pleasure/satisfaction was

Milking the cows, I loved resting my head on the cows side and hearing the milk hit the bucket

Memories of work friends and colleagues

I really didn't have anyone I worked with, sometimes George hired some men to help with the harvesting but I didn't really have much to do with them. George once hired a wife of one of the men helping in the field. She was to help me with meals and the children but it didn't work out so I didn't get to know her very well

My War Memories

Memories of the war years

My brother John went to war. He enlisted in the army. When he came back he wouldn't talk about the war. He was wounded in his left arm, I think it was from shrapnel but he wouldn't talk about it. I wasn't too bad on the farm, we had food. My husband George didn't go to war because he was growing food for the armed forces. There wasn't much fun at the time. I was worried about my brother John, my younger sister Tess enlisted as a nurse but she wasn't sent overseas. She was based at a hospital in Brisbane. There was some talk about her being sent on a hospital ship but in the end she didn't go

My military history / My spouse's military history

George didn't go to war because he was growing food for the armed forces

Medals/awards

My brother John was awarded a medal but he never spoke about it and he wouldn't show it to anyone

I will never forget

The day John came home. I went to Mum and Dad's farm to wait for his arrival. Someone was picking him up and bringing him there. When he got home he was skin and bones. He could barely move his left arm and he wouldn't look anyone in the face. Mum ran to him and gave him a big hug but he just stood there as stiff as a poker. I'll never forget that day.

On a Personal Note

My best friends

Margaret Brown, I met her at school and we used to play outside the Church while the grown-ups were talking. Later she was my bridesmaid.

The people who influenced me most

My Mum, she was always cheerful, she always had a smile for everyone, she said it didn't cost anything to smile so she could give lots of smiles away. Mum could make a dress out of scraps, and often did. She taught me to sew, how to mend clothes, especially socks. She taught me to cook and how to make food go as far as possible.

My special achievements

I made my own wedding dress and later on I used the material from my wedding dress to make a christening gown for my first grandchild. I made Sonia's wedding dress and the dresses of her 3 bridesmaids.

Hobbies and voluntary work

I didn't have much time for hobbies when I was young but later on my friend Margaret taught me how to embroider and how to make lace. During the war years I would cook and send food to the soldiers, especially to my brother John.

Travel and holidays

Once, after the war, George borrowed a caravan and with another family, took me camping to the South Coast, you might know it better as the Gold Coast. There wasn't much time for holidays when I was young and we didn't go far in those days. My sister Tess went to stay with friends all the way to Redcliffe. For my 60th birthday Margaret, my childhood friend, and I went on a cruise!! What excitement it was. We had a great time, so much food and fun. There was always something to do.

Special memories

Spending time with my daughter especially playing hide and go seek. The places she found to hide!! I remember sitting with George when he was very sick in hospital. He was only 55 years old, they said he had pancreatic cancer. I would go to the hospital each day and read to him, he loved keeping up with things so I would read the newspaper to him. Sometimes I would try to tempt him to eat with his favourite foods. I remember sitting with him when he died. He just seemed to close his eyes and then he was gone. It was just me and him in the room, it was very peaceful for George. I remember when my daughter Sonia got married. What a wedding.

My Favourite Things

My favourite music

I love songs by Bing Crosby and Frank Sinatra also the big bands like Glen Miller

My favourite songs

Bing Crosby singing White Christmas

My favourite books

I remember reading 'The Diary of Anne Frank', I cried when I read it

My favourite movie stars

Danny Kaye, Bette Davis and Gene Kelly

My favourite films

The secret life of Walter Mitty, All about Eve, An American in Paris

My favourite flowers

Roses, my Mum grew white roses near the front door

My favourite colours

Navy blue and canary yellow

My most prized possessions

My Mum's silver napkin rings, we only used them at Christmas when I was little and I used them at Christmas when I got married. She gave them to me as a wedding gift. I think they were her mother's

My favourite sports

I *was never fussed about sport*

My favourite sporting teams

I didn't have any

My favourite sporting personality

I didn't have any

What Makes Me Me!

What I feel strongly about

Children, they're such a blessing, I wish I had more but George and I were only blessed with one.

My faith, I love going to church.

My pet likes

I like spending time watching people, I did a lot on the cruise

My pet dislikes

People who yell and hit children

My heroes

My Mum, she could do anything

My philosophy of life

The Golden Rule, do unto others as you would have them do unto you

How I would like to be remembered

As a good mother, a good wife and a good cook

Our Wedding

My spouse was born on

3rd March 1925 at *Logan*

How we met

We met at a Church function, George went to a different Catholic Church.

We became engaged on (*date*)

4th November 1946 at *Mum and Dad's*

How we celebrated

It was a very quiet engagement. John was just back from the war and Tess was still nursing the sick and injured soldiers in Brisbane. There was only Judith still at home with us. We had a quiet family dinner at Mum and Dad's. George's parents came. Father Mulchany came to bless the engagement ring.

We were married at (*where*)

St Paul's on (*date*) *22/2/1947* By *Father Mulchany, my old teacher*

Our reception was held at

The Church Hall which had been decorated and catered by Mum's Ladies Guild. Mum and George's Mum did a lot of the cooking.

Our attendants/witnesses were

Best Man, Mark, George's old school friend Maid of Honour, Tess, my sister Groomsman, John, my brother and Bridesmaid, Margaret, my old friend.

Memories of our wedding

Something funny happened at our wedding when it came time for George to put the wedding ring on my finger. It was a very hot February and my fingers were swollen with the heat. The wedding ring wouldn't slip on and I had to help him with it. People in the congregation started to laugh.

Where we honeymooned

War had just ended and there wasn't a lot of money for honeymoons in those days. We spent our first night together in our new home that George had built on his father's market garden property.

My Marriage and Children

My spouse grew up in	*Logan*
Their occupation	*Market Gardener*
Their work history	*Market Gardener*

Our children (*in order of age, including dates of birth*)

We only have one child, our daughter Sonia. She was born 29th November 1949. I named her after the famous film star Sonja Henie, though I spelled my daughter's name differently.

Our close friends were

Margaret, my old school friend and Mark, George's old school friend.

Our first home together was

A home that George had built on his father's market garden property.

We lived there for (*number of years*)

Since I was married and until I moved into care.

Our favourite neighbours were

Our neighbours were George's parents who lived on the same property. Even when they were too old to work the property they still lived there and I helped them when they couldn't manage cooking and cleaning.

We spent our weekends doing

Most of the time we worked on weekends but we always made time to go to church. Church met our social needs as well as the spiritual ones. Sometimes we would take Sonia to the local swimming hole for a quick dip.

Subsequent homes

The market garden home was the only married home that I've had.

We shared our life together for (*number of years*)

33 short years.

Care Plan Report for Daisy Test

Resident Details

Our staff support residents to reach their full potential each day by embracing their strengths, fostering independence, respecting choices, supporting decision-making, ensuring privacy and always promoting the dignity of each individual.

First name	Daisy
Surname	Test
Preferred name	Daisy
Admitted location	Care lodge bed 007
ACF ID	123456
DOB	27/2/1930
Admission date	6/1/2014
Medicare no	987456321
Pension no	123-456-789
Diabetic Assoc no	99988876
Next of kin	Sonia Murphy (nee Test)
Home ph	9988 7766
Mobile	0123 456 789
Medical practitioner	Dr Jekyll
Dr’s work ph	07 7778 4445

Allergies	
Drug allergies	Penicillin (skin rash)
Risks/Safety Issues	
Details of clinical needs and risks (e.g., oxygen use) Including infection risks, cytotoxic use and PPE	None
I can be sat in the regency chair when I am very unsteady on my feet. I am a high risk for sliding out of the chair so need to be monitored closely when in the chair.	
Participating in activities	I like spiritual activities
Altered behaviour patterns	Yes
Continence problems	Yes
Insight into own safety	Yes
Medications that may affect safety	Yes
Impaired mobility	Yes
Nutritional problems	Yes
Behaviour puts safety of others at risk	Yes
Restraints used for risk activities	Yes
Sensory deficits	Yes

Religion / Culture	
Nationality	Australian
Religion / Belief	Catholic
Religious needs	I would like a visit from the catholic pastoral team
Languages spoken	English

Relevant Medical History	
Diabetes	Yes
Dementia	Yes

Other Medical Diagnosis

hypertension, depression, Type 2 diabetic-insulin dependent

Vital information

11/8/14 Daily massage to lower back and legs. Please do massage after lunch and record on pain assessment that massage given. Care plan updated to show massage to legs and lower back after lunch. Daily massage was on care plan but is not being signed for. Thanks, Amos Keeto, RN

Please ensure that Daisy is not sitting in regency chair for extended periods of time and regency chair only used when required.

AROMATHERAPY HAND MASSAGE-TUESDAY & FRIDAY AM

Care Plan Report for Daisy Test

Summary of Preferences / Needs

Relevant Social History / Needs	
Eating Assistance	
Requires prompting to eat food	Yes
Requires prompting to drink fluids	Yes
Requires assistance to cut up food occasionally	Yes
Own teeth or dentures	
Upper denture	Yes
Lower denture	Yes
Social History	
Please read "My Story" for a full understanding of what makes me "Me"	

Diet Type	
Diabetic	Yes
Type of Diabetes	Type 2
Diabetes monitoring requirements	Take BSL as per Dr's instructions
Diet	
Drink	I dislike bubbly drinks
Protein	I love chicken, fish, lamb and beef
Vegetables	I dislike broccoli
Dessert	I prefer soft
Soup	I prefer smooth pureed
Snacks	I prefer stewed fruit no sugar

Hygiene / Grooming Assistance	
Showering	Supervise, prompt
Washing face	Supervise, prompt
Washing body	Supervise, prompt
Washing extremities	Supervise, prompt
Drying face	Supervise, prompt
Drying body	Supervise, prompt
Cleaning dentures	Assist
Washing hair	Assist - I like Dove shampoo no conditioner
Makeup	Lipstick only
I like showering in the morning. I like to shampoo my hair once a week. I like to use a soft flannel and soft towel as my skin tears easily. I like the taste of a minty toothpaste. I like to sit on a shower chair	
Toileting Assistance	
Clothing adjustment before toileting	Verbal and physical prompt
Position on the toilet	Guide as needed
Getting off toilet	Assist if unstable on feet
Clothing adjustment after toileting	Verbal and physical prompt
Washing hands	Verbal and physical prompt
Urinary Aids	
Morning aids	TENA pants plus medium
Afternoon aids	TENA pants plus medium
Night time aids	TENA pants plus super medium

Care Plan Report for Daisy Test

Communication / Hearing

Goals of Care
Effective communication will be achieved at all times. Hearing ability will be optimised with staff interventions

Relevant Assessment Details Related To	
Speech difficulties	I find it difficult to express my needs verbally, please look for non-verbal cues, especially relating to pain
Cognitive deficit or speech disorder affecting comprehension or speech	I can understand you if you simplify your speech and give me time to process what you say. Please see above also
Speech / Comprehension Difficulties	
Receptive Aphasia	Yes
Confused	Yes
Slurred words	No
Single words	Yes
Clearly spoken words	At times
Hearing	
I can hear well if you show patience, gain my attention by calling my name, gaining eye contact and using gentle touch on my hand	
Memory – recent / past events	
I have short term memory loss so I may forget what happened or what you said 5 minutes ago but I might still be able to tell you what my Mum said to me years ago. Sometimes I forget that George has passed away or other things that happened in my past. Most times I still remember lots about my past. Please read "My Story" so you can prompt my memory with reminiscences. My photo albums will help you validate me as a valued person	

Interventions	
Call bell	I am not always able to use the call bell as sometimes I can't find it, so please check on me hourly to see if I need anything
Emergency response alarm	No
Interpreter	Not required
Communication Aids	
Glasses	Yes
Picture board	Yes
General Communication Strategies	
Please me show patience, gain my attention, speak slowly and clearly, 1 idea at a time, give me time to process what you say, when I get words mixed up, please look for what I mean in my tone and non-verbal cues. If I still can't understand you, please use physical prompts	

Care Plan Report for Daisy Test

Mobility and Dexterity

Goals of Care
To transfer and walk safely To maintain my abilities to move as independently as possible To increase and maintain my flexibility in my joints and muscles as much as possible To minimise the risk of my falling

Details from Functional Assessment	
Walking	I am able to use my Wheelie Walker but at times I forget that I need one
Getting up from chairs	If my Wheelie Walker is immediately in front of me, I will try to get up by myself. It's better that my Wheelie Walker is put aside, and you assist me to get up
Getting on and off the toilet	I sometimes need help getting on and off the toilet
Standing and transfer	I can stand and transfer myself, but I may need prompting and supervision for my safety. My abilities may vary so sometimes I need assistance from 1 person
Cooperation	Please remember to use communication strategies when you need my cooperation

Interventions	
Seating preferences Chair type	Standard armchair 
Walking	High falls risk, prompt to use Wheelie Walker. Supervise and assist as required 
Hip protection	I wear hip protection unless I'm in the shower

Care Plan Report for Daisy Test

Behaviour and Safety Issues

Goals of Care	Behaviours	Intervention Strategies
• To maintain Daisy's safety • To maintain the safety of others in the immediate area • To establish interventions to reduce Daisy's anxiety levels • To establish interventions to reduce the incidence of Daisy's agitated periods • To establish interventions to minimise the incidence of behaviours affecting other residents	I sometimes become agitated	Mid-afternoon take Daisy for short walks and when you bring her back to her room reinforce how good it is to be finally home
	I sometimes yell out and make loud noises	
	I sometimes grab other residents	
	I sometimes walk into the wrong room and accuse other residents of being in my room	Place a distinctive picture from Daisy's past on her door and reinforce to her that this is her room at every opportunity
	I sometimes at mealtimes I take food off other residents' plates	Sit with Daisy and, using "My Story", reminisce with her about her past experiences
	I become distressed when people don't understand me	Sit with Daisy and interest her in her photo album to validate her life experiences. Once she is absorbed in the activity of turning the pages, she may be content to sit on her own
	I become anxious when it's getting late, and I can't find my way home	Sing old-fashioned hymns or play them on CDs to encourage Daisy to relax while sitting
		Use the communication tips to gain Daisy's cooperation
		When seating Daisy in the armchair ensure other residents are not within reach
		When setting Daisy's place at the dining table ensure a single and contrasting colour placemat demarcates her area

Creating a stable and familiar environment

People with dementia may retain sections of their memory and will still be able to successfully complete functions and tasks as long as they are appropriately supported. The key to a client gaining a sense of satisfaction and increasing their self-esteem is being able to "do for themselves" rather than have someone "do for them".

One of the methods you can use to support a person with dementia to "do for themselves" is to make sure that their physical environment - everything that surrounds them, the furniture, the decor such as the colours of the walls, the lighting, the layout of the room, the bathroom – all of these clearly re-enforce the purpose of the items within that area and therefore the person's behaviour within that area.

If you look at *figure 1* below you will see a normal toilet as part of an everyday bathroom. If clients have a sensory loss (poor vision) as well as dementia, they might have difficulty seeing the toilet and recognising it as a toilet. A person with dementia entering the bathroom in *figure 1* may not be able to recognise the toilet and may become agitated. If they are not supported, they could have a continence accident leading to feeling of embarrassment and poor self-esteem.

figure 1

figure 2

In *figure 2* the toilet is far more recognisable as the toilet seat is a different colour and the toilet lid has been left open in a universally recognisable symbol for a toilet. The same client with sensory loss (poor vision) and dementia would find this toilet far easier to recognise and would therefore require less assistance and support. They would be more independent which would boost their self-esteem.

You play a very important role in supporting a client's independence and in maintaining and increasing a person's self-esteem. One of the ways you can do this is to support the client's "lost" functions and abilities. It is essential that you read the client's individualised care plan to see what level of care and support they need. If you provide additional assistance and support to a client, you could be "robbing" that client of the feeling of satisfaction of being able to do things for themselves. If you continue to provide more than necessary assistance and support over a period of time the client will learn to wait until the task is done for them. This is termed as learned helplessness. The client will develop a dependence on the support workers to "do" things for them.

Let me provide this example:

Mrs Mavis Mitchell is able to make her own bed up in the morning. She takes a long time making her bed. A caring support worker, Vicky, sees Mrs Mitchell slowly making her bed and asks if she can help. Mrs Mitchell smiles and accepts Vicky's help. Vicky, being younger and able bodied, makes the bed much quicker than Mrs Mitchell. The bed is perfectly made. Mrs Mitchell comments on how Vicky makes bed-making seem so effortless and thanks Vicky for helping.

The next morning Vicky sees Mrs Mitchell going down to breakfast and stops to ask Mrs Mitchell if she can make her bed for her while she is at breakfast. Mrs Mitchell smiles and agrees. Vicky continues to make Mrs Mitchell's bed each morning she is rostered on. Eventually Mrs Mitchell stops attempting to make her bed and waits for Vicky or someone else to make it for her.

In this example Vicky has, without meaning to, "robbed" Mrs Mitchell of the opportunity to maintain a residual skill of bed-making. She has "taught" Mrs Mitchell to rely on support workers even more than necessary. This may not seem important as you might think that having someone make our bed would be a very welcome treat. We need to think from Mrs Mitchell's point of view.

Without meaning to, Vicky has shown Mrs Mitchell that she can't do things as well as her. Bed-making is another skill Mrs Mitchell has lost. What started off as being kind and well intentioned has turned out to be "harmful" to Mrs Mitchell's self-esteem. At first Mrs Mitchell could "do bed-making for herself", then she had Vicky "do bed-making for her". The saddest outcome will be that eventually Vicky will probably come into Mrs Mitchell room while she is still in bed and will ask Mrs Mitchell if she wouldn't mind hopping out of bed so that it can be made. At this stage what has now occurred is that "bed-making is being done to her".

When clients enter a residential aged care facility, they are often anxious and fearful. When those clients have dementia, these feelings are very often heightened. What will help them to settle in quickly and easily is the harmonious atmosphere workers can create. To create this harmonious atmosphere, workers should leave their personal problems at the door when they come on duty.

This is the way that workers should think about where they work:

> *Our clients do not live in our workplace*
> *We work in their home*

As with all workplaces with a large number of workers, not all workers get along with each other. When working in aged care it isn't necessary that you "like" each other personally, but it is essential that you respect each other's positions within the organisation. All interactions about and between workers should be respectful. Any other type of interactions will be noticed or felt by clients.

It's good practice for you to be welcoming to family members. By being as friendly and welcoming as possible, you're encouraging families and friends to visit. Having families visit will have a positive impact on the person with dementia and will help them to feel safe and secure in their new environment.

Appropriate Communication Strategies

Communication strategies

People with dementia will experience losses associated with the illness. Eventually they may lose their ability to communicate. Any loss of communication skills will impact on a person's ability to make their needs known. People with dementia are already feeling vulnerable therefore any deterioration of their communication skills will have a profound effect on them.

People with dementia may become apprehensive that their needs will not be met and frustrated at their inability to do anything about it.

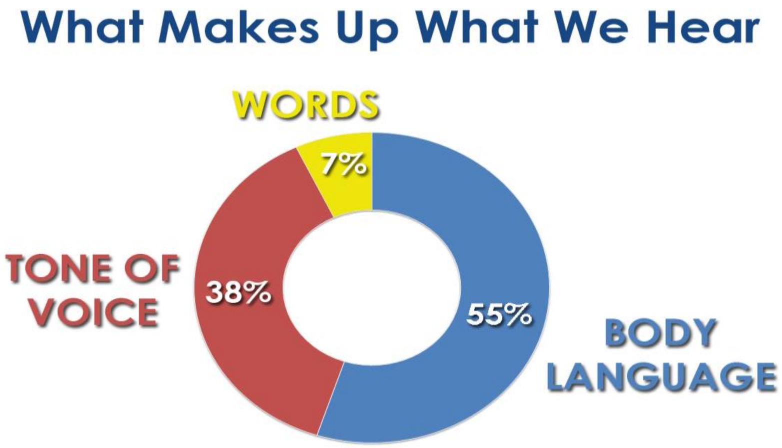
It's dependent upon you to develop effective and respectful communication strategies and to develop your ability at reading body language and non-verbal communication.

What is so very sad is that it's estimated that in residential aged care over 75% of interactions between workers and clients were concerned with specific care tasks and took place mainly in silence. It was further noted that where there was verbal input by staff it was mostly considered as "care-speak" and that workers seemed to avoid rather than encourage communication.

Imagine this:

> *You are in a very deep sleep, someone starts to shake you awake, you think you hear your name. You rub your eyes and look around, but you can only see someone walking away.*
>
> *You doze off again only to be woken up by someone calling your name and shaking you awake. You are not sure who they are, though you think they look familiar.*
>
> *They are talking to you, but you can't seem to follow what they are saying as they are talking too quickly for you to understand.*
>
> *They pull the covers off your bed and help you get up. They seem to expect that you follow them into the bathroom.*

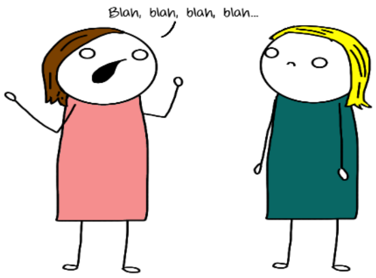
Unfortunately, this is a common experience for people with dementia living in residential aged care. They are not able to cope with the many faces that attend to their needs and therefore they feel surrounded by strangers telling them what to do and when to do it. The situation is made worse when workers are focused on providing the care rather than the people who require the care.



So much can be conveyed with a smile. When communicating with people with dementia, non-verbal communication can be much more powerful than verbal communication. It's essential that you match what you are saying with the non-verbal signals you're sending. If you don't match what you are saying with the non-verbal signals you're sending, you will increase the confusion of the person with dementia.

Communication tips:

- Always approach the person with dementia from the front
- Approach with a smile
- When possible, make sure they can see your hands are open and empty
- Approach slowly and calmly
- Identify yourself and anyone with you
- Where possible use gestures or visual prompts such as a bar of soap and a towel to communicate its shower time
- Speak slowly and clearly
- Watch your tone as tone conveys your attitude
- Speak respectfully
- Use gentle and appropriate touch
- Use simple words, but always at an adult level
- One idea at a time
- Give them time to process what you have said
- Ask simple, not complex, questions
- When seeking information ask open questions
- When confirming information ask closed questions
- Provide choice, but don't overload them with too many
- Don't correct
- Don't criticise
- Don't argue
- Be consistent



Reality Orientation

Reality orientation is the process by which you can orient the person with dementia to where they are currently, the time and the stage they are in life. Reality orientation is more successful in the early stages of dementia.

Reality orientation is about presenting information about time, place or about the client in order to help them understand their surroundings and situation. It can be implemented using easy to read clocks and calendars or a combination of calendar clock to remind clients that today is Monday 2nd March and it's ten minutes past 10.

Another way you can use reality orientation is in simple conversational terms such as:

- "I really enjoyed lunch"
- "you seemed to enjoy your lunch Peter"
- "I feel very full after lunch"

In this way you are letting clients know that they've finished lunch and its afternoon. Rather than formally remind clients that it's March you could say:

- "it's such a hot day for March"
- "it's autumn but it's very hot today"

Before using reality orientation, you should first consider if there will be benefits to the client to orient them to the here and now. In the early stages, when the person with dementia is living at home, reality orientation could be used to assist them to know when they have appointments etc by using a large calendar with appointments written on the appropriate day. For this to be successful, days that have passed need to be crossed off.

MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
		1st ✗	2nd ✗	3rd ✗	4th ✗	5th
6th	7th	8th	9th	10th	11th	12th
13th	14th	15th 2.30 Doctor appt	16th	17th	18th 10am Hairdresser	19th

20th	21st	22nd	23rd	24th	25th	26th
27th	28th	29th	30th	31st		

There are times that reality orientation should be avoided. An example of when NOT to use reality orientation would be if a person with dementia is asking for her husband and you know that her husband died several years ago. It would be much more kind to divert her attention rather than use reality orientation. Another example of when NOT to use reality orientation is when a person with dementia has a fixed belief. Using reality orientation in this instance would only distress the client and could cause a behaviour of concern. If a client has a fixed idea or belief and you attempt to use reality orientation, they will probably think you are arguing with them.

Empathy and acceptance of a person’s reality

Put yourself in their shoes. Imagine, for a moment, that you are getting dressed for work. You've worked in the same office for thirty-five years, and today is like any other weekday. Perhaps you're having trouble tying your tie, which makes you wonder whether your daughter is home because she's great at fixing your tie. You call out her name. She comes into the room and asks where you're going. You tell her you've got 10 minutes to catch the train, or you'll be late for work. Your daughter tells you that there is no train and you've been retired for 10 years. She tells you that you have no job, but you do have dementia.

Reality orientation seems very harsh in this situation even though it might have been said gently, maybe it might have been said with a wistful smile from the daughter. Even though a person with dementia may forget this incident the emotion attached to the incident will stay with them. When working with people with dementia you should always remember that human kindness goes a long way.

Redirection

Redirection is when we divert a person from a stressful or upsetting situation and help them focus on a more positive or pleasant situation.

Here’s an example:

> Mavis Mitchell is very agitated, she says to Vicky, a caring support worker, “I have to get home before dark. Mum and Dad get very angry if I get home late. I haven’t done my homework and I won’t get any dessert”.
>
> Vicky replies, “Oh Mavis, we can’t have you going without dessert. Come with me, I believe there’s some books in the lounge room, I’ll help you pack them up”. Vicky takes Mrs Mitchel into the lounge room talking about favourite desserts as they are walking. When they get to the lounge room Vicky

suggests “I think a cup of tea to go nicely with that slice of chocolate cake we were talking about, would you like to help me get it?”

After Vicky and Mrs Mitchell get the cuppa and cake, Vicky picks up a copy of the local newspaper and they start to discuss how expensive things are. Vicky has successfully redirected Mrs Mitchell from a distressing situation and brought her to a comfortable situation.

Going home before dark is a deep-seated urge. It starts when we are children and is reinforced when most of us start work and/or get married and need to get home for the children, get tea ready, catch the last train or bus home, water the vegetable garden or stop off the local pub for a quick beer before 6 o’clock closing. Any or all of these points reinforces the need to get home before dark.

When redirecting a person with dementia you must always remember that body language sends a stronger message than the words you use. Equally important are the tone of your voice and the speed at which you speak. You need to establish a connection with the person with dementia, to accept their reality, to enter their reality to redirect them successfully.

Redirection techniques can work wonders when other communication techniques are not helpful. If someone with dementia is upset or preoccupied, try introducing a new activity that you know they enjoy, such as listening to music or looking at a photo album. One of the benefits of looking through photo albums is that you are able to reinforce their identity as mother, father, husband, wife or sister and you are also able to remind them of their relationship with others.

Validation and acknowledgment

Validation therapy, first conceived of by Naomi Feil, runs the fine line between reality orientation and simply allowing a person with dementia to believe what he or she wants. Validation therapy often uses redirection techniques, but it is not solely about moving the person's attention from one thing to another. Validation is about acknowledging and validating a person's feelings and emotions.

When using validation, you should consider the emotion the person with dementia is demonstrating, not just what they are saying or doing. What the person with dementia may be saying may not make sense, they may not even be using words but are 'mumbling sounds'. If they are distressed or agitated the worker should address the emotion. Saying "I can see you are upset", "I think I would be upset in that situation" is validating the emotion the person is demonstrating. The focus is on the emotion rather than on the facts or accuracy of what the person with dementia is saying.

Here's an example:

Mr Henry Kidman is a resident in an aged care facility. It's late in the afternoon and Henry approaches Vicky, a caring support worker, and asks, in an agitated tone, if she can show him how to get out as he needs to go home to his wife. He says it's getting late, and he doesn't want her worried.

Vicky knows that Henry's wife died 5 years ago. Rather than use realty orientation, which might be extremely distressing for Henry, Vicky uses validation and redirection. "I can see that getting home is very important to you Mr Kidman, let's try this way" says Vicky as she guides him through the facility, walking slowly and talking as they walk. "You are such a good husband, I can see that you love your wife very much, you both love gardening, don't you".

As Vicky and Mr Kidman are walking, Vicky guides the conversation to flowers, herbs and vegetable growing. "Let's have a look at how those seedlings you planted last week are coming along" says Vicky as she stops with Mr Kidman in the garden area. "They look a bit dry Mr Kidman; I'll get the hose and we can water the garden before going in for tea".

By using validation of Henry's emotions as a tool to bond with him, Vicky is able to redirect Henry to another door and into the garden. Along the way she has redirected the conversation to an enjoyable topic. She then redirects Henry to a relaxing activity that validates his love of gardening and reinforces his identity as a gardener.

Reassurance and allowing expressions of distress

When validating or redirecting it is important that you use a reassuring, but not condescending, tone. Always remember that the people in your care may have dementia but they never stop being adults. They should never be addressed or spoken down to as children. Using simplistic language doesn't mean baby talk. It's also important that you don't use empty phrases when trying to reassure. "Don't you worry, everything is okay" is not reassuring to someone who is distressed about getting home.

People with dementia are able to be reassured verbally and physically. The type of reassurance used should be based on what we know about the person. Do they like to be touched? Do they like someone sitting close to them? When using physical reassurance, we must always consider what the person might deem as appropriate. For some people holding their hand might seem too intimate whereas placing your hand on theirs and using a soft rubbing or patting motion may be acceptable. Others might respond well to a hug.

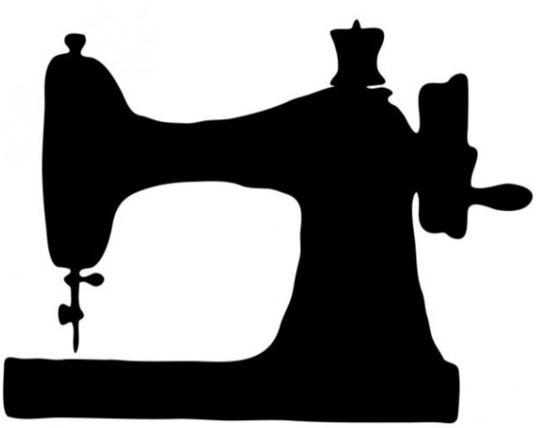
There will be times when a person with dementia may re-experience a sad emotion from the past, perhaps without remembering the situation that caused the sadness. It could be possible that smelling someone's perfume or hearing an old forgotten song could trigger an emotional response such as crying. The person with dementia may not know why they feel sad, only that they are crying. Sitting for a while with them and allowing them to express their feelings for a short while may be therapeutic. You can acknowledge their emotion using validation techniques and then redirect them to another activity.

Activities

Activities to maintain independence

Activities have many purposes for people with dementia. For some, being busy around the house is helping to meet their needs, to maintain their identity, their sense of belonging and self-worth.

We must consider that leisure time may not be a concept that a person from an earlier generation is overly familiar with. Quite often leisure or social activities were linked to achievement. Sewing bees and cooking bees to provide for a bride-to-be would also be a social event. It would provide the women in the community the opportunity to come together and showcase their skills.



Betty could show her skills at embroidery, Daphne might prepare her famous fruitcake. Mildred might supply the flour and eggs while the dried fruit might be prepared and supplied by Marjorie. The men might get together for a working bee to fix the roof on the school. While working on the roof and when they have a break, they are socialising.

Some of these habits are carried through into retirement. Some of the people in care facilities are not used to just sitting for long periods of time. Providing activities which tap into old or residual skills is a way in which positive structure can be reintroduced into their lives. Activities can give them a sense of purpose and a feeling of still being able to contribute in a way that strengthens their feeling of self-value and self-esteem.

Activities include activities of daily living (ADL's) as well as special activities. A simple activity such as shaving could be a pleasurable experience if you reminisced with the client at the same time. It is important that a person's functional abilities are assessed so that you can involve them in the activity as much as possible. However, keep in mind that it's about engagement, not about the outcome or achievements.

Some features of successful activities are:

- To fulfil a person's need to feel needed and of value
- To have a clear purpose and not just to fill in time
- Aimed at adults and are not child-like
- To use their old, residual skills and abilities
- Based on their likes and interests
- Promote their old routines to build self-confidence
- Promote socialisation to support them to build friendships
- Provide a physical outlet to promote mobility, reduce the risk of falls and minimise sleep disturbances

Some socially valued activities could be:

- singing – if they aren't able to manage singing, they may like to listen to their favourite music
- dancing – if they are no longer able to dance, they may be able to manage chair exercises to music

- craft activities – though this could be a group activity, each person should have the activity adapted to their ability
- getting dressed – some may need full assistance but might still be able to choose what they would prefer to wear
- cooking – remember, it’s important to adapt the activity to a person’s ability and skill level
- quizzes – additional prompts may be needed such as sounding out part of the answer

- crossword puzzles – this may not be suitable for people who have lost the ability to remember names of things
- studying photo albums and life books – this will reinforce a person’s identity and remind them of import aspects of their life
- watching favourite videos – could bring pleasure and induce laughter
- tidying up – this might seem like a chore to us but could provide a person with dementia a worthwhile and satisfying activity
- bus trips – a welcome break from the same old routine
- folding washing – as with the tidying up
- polishing shoes – as with the tidying up
- gardening – this may need to be adapted to what they are physically as well as cognitively able to do – if they can’t garden, they could look through seed catalogues or watch gardening shows
- balling up wool – this could be a pleasurable activity for someone who liked to knit but now finds the activity frustrating
- sorting buttons – could be used to retain abilities to sort using colour or type
- sorting nuts and bolts – as for sorting buttons only aimed at men
- setting the table – they may be able to assist with the tablecloth
- set up a ‘Men’s Shed’ – where a man might potter
- set up a small desk area – with adding machine, paper, pens, telephone books
- armchair travel – using maps and pictures to jog past memories of travel

The list is endless.

When setting up an activity for a person with dementia there are some things, we need to take into account such as:

- Try to find a distraction free environment as this will aid their concentration and enhance limited attention span
- Decrease visual distractions, don't have too many items in front of them
- Reduce background noise to aid their concentration
- Try to have comfortable seating so they won't feel prompted to get up and leave
- Adjust the activity to their abilities – if you make an activity too hard, they could feel inadequate, if you make it too easy the activity may not hold appeal for them
- Use colours and textures for contrast
- Identify the times of day that the person's attention span is best – it is thought that an activity aimed at using cognitive abilities (thinking skills) are best in the morning whilst physical activities are best in the afternoon
- Doing the tasks at a particular time each day, within a set routine, will benefit you as well as the person with dementia

Reminiscence

While reminiscing is considered a communication technique, using reminiscence is an activity.

With dementia, memories seem to be lost in reverse order. Memories formed recently are more fleeting than those from many years ago. Alzheimer's disease starts in the hypothalamus, the region of the brain responsible for putting experiences into memory. When the hypothalamus is damaged, recent experiences never have a chance to become memories. Not until much later in the disease's progression does it affect the regions in the brain in which older memories are stored, and so those memories are available even into later stages of the disease. This phenomenon is responsible for much of the behaviour and the symptoms commonly associated with Alzheimer's disease. You need to consider its effects when communicating with and selecting activities for people affected by the disease.

As care providers you need to learn new communication skills; otherwise, your attempts at conversation might be the cause of frustration rather than comfort. Steer clear of talking about recent events, those things that rely on short-term memory.

A person with Alzheimer's disease, for example, might have a detailed and lucid conversation about something that happened after the war (World War II or the Korean War) than what he or she had for breakfast, or experienced at the theatre the night before.

A person with dementia may feel that their long term memories are more real to them than the present. They may find spending time dwelling on their past experiences to be more pleasurable and more calming than dealing with the insecurity of the present. When you reminisce, you are tapping into a person's long term memory, helping them to recapture and re-experience their past.

Reminiscence can be a group activity, or it can be a one-on-one activity. There are many reminiscence products available however, you can use many inexpensive items to introduce a reminiscence activity. A newspaper is something that is readily at hand as well as being inexpensive.

Imagine this:

> Vicky, a caring support worker, is sitting with a small group of people with dementia. She has a newspaper in front of her and she is reading out the food "specials" at the local supermarket.
>
> "My goodness" says Vicky, "apples are selling for $6.95 a kilo!"
>
> "Were apples that dear, Mavis, when you were just married?"

Vicky has just started a reminiscence session. The same outcome can be achieved talking about cars or house prices. Topics are only limited by your knowledge of the client's background.

A variation of the previous example:

> Vicky, a caring support worker, is sitting with a small group of people with dementia. She has a newspaper in front of her and she is reading out the food "specials" at the local supermarket.
>
> "My goodness" says Vicky, "apples are selling for $6.95 a kilo!"
>
> "Henry, you were a farmer, did you grow your own fruit?"

When providing a one-on-one reminiscence activity, photos are a great resource. Sitting with a person and browsing a photo album can be a gratifying experience. Even if the person with dementia doesn't remember the story behind the photo, a worker can always improvise and start a conversation with "it looks like it was a hot day in this photo" or "doesn't the bride look happy".

Another tool to use to create a reminiscence session is music from their era. Music is able to trigger memories, though at times only the emotion linked to a memory. A person doesn't need to remember that this song was played at their wedding, it's enough to have this song make them feel happy. The more familiar the music, the stronger the emotional response.

Safety versus risk

Risk taking is a right that everyone has. We take risks every day, in fact we take risks several times a day. When we travel to and from work, we take a risk, the train could de-rail, the bus you are riding in or the car you are driving could be involved in an accident, when walking you could be bowled over by a child on a skateboard. Equally, every time we eat or drink something we are taking a risk with food poisoning or something similar. The point is that we understand that these things could happen and so we take as many precautions as we can to minimise the risk to an acceptable level.

People with dementia have the same rights as we do. You need to use the same principles to minimise the risk to the person with dementia without trying to make life so safe that it seems like a prison. The question you need to ask is – how can I provide valued activities while balancing benefits against risk taking?

It’s a natural reaction to want to keep the person you are caring for safe – and this sometimes means that your actions contribute towards people losing their skills and becoming really dependent. Try to help people to retain their skills and independence for as long as possible, and don’t try to stop them from doing something they want to do, because you don’t feel it's safe. If the person you are caring for is restless and wandering, then joining a walking group might be most beneficial for them.

“Each day brings its own catalogue of risks, some minor and some dangerous. But over time and with forgetting, there is the risk of being put on the sidelines, of being seen as a hindrance, and having control taken away from you, under the guise of it being for your own good. So, while we can, we must challenge the risks… People living with a dementia must be allowed to take risks, because if we don’t, we are in danger of relaxing into the disease. At times we feel hopeless. At times the hurt we feel is indescribable and we can let it be a barrier to life. But there is a life for us, if we risk it.”   (Personal account of living with dementia, Morgan, 2009, 28)

When trying to decide on the benefit balance of the risk involved, we need to first look at the activity and see if there’s a way of making the activity safer. Perhaps there’s a way of bringing the level of risk down to an acceptable level.

An example:

Mr Brian Cotton loved playing golf. He once played at St Andrew's Golf Club in Scotland. He was so good at golf he could have been a professional golf player. Once he developed dementia his ability to play golf suffered but he still loved to play golf.

Mr Cotton's sons were very keen to keep him playing as it brought much pleasure into his life and it also kept him fit and mobile. One day when his oldest son, Richard, took him for a game of golf things didn't go too well. On the third hole Brian hit the ball into a sand bunker. This upset him and he became flustered.

Richard suggested that perhaps they should just 'play on' and disregard the golf ball in the sand bunker. Brian became angry saying he would never cheat.

Brian tried to find the correct club to use in the sand but became more flustered. When Richard made a suggestion regarding the correct club to use Brian totally 'lost it'. He started throwing golf clubs and golf balls at Richard and things got very dangerous for Richard, Brian and other golfers in the near vicinity.

Once Richard finally calmed Brian down enough to get him in the golf buggy, he drove straight to the golf club and took his father home. Later that night, after Brian was asleep the brothers discussed the situation and Richard said that playing golf was no longer safe as an activity.

His brother Murray suggested that perhaps they could take their Dad to the driving range for practice shots. They tried this and found it to be a successful substitution.

The activity that Mr Cotton loved so much, that reinforced his identity and gave him so much pleasure, was not working out because of the effect of dementia. His sons found a way of keeping all of the positives of the activity and only taking away the negative aspects. By adapting the activity, Mr Cotton's sons were able to eliminate the behavioural and psychological symptoms of dementia.

Autonomy is another way of saying a person has the right to make decisions about themselves and what they will or will not do.

Dr Megan Best addressed an audience of 750 delegates at the plenary session at the 'Risky Business Conference'. She emphasised that capacity [the ability to make decisions] was "task specific" and that one way of strengthening autonomy for the person with dementia was recognising that even though they might not have the capacity to make a very large, complex decision, they were capable of many smaller decisions.

"Capacity is task specific - the ability to make a decision will change with the nature of the decision. There's no such thing as 'global capacity'. Just because a person may not be able to decide about open heart surgery, doesn't mean they haven't got capacity for other decisions."

In terms of "comprehending", Dr Best cited the example of an older person with a broken arm not cooperating in a hospital so that staff began to suspect she was suffering from delirium. Then her niece arrived with her hearing aid and she was able to cooperate and make choices.

This highlighted how important it was to work carefully with people to understand their level of comprehension.

As with the previous example, it is important that you don't jump to conclusions and assume that just because a person has dementia, they don't have the ability to choose. A person's ability to understand can vary day to day, sometimes hour by hour.

You can maintain a person's autonomy by providing choice. Choice can be provided:

- When taking the person shopping, let them choose what brands they want. It doesn't matter that we think the brand they've chosen is too expensive or not as good as another brand. It is their choice.
- If they are still living in their own home and you're helping with household chores, give them the choice of the order in which you will complete the tasks. Provide this choice each time you arrive.
- When assisting them with a shower, ask them if they're ready. If they say no, then come back later. If they don't want a shower until the afternoon, speak with your supervisor to get approval.

- Let them choose what they will wear
- Let them choose when they will have lunch
- Give them options when offering activities – take it or leave it is not the options of choice we are discussing

Obtaining information from family and carers

Gaining information regarding the past life of a person with dementia can be a difficult and demanding task unless you are clear about what information you are trying to capture. It is always best to start capturing information from the person with dementia, though you may need to verify the information as it may not always be accurate.

When capturing information from others, the problem arises when the people you are asking to have not known the person with dementia when they were children or teenagers. If you are asking a son or daughter about their parent, you must take into consideration that they only have known them as a parent and only since they were little children.

As an example:

> Bob is Warren Dixon's son. Bob was born when Warren was 38 years old. Bob would not know what Warren was like as a teenager or, as a young man in his 20's or early 30's.

There could also be perceptual differences. Using the previous example, Warren's wife, Liz, would know and understand what Warren was like as young man but not as a child and perhaps not as a teenager. Liz's knowledge and understanding of Warren is based on their relationship of husband and wife. Warren's work mates, who used to share a beer at the local pub, might know a different aspect of Warren.

It is important to try to capture information from as many sources as possible or, if the family are in agreement, you could ask them to provide the information as a group. In this way you may be able to capture a few different perspectives. It would be beneficial if the client, their family and friends could provide the same type and amount of information captured in the "My Story" of Daisy Test.

Supporting family and carers

Before discussing what type of support and guidance carers might need, let's look at what is a family carer?

According to youngeronset.net, a carer is a family member or friend who provides ongoing, unpaid care and support to a person who has a dementia, disability, mental illness, chronic condition, terminal illness or who are frail.

The physical and emotional elements of caring for someone with dementia are ongoing and can be demanding. As the disease progresses, the amount of care that is needed increases and more time and energy is required from the carer. At times the carer may put their own needs aside in order to keep caring for their loved one. When carers are run down, caring will become even more difficult and this is especially so when the carer is trying to balance the needs of the person with dementia against the responsibility of running a home, the needs of their spouse and children, sometimes even a job.

Unfortunately for a lot of carers, this means that may become ill, run down and may need to access respite services or place their loved one in permanent residential care.

There are many dementia specific support groups for the family and friends of people with dementia. Information is available through:

- Alzheimer's Queensland: Dementia Help Line 1800 639 331 (24 hrs / 7 days)
- Alzheimer's Australia: National Dementia Helpline 1800 100 500
- Carers Queensland: Carer Advisory Service 1800 242 636 (office hours)

Carers are able to call these phone numbers and speak with professionals who have a deep understanding of dementia, the demands on family members, the issues they face or on how to deal with behaviours of concern.

Depression and despair:

While we all feel sad, moody or low from time to time, some people experience these feelings intensely, for long periods of time (weeks, months or even years) and sometimes without any apparent reason. Depression is more than just a low mood – it's a serious illness that has an impact on both physical and mental health.

According to the organisation, Beyond Blue, a person may be depressed if, for more than two weeks, he or she has felt sad, down or miserable most of the time or has lost interest or pleasure in usual activities and has also experienced several of the signs and symptoms across at least three of the following categories.

Behaviour

- not getting things done at work/school
- withdrawing from close family and friends
- not doing usual enjoyable activities
- not going out anymore
- unable to concentrate
- relying on alcohol and sedatives

Feelings

- overwhelmed
- irritable
- lacking in confidence
- indecisive
- miserable
- guilty
- frustrated
- unhappy
- disappointed
- sad

Thoughts

- 'Nothing good ever happens to me.'
- 'Life’s not worth living.'
- 'People would be better off without me.'
- 'I’m a failure.'
- 'It’s my fault.'
- 'I’m worthless.'

Physical

- headaches and muscle pains
- sick and run down
- loss or change of appetite
- significant weight loss or gain
- tired all the time
- churning gut
- sleep problems

It’s important to note that everyone experiences some of these symptoms from time to time and it may not necessarily mean a person is depressed. Equally, not every person who is experiencing depression will have all of these symptoms. Beyond Blue can be contacted on 1300 224 636 or you can web chat between 3pm to 12am.

Loss and grief:

Though family carers may not have physically lost the person they are caring for, the progression of dementia robs them of the relationships they once had with the person. Wives and husbands, sons and daughters become nurses or personal carers, they lose their best friend, the one they used to talk things over with. In some instances, they may lose the person they used to go to when they needed advice. Now they find themselves on their own. This is not unlike experiencing a death in the family.

Losing someone or something you love or care deeply about is very painful. Carers may experience all kinds of difficult emotions and it may feel like the pain and sadness they're experiencing will never let up. These are normal reactions to a significant loss. But while there is no right or wrong way to grieve, there are healthy ways to cope with the pain that, in time, can renew them and permit them to move on.

Grief is a natural response to loss. It’s the emotional suffering a person feels when something or someone they love is taken away. The more significant the loss, the more intense the grief will be. They may associate grief with the death of a loved one – which is often the cause of the most intense type of grief – but any loss can cause grief.

It is often said, the more significant the loss, the more intense the grief. However, even subtle losses can lead to grief. Grieving is a personal and highly individual experience. How a person grieves depends on many factors, including their personality and coping style, their life experience, faith, and the nature of the loss. The grieving process takes time. Healing happens gradually, it can’t be forced or hurried – and there is no “normal” timetable for grieving. Some people start to feel better in weeks or months. For others, the grieving process is measured in years. For family carers of a person with dementia, the added complexity is that they are grieving for the person while they are still alive. They are grieving the loss of the relationship they had with them, the loss of the person’s diminishing skills and abilities, the loss of a person’s personal functions. The personal functions lost could be the ability to carry a conversation, the loss of social skills or even the ability to remain continent.

In 1969, psychiatrist Elisabeth Kübler-Ross introduced what became known as the “five stages of grief.” These stages of grief were based on her studies of the feelings of patients facing terminal illness, but many people have generalized them to other types of negative life changes and losses, such as the death of a loved one or a relationship break-up.

The five stages of grief are:

- **Denial** "This can't be happening to me."
- **Anger** "*Why* is this happening? Who is to blame?"
- **Bargaining** "Make this not happen, and in return I will ____."
- **Depression** "I'm too sad to do anything."
- **Acceptance** "I'm at peace with what happened."

> Instead of a series of stages, we might also think of the grieving process as a roller coaster, full of ups and downs, highs and lows. Like many roller coasters, the ride tends to be rougher in the beginning, the lows may be deeper and longer. The difficult periods should become less intense and shorter as time goes by, but it takes time to work through a loss. Even years after a loss, especially at special events such as a family wedding or the birth of a child, we may still experience a strong sense of grief.
>
> Source: *Hospice Foundation of America*

The single most important factor in healing from loss is having the support of other people. Even if a person isn't comfortable talking about their feelings under normal circumstances, it's important for them to express their feelings. Sharing their loss makes the burden of grief easier to carry. It's best that they do not grieve alone**.** Connecting to others will help them.

Anger:

Anger is not an unusual emotion felt by those family members caring for someone with dementia. Even though there's no one to blame, family carers may feel angry, perhaps resentful. Why is this happening to us? This, and variations like this question are often heard from family carers.

Sometimes it's easier to blame someone, anyone so they don't have to face their loss. They may see dementia as something the doctor should have dealt with earlier then maybe it would have gone away, or the disease might have progressed more slowly. They may even see dementia as an injustice delivered by an angry God.

Anger could be a coping mechanism. The intense emotion is deflected from their vulnerable core, redirected and expressed instead as anger.

Social embarrassment and isolation:

Due to the damage occurring in the brain, people with dementia may lose their inhibitions and/or may not have the insight to realise that they are not in an appropriate environment for the function they are performing.

An example:

> John was diagnosed with Frontotemporal Lobe Dementia 3 years ago. He sold his farm and moved in with his daughter, Julie, and her husband, David, 6 months ago. John was at the bank with Julie to sort out his bank accounts. While they are waiting in the long queues John appears to get restless. He shifts his weight from foot to foot. By this time Julie has finally moved up in the queue and is in deep discussion with the bank teller. Meanwhile John looks around and sees a large pot plant against the wall. He walks over to the wall, unzips his pants and urinates in the pot plant. This causes quite a stir in the bank and Julie is totally embarrassed.
>
> After apologising to everyone, she hurriedly takes John home. She rings David and tells him that she's never going back to that branch of the bank again and she's not taking John out with her ever again.

Although family carers may find the person's behaviour disturbing or odd, the person with dementia might not necessarily be concerned about it. The person may, however, be surprised and disturbed by their reaction to the behaviour and this could lead to an over-reaction or aggressive behaviour.

Sometimes the behaviour is particularly embarrassing because of where it occurs or because the carer is in the company of other people. They may feel embarrassed or afraid that the behaviour will shock others.

The previous example progresses:

> Several months have passed and Julie no longer takes John with her when she leaves the house to do the shopping or to run errands. She either waits until her husband David gets home, or she asks her only child, Margaret, to "sit" with John. Julie has stopped going out with her girlfriends unless Margaret is available.
>
> Several of her friends are concerned and Julie's best friend Louise has gotten some of the friends together and they arrive at Julie's place on her birthday with several pizzas and a couple of bottles of bubbly. Julie is surprised but

also pleased that her friends care for her. They decide to have the pizza and bubbly on the back deck.

John joins them for some pizza. While everyone is eating and talking John removes his upper denture and rinses it out in his glass of bubbly. A hush falls over the group of previously chatting women. Julie apologies to everyone and asks them to leave while she takes John back into the house and his room.

When considering the situation of John and Julie it's easy to see how Julie could become socially isolated. Sometimes it's easier to withdraw from family and friends rather than be constantly on guard for what the person with dementia might do.

Financial issues:

According to "Dementia in Australia", a publication of the Australian Institute of Health and Welfare 2012, caring for a person with any type of disability or chronic condition can be physically, mentally, emotionally and economically demanding, but existing research suggests that the burden of care giving is particularly high for those caring for a person with dementia.

For caregivers in the paid workforce, the demands of caring for a person with dementia may have implications for their employment.

Let's look at the example of John and Julie described earlier:

Julie is talking to her friend Louise on the phone. She is bemoaning the loss of her job, the satisfaction it gave her, as well as the additional money to do with as she pleased. Her friend reminds her that Julie doesn't really need to work, David's job pays very well, their house it fully paid, and they own each of their cars.

While Julie agrees, she also points out that Margaret is expecting her first child. Julie explains that Margaret has been her main support in looking after John and she doesn't know how she's going to cope once Margaret has the baby. Julie explains to Louise that she's looked into the community services that are available to support her in her caring role however, these services come at a cost. The money Julie says she had squirreled away, was spent on the expensive tests and scans for John when he was first diagnosed. Julie explains that most of the scans are not covered by health insurance. What little money was left will soon be gobbled up by the services she will need.

Louise suggests she contact the Government Services to apply for a Carer Payment. Julie tells her that she's already tried that, but the Carer Payment is means tested and David earns too much money.

Julie reassures her friend that everything will be alright eventually, it's just a matter of some changes that need to be made to their lifestyle. She says that she loves her Dad and that this is a way of repaying everything her Dad did for her growing up. She said she just hadn't counted on such an emotional, physical and financial cost when she agreed to look after John.

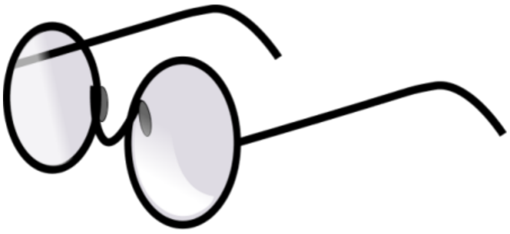
Behaviours of Concern

Behaviours of concern and possible triggers

When identifying behaviours of concern, it is important to consider any sensory loss or additional factor which a person with dementia may be experiencing and how this may impact on them.

Poor vision:

Most of the people in your care are elderly and may be experiencing poor vision perhaps made worse through cataracts or macular degeneration. Poor vision combined with an inability to accurately process what is being seen can lead to not understanding their surroundings. It could also have an impact on their being able to recognise people.



If a person is not able to recognise their surroundings and therefore understand the purpose of the area they are in, they won't know how they should behave in that area.

Poor hearing:

As with poor vision, some of the people in your care could be experiencing difficulties with hearing. They could be experiencing poor hearing such as industrial deafness or as a result of an ear infection or it may be a result of age-related deterioration. Whatever the cause, poor hearing will impact greatly on a person with dementia who is already experiencing difficulties in understanding what is being said to them.

This could lead to misunderstandings which could result in the person becoming frustrated and angry.

Additional illnesses:

There could be other factors which are impacting on the person with dementia. People with dementia are as prone as other elderly people to catching colds, getting the flu and developing other illnesses such as diabetes and heart problems. Elderly people are prone to urinary tract infections (UTIs) because they are reluctant to drink sufficient amounts of water throughout the day. The risk of UTIs and dehydration increases during the hotter months. Constipation will affect a person's functional abilities and add to their confusion. Infection will increase the confusion felt by people with dementia and this could result in behaviours they might not have if it wasn't for the infection or illness adding to the effects of dementia.

Medications:

Medications sometimes have a side-effect on the person. Prescribed medications such as tranquillisers, anti-depressants and behavioural modification medication may have an undesired effect on the person with dementia and their behaviour may be affected. They may appear "spaced out", drowsy, less alert or more cognitively impaired than is usual for them. They may become stiff or lean to one side when they walk. They may start drooling or become restless and fidgety.

Pain:

Difficulties could arise when a person with dementia is in pain. Due to the effects of dementia the person may not be able to tell you they are in pain. This could be due to their communication difficulties or it could be due to their inability to process what they are feeling.

An example:

Albert Hunter is a client with dementia who lives in a residential facility where Vicky, a caring support worker, is on duty. Mr Hunter, known to everyone as Bert, is usually an easy-going gentleman.

When Vicky goes into his room, she sees Bert sitting on the chair. He is dressed and has his socks on but not his shoes. He is grimacing and rubbing his upper left arm. Vicky asks him if he is in pain. Bert looks at Vicky but doesn't respond. He appears confused and continues to rub his arm.

Vicky drops into a crouch to maintain eye contact, she looks at Bert and gently says "Hi Bert, you're not looking well today, does your arm hurt?" Bert looks at Vicky and replies "no". Vicky touches Bert's arm but Bert doesn't react as though it hurts to touch.

Vicky tries to redirect Bert. "Can I help you with your shoes Bert?" Bert doesn't say no, so Vicky starts to put his shoe on his left foot. Bert cries out and pushes Vicky away. Vicky loses her balance and ends up sitting on the floor. This behaviour seems very strange for Bert.

Vicky waits for Bert to settle and then very gently she removes the sock off Bert's left foot. She sees that Bert's little toe is swollen and appears very bruised. Bert is in pain from his sore toe, but he has been rubbing his arm.

The most common behaviours of concern are:

- Aggression
- Anxiety
- Wandering
- Repetitive behaviour
- Withdrawal and/or isolation
- Agitation
- Sleep disturbances
- Hoarding
- Sundowning

When looking for possible triggers to these behaviours we need to eliminate treatable causes. Factors such as:

- Poor vision
- Additional illness
- Medication
- Poor hearing
- Pain

These are some of the contributing factors or triggers which can cause a person with dementia to behave in a manner which causes concern.

Other factors are:

- Being asked or expected to function at a higher level than they are able
- Being treated as though they are incapable of doing anything
- Communication difficulties are an additional factor which can lead to behaviours of concern.

Needs Driven Behaviour Model (NDB Model)

The NDB model states that:

- *Disruptive, agitated, and aggressive behaviours often result from one or more unmet needs — physical, psychological, emotional or social.*
- *Loss of ability to express needs in language causes the person to "communicate" through behaviour.*
- *NDB Model emphasizes the interaction between stable individual characteristics and fluctuating environmental factors that may cause stress or discomfort.*
- ***Assessment is the key** to accurate interventions and quality of care.*

According to Algase, D. *et al*., in the American Journal of Alzheimer's Disease, November/December 1996:

> "Disruptive behaviour is a term that reflects the caregiver's view more than the cognitively-impaired (CI) person's perspective in a situation. While behaviours such as wandering or repetitive questioning may interfere with or disrupt clinical care routines, they may actually express or embody the CI person's goal or needs. Seen this way, these behaviours become meaningful and therefore, potentially useful in directing nursing care."

It is strongly suggested in this article, that behaviours of concern are an expression of need by the person with dementia. It is thought that the person's neurological, cognitive, psychosocial and general health combined with the person's personal, physical and social environment could be the causes of wandering, vocalising and physical aggression.

Comprehensive and ongoing **ASSESSMENT** is vital.

1. Describe the behaviour: WHO? WHAT? WHEN? WHERE? HOW LONG? HOW OFTEN?
2. Ask: Who is this a problem for?
    - The person with dementia?
    - Other's clients around him/her?
    - Staff?
3. Listen carefully for the message the person is attempting to convey.
4. Observe for possible "hidden meanings" in actions, words.
5. Involve family who may understand meanings of words or phrases.
6. Look for patterns and document habits.
7. Attend to nonverbal cues and messages.
8. Rule in, rule out medical and/or physical problems.
9. Seek to understand the person's internal reality.
10. Re-frame the problem: Think of the person as distressed rather than distressing
11. Brainstorm with staff and family regarding possible causes and interventions that work even part of the time.
12. Re-evaluate frequently.

As a person's status changes due to dementia, your response and the way in which you implement interventions will need to change. Keep trying!

When faced with behaviours of concern your supervisor may call a meeting so that all who are involved in the care of that person are able to put forward their perspectives of the behaviour. Everyone will also be able to put forward suggestions on how to support the person with dementia. Before you are able to assess the behaviour to formulate intervention strategies you will need to eliminate the possibility of other treatable factors causing distress to the person with dementia.

The following questions may assist when trying to pinpoint treatable factors.

- Is their vision poor? Are they wearing their glasses? When did they last go for a sight test?

- Is their hearing poor? Do they need hearing aids? Do they wear their hearing aids? Are the batteries in the hearing aids flat?

- Are they socially isolated? Are they spending too much time alone in their room? Do they get visitors? Do they have family and friends in the area?

- Are they able to mobilise? Do they need a mobility aid? Do they have a prosthesis? Does their prosthesis fit properly?

- Are they over stimulated? Is the area too noisy, too bright? Are there too many people around? Do they feel bombarded from differing angles? Is the personal space being encroached?

- Are they being hurried? Are they being asked to do too much at once?
- Are support workers "doing to them" what they can "do by themselves"?
- Could they be in pain? Do they have conditions which could cause pain? Do their dentures fit? Are they frowning or grimacing? Are they rubbing any part of their body?
- Could they be feeling unwell? Are they hot to touch? Are they running a fever? Do they look pale and/or sweaty?
- Could they have had an incontinence episode?
- Could they be constipated?
- Could they be thirsty of hungry?
- Do they require repositioning?
- Do they feel restrained?
- Could they be depressed? Do they look sad? Have they been crying? Has their energy level changed? Do they look tired?
- Are they lost? Can they find their room, the toilet, the dining room? Are they looking for someone in particular?
- Are comfortable chairs available? Are they sitting next to someone they dislike?
- Are they bored? Do they have access to activities to promote their self-esteem?

You are able to provide your "take" on the behaviour. You may be able to offer possible solutions when working through the behaviour assessment. Throughout the brainstorming session you must remember that the person with dementia is experiencing a problem – THEY are NOT the problem.

There are 2 main types of behaviour:

- Persistent behaviour – these are behaviours that happen regularly and are not the result of a trigger. An example is a person with dementia asking the question "What day is it?" several times a day. This type of behaviour is normally a direct result of the damage occurring in the brain.

- Triggered behaviours – these are occasional behaviours which tend to be the result of a trigger or a combination of triggers. An example could be an unexpected verbal outburst from a person with dementia who is normally very quietly spoken and mild mannered. These behaviours are preventable once we identify why the behaviour is occurring and implement a strategy to meet the need of the person with dementia.

It is possible to have triggered persistent behaviours. These are behaviours that are persistent because the trigger is occurring consistently.

Developing behavioural solutions

When faced with a person who is demonstrating an unmet need by behaving in an unusual and un-social manner, you can de-escalate the situation by:

- Not arguing. Not explaining. The minute you start to explain, the person with dementia could think you are arguing with them or that you are "siding" with others

- Always speak with a calm and pleasant manner. Try to soothe the person but don't treat them like a child. Make sure your facial expressions are pleasant. Face the person and let them see you have nothing in your hands, that your body is relaxed and that you do not pose a threat to them

- If you are in a noisy environment, take the person to a quieter and calmer area. If you are not able to remove the person, try to reduce the external stimuli. Reduce the noise, soften the lights and, if possible, guide others out of the area to give the person some space and time to calm down.

We need to minimise the likelihood of behaviours and develop strategies to support the person with dementia. By doing this we will reduce the impact of their behaviours on themselves and others.

The problem solving process:

Step 1: Assess the behaviour:

Establish a database – it is essential that a detailed and accurate description of the behaviour is documented. To obtain the required information the following 5 W's must be asked and answered.

Why is it a problem?

Is it a problem to workers, to the family, to the person with dementia? Who owns or has the problem?

What is the problem?

A full description of the behaviour, what happened before? Who was there before?

Where is the behaviour occurring?

What room is the behaviour occurring? In which area of the room? Were they sitting or standing?

When is the behaviour occurring?

Is the behaviour happening at a set time? Is the behaviour happening at set intervals? Is the behaviour occurring immediately after or before an activity such as showering?

Who was involved?

Who played a part in this behaviour? Who spoke with the person and what was said or done?

How is the person with dementia saying or doing it?

Are they angry, frustrated, tired, crying?

Once you have the answers to these questions, we must eliminate the possibility that the person may have another additional health or medical problem. We need to look at the physical environment and make sure that the person with dementia didn’t misunderstand their surroundings and act according to where they thought they were. We must consider that possibility that workers, visitors or other clients may have unwittingly sparked this behaviour by something they said or did or perhaps by their attitude.

Once you have eliminated these considerations you will move on.

Step 2: Diagnosis

Analyse the data that has been amassed

Compare the data, look for patterns and consistencies

Determine if the behaviour is:

- a triggered behaviour
- a persistent behaviour
- a triggered persistent behaviour

Step 3: Plan the interventions

Determine appropriate interventions using the following 4 R's

Reconsider

Look at the behaviour from the perspective of the person with dementia. Consider the impact of poor hearing and poor sight combined with the effects of dementia on their ability to process what is happening around them. Consider the aspect of having people they don't know, strangers, telling them it's time to get out of bed and to hop in the shower. Consider the effect of having a young person telling them what to do or that they are doing things incorrectly. Consider the effect of dementia on their memory, why should they have a shower, they just had one this morning? Consider that a grown person has no control over their surroundings or their lives. These are just some of the considerations, once you start looking at things through their eyes you might begin to understand just how difficult life is for them.

Redirection

Change the focus from the negative to a positive. Use what you know about the person, what is important to them and what brings them a sense of pleasure or peace. For redirection to be effective the alternate activity or redirection needs to be of at least equal importance, to be interesting and desirable to the person with dementia.

Reassurance

You must remember that some behaviours are caused by the disease damaging areas of the brain. As a result, people with dementia may become distressed. They may become confused as to where they are and want to look for the comfort of home or Mum and Dad to make them feel safe and secure. They may be fearful that someone wants to hurt them. It doesn't matter that you know they are safe or that no-one will hurt them. Their fears are real fears and should be treated as such. These feelings must be acknowledged and validated.

Restraint

Restraint should only be a last resort and should only be used to prevent the person with dementia from SERIOUSLY hurting themselves or others. The restraint should only be equal to the situation and must cease as soon as possible.

There are 2 types of restraint:

- Mechanical/physical restraint such as the use of "fallout" chairs, bed rails, fixed recliners and vests
- Chemical restraint such as medications, tranquilisers and the use of psychotropic drugs for their secondary effect.

Step 4: Implementation

- Document the intervention your team has chosen in the person's care plan. Set a date for a full evaluation of the intervention
- Make sure everyone involved in the care of the person is aware of how they should respond should the situation arise. Monitor the situation to make sure everyone is implementing the intervention correctly
- Support everyone involved in implementing the intervention
- Reassess the person with dementia continuously and document any reoccurrence of the situation and whether it was minimised.

Step 5: Evaluation

- Collect feedback from everyone involved in the process and document the results in the person's care plan
- Debrief everyone involved while assessing the effectiveness of the intervention
- Enter the new data into the care plan.

An example:

Mark Croft was diagnosed with Frontotemporal Dementia 2 years ago. Mark is 84 years old and lives at home with his wife Winifred, known to her friends as Winnie. Mark has started going to a dementia-specific day respite centre 3 days per week. The workers at the centre have approached the Centre Manager, Susan, because of a complaint from the next door neighbour. She and her young daughter have seen Mark urinating on the back fence of the centre which adjoins her back yard.

Susan has called a meeting to discuss what is happening and to apply the problem solving process.

Step 1 Assessing the behaviour

Why is it a problem?

It isn't a problem for the staff, or Winnie, or for Mark. It is a problem for the neighbour and her young daughter.

What is the problem?

At the meeting workers report the following:

- Tracy – I've seen Mark at the back fence urinating
- Trish – he tends to go between the rosemary bush and the fence
- Carla – I've only seen him doing this after lunch
- Fiona – I've seen him going down there during the last concert, but I didn't see him urinating

- Lorraine – He uses the toilet when he arrives at the centre

Where is the behaviour occurring?
The behaviour is occurring at the back fence, specifically between the rosemary bush and the back fence.

When is the behaviour occurring?
The behaviour is occurring in the afternoon, straight after lunch. It's possible that it could have occurred during the last concert.

Who was involved?
Mark, the neighbour and her young daughter.
How is the person with dementia saying or doing it?

There appears no particular anxiety or other emotion involved.

Step 2 Diagnosis

The workers and Susan look for patterns in the data and realise the behaviour is more likely to occur after lunch. The workers analyse why the behaviour occurs after lunch but not in the mornings when he arrives. They realise that the after lunch activities tend to be noisy and this could also tie in with Mark walking outside during the last concert. They decide the tendency for Mark going to the back fence could be due to the noise in the centre at those times. They decide this is a triggered behaviour.

Step 3 Plan the interventions

The workers re-read Mark's social history looking for clues. They find reference that Winnie has had difficulty in the past when taking Mark to large shopping centres and when the family gets together for Christmas etc. They also noted that while Mark should wear glasses for distance vision, he doesn't always wear his glasses.

They consider the effect of a noisy environment on Mark, especially when he hasn't had time to settle in. After lunch he must feel that he is surrounded by noisy strangers and might be too embarrassed to ask directions to the toilet. If he isn't wearing his glasses, he may not be able to read the sign on the toilet door.

The workers suggested they redirect Mark to the toilet at regular intervals and especially immediately after lunch. They have also decided that they could trial the effectiveness of a large black and white picture of a toilet placed on the toilet door.

The workers decided they would use a reassuring tone when redirecting Mark to the toilet. They would use phrases such as "Hi Mark, could you come with me for a moment please?" They would gently guide Mark use a light touch to the elbow.

It was decided that there would be no basis for either physical or chemical restraint.

Step 4 Implementation

Susan documented the planned intervention in Mark's file and "talked" the workers through the process. She stipulated that unless something significant occurred they would commence the intervention tomorrow and they would trial the intervention for a week. Susan asked the workers to support each other during the trial period and to note any changes as well as continuation of the behaviour. A time was set for the next meeting.

Step 5 Evaluation

At the next meeting Susan asked the workers what they had observed during the week's trial intervention regarding Mark urinating on the back fence. The workers reported a positive outcome. Lorraine said that during yesterday's concert she noticed Mark looking around and guided him to the toilet. Once he came out of the toilet, she guided him to the table in the back yard where it was quieter and brought him a cup of tea. Staff decided that taking Mark outside during noisy periods was a great idea as in this way he could still enjoy the music but not be subjected to the loudness. This was then added to Mark's care plan.

Elder Abuse

It would be wonderful to live in a world where older people are always respected and treated with dignity. In reality, this isn't always the case. Sadly, abuse occurs and it's your responsibility to report a situation of abuse, even if you only suspect abuse is occurring. This is commonly called mandatory reporting.

Elder abuse is any act within a relationship of trust which results in harm to an older person. It can be emotional, psychological, financial, physical or sexual abuse, or neglect.

Many people do not discuss their concerns with others because of feelings of shame, fear of retaliation, the involvement of family members or fear they will be institutionalised. Some people may not realise what they are experiencing is abuse, or feel that somehow it is their fault.

Abuse can be unintentional or deliberate. The harm caused to an older person may range from the unintended effects of poor care through to serious physical injury inflicted deliberately. Harm can also include emotional harm and financial loss including the loss of a home and belongings.

The older person may be dependent on the abuser, for example if they rely on the abuser for care. It is also common for the abuser to depend on the support of the older person, for example for accommodation. Sometimes, there may be a co-dependent relationship where both the older person and the abuser depend on each other.

If someone other than a person in a trusting relationship is abusing an older person it isn’t considered Elder Abuse.

An example:

> Mavis goes to the supermarket to buy her groceries. When she goes to pay at the checkout she gives what she thinks is a $50 bill but it’s really 2 bills stuck together. The person at the checkout realises that there are two $50 bills but says nothing and pockets one of the bills. This isn’t financial abuse, this is theft.

Types of abuse

Elder abuse can take many forms. Often more than one type of abuse can be used.

Emotional (or psychological) abuse:

Is using threats, humiliation or harassment causing distress and feelings of shame, stress or powerlessness. It often occurs in combination with other forms of abuse.

Examples of emotional or psychological abuse:

- pressuring, bullying, belittling
- name-calling
- threatening to harm the person, other people or pets

You might see:

- depression or low mood
- feeling of helplessness
- loneliness
- fear
- confusion

Neglect:

Is failing to provide the basic necessities of life, either intentionally or unintentionally.

Examples of neglect include:

- not giving the person the care they need such as, adequate food, medical care, warmth or dental care
- receiving the Carers’ Allowance and not providing the care required

You might see:

- an older person who is hungry, thirsty or has lost a lot of weight
- an older person who is wearing the wrong clothing for the weather conditions
- an older person who is living in an environment that is dirty or unsafe
- an older person whose health problems have worsened due to their medications being mismanaged
- an older person with unexplained conditions such as hypothermia, dehydration or pressure sores

Financial abuse:

Is using someone's money, property or other assets illegally or improperly or forcing someone to change their will or sign documents. This is the most common form of abuse.

Examples of financial abuse include:

- moving into the home of an older person without their consent and failing to contribute to household costs
- forcing, coercing or misleading an older person into signing paperwork concerning loans, property, wills or powers of attorney
- using powers of attorney to manage an older person's finances inappropriately
- stealing goods, whether expensive jewelry, electronic equipment or basic necessities such as blankets and food
- using bank or credit cards without the person's permission
- promising to care for someone in exchange for their financial help, then not providing the care

Signs of financial abuse include:

- missing belongings
- inability to find the money for basics such as food, clothing, transport costs and bills
- large withdrawals or big changes in banking habits or activities
- property transfers when the person is no longer able to manage their own financial affairs
- fear, stress and anxiety

Physical abuse:

Is inflicting pain or injury by hitting, slapping, pushing or using restraints.

Examples of physical abuse include:

- pushing, shoving, slapping, biting, kicking, burning
- rough handling
- restraining with rope, belts, ties or locking them in a room, building or yard
- using chemical restraints such as alcohol, medications, household chemicals or poisons (a blood test would be required)
- holding a pillow over a person's head

Signs of physical abuse include:

- pain or restricted movement
- bruises, bite marks, cuts, burns, scratches
- unexplained accidents
- unexplained injuries such as broken bones, sprains, punctures
- over or under-use of sedation
- fear or anxiety
- stories about injuries that conflict between the older person and others

Social abuse:

Is forcing someone to become isolated by restricting their access to others including family, friends or services. This can be used to prevent others from finding out about the abuse.

Examples of social abuse include:

- preventing contact with family and friends
- withholding mail
- not allowing phone calls or listening in to calls
- preventing involvement in religious or cultural practices

Signs of social abuse include:

- sadness or grief at loss of contact with others
- withdrawal or listlessness
- loss of self esteem

Sexual Abuse:

Is any sexual activity for which the person has not consented.

Some forms of abuse are criminal acts, for example physical and sexual abuse. Alleged criminal activity should be reported to the police.

Examples of sexual abuse include:

- non-consensual sexual contact, language or behavior
- inappropriate touching
- sexual assault
- rough or inappropriate cleaning or treatment of an older person’s genital area
- viewing sexually explicit material or making sexually explicit phone calls in the presence of an older person without their consent

Signs of sexual abuse include:

- unexplained sexually transmitted disease
- recent incontinence (bladder or bowel)
- internal injuries
- bruises, bite marks, pain, burn marks
- trauma including bleeding around genitals, chest, rectum or mouth
- torn or bloody underclothing or bedding
- anxiety when near, or contact suggested with the abuser

Mandatory reporting of abuse

Compulsory reporting of abuse of older people in aged care was introduced by the Australian Government in the Aged Care Amendment (Security and Protection) Bill 2007 to the Aged Care Act 1997 (Cth). This means that residential aged care facilities have a zero tolerance for elder abuse. All witnessed abuse, or where abuse is suspected, must be reported. Allegations or suspicions of sexual and physical assault must be reported by the organisation within 24 hours to the police and the Department of Health and Ageing.

If you think that one of the clients in your care is being abused in any way, shape or form, you must report it immediately to your supervisor. Your supervisor will guide you from there on.

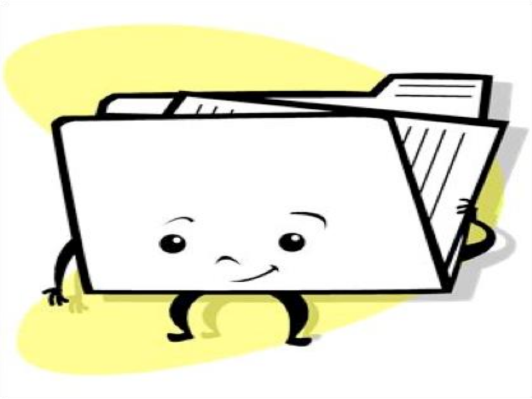
Complete documentation

Reporting requirements

When reporting, it is essential that the organisation's policy and procedures be followed. Failure to do so could put a person with dementia, a colleague or yourself, at risk.

Though you might consider what you have observed as not being important, when combined with something a colleague had observed, it could lead to a behavioural intervention.

Equally, you may observe that a client is more tired than normal. It is essential that you report this to your supervisor as, once investigated, it could be the onset of an illness. If you hadn't reported your observations to your supervisor, it could have delayed the diagnosis and therefore delayed the client's treatment.



Maintaining and storing documentation

Everyone has an obligation under the Privacy Act 1988 (Cth) to maintain confidentiality. You must not divulge any information regarding a client to anyone external to the organisation you work for. You shouldn't talk about specifics when talking about work. This means you shouldn't say anything about your workday that might lead someone else to identify the client you are speaking about. Even if you don't use names, in describing the situation, you might drop hints that could lead a colleague in identifying the client you are referring to. You should NEVER discuss work on social media.

Even posting something that appears harmless such as:

> *"It was so sad today, one of my clients died today. She was always nice. She always had a joke for me (most times it was the same joke). That funny accent of hers always cracked me up. I will miss her."*

This could lead someone to recognise who you were referring to. Breaching confidentiality is a serious offence. It could lead to disciplinary actions or to you losing your job.

You also have a responsibility to only request and record information which is pertaining to the care of the client. You must not ask questions or seek information through other sources if it has nothing to do with the services provided. While it might be necessary for the book-keeping section of administration to know about the client's bank details, it would not be appropriate for you to ask about a client's bank details as it has nothing to do with the care you provide.

All recorded information regarding clients must be stored securely and should only be accessible to authorised staff. Most information is kept on computers. Whenever you are using a computer to access information regarding a client you should consider who else may be able to read the information on the screen. If you need to leave the computer, you should always log off or lock on the screen saver.

Your password is also your identifier. If you give your password to someone else, even your colleague, when they log on, they are logging on as you. Anything they do while logged on will be attributed to you. NEVER provide your password to others.

Self Care Strategies

Monitoring your stress levels

It's important that you monitor your stress levels.

You may be required to work shift work. Even though a work cycle should consist of no more than 6 eight hour shifts or 4 twelve hour shifts, you may find the change of morning to afternoon shift place an additional burden on your family's lives and add to your family responsibilities. Night shifts may add to you feeling you are not fulfilling your family responsibilities or family responsibilities may affect the amount of restful sleep you are able to get during daytime.

This may affect your ability to work effectively and your fatigue may put you at risk of accident or injury.

You may experience stress due to your closeness to clients with a debilitating illness, such as dementia, or entering the palliative stage of their care.

Though rewarding, working in dementia care can also be very demanding and draining.

Some of the indicators of stress are:

- Needing more and more time off work
- Not working to your usual standard and making more mistakes
- Not getting along as well with colleagues as previously
- Developing a shorter fuse than normal
- Developing headaches and other muscle tension
- Not sleeping well
- Digestive disorders
- Becoming more tired, not as interested in anything new
- Becoming less sure about making even small decisions
- Your standard of personal appearance is becoming "sloppy"
- Not mixing with colleagues, sitting on your own at lunch
- No longer delegating, trying to do too much

While some workplace stress is normal, excessive, and continuous stress is not. Admitting that you are stressed is not a sign that you can't do your job. It is crucial that you seek help as soon as possible.

Looking after yourself

One of the ways that workplace stress can be reduced is for you to take care of yourself. Even small changes to lifestyle can lift a mood and increase energy.

You may wish to enquire if your organisation has an Employee Assistance Program (EAP). EAP sessions are confidential, and your identity and information regarding what was discussed is not passed on to your employer.

The following are stress reduction tips from "Guide for improving your mental and emotional health" at Helpguide.org, by Segal, J., et al. February 2015.

Get moving:

Regular exercise is a powerful stress reliever—even though it may be the last thing you feel like doing. Aerobic exercise—activity that raises your heart rate and makes you sweat—is a hugely effective way to lift your mood, increase energy, sharpen focus, and relax both the mind and body. For maximum stress relief, try to get at least 30 minutes of heart-pounding activity on most days. If it's easier to fit into your schedule, break up the activity into two or three shorter segments.

Make food choices that keep you going:

Low blood sugar can make you feel anxious and irritable, while eating too much can make you lethargic. Healthy eating can help you get through stressful work days. By eating small but frequent meals, you can help your body maintain an even level of blood sugar, keep your energy up, stay focused, and avoid mood swings.

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 may also eventually lead 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.

Get enough sleep:

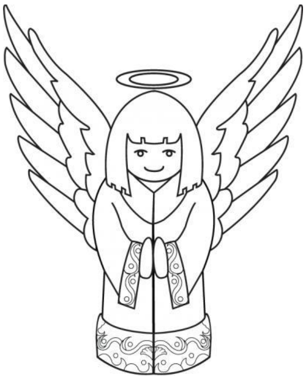
Not only can stress and worry can cause insomnia, but a lack of sleep can leave you vulnerable to even more stress. When you're well-rested, it's much easier to keep your emotional balance, a key factor in coping with job and workplace stress. Try to improve the quality of your sleep by keeping a sleep schedule and aiming for 8 hours a night.

Get support:

Close relationships are vital to helping you through times of stress so reach out to family and friends. Simply sharing your feelings face to face with another person can help relieve some of the stress. The other person doesn't have to "fix" your problems; he or she just has to be a good listener.

Accepting support is not a sign of weakness and it won't mean you're a burden to others. In fact, most friends will be flattered that you trust them enough to confide in them, and it will only strengthen your bond.

Resist perfectionism:



No project, situation, or decision is ever perfect, so trying to attain perfection on everything will simply add unnecessary stress to your day. When you set unrealistic goals for yourself or try to do too much, you're setting yourself up to fall short. Aim to do your best, no one can ask for more than that.

Clean up your act:

If you're always running late, set your clocks and watches fast and give yourself extra time. If your desk is a mess, file and throw away the clutter; just knowing where everything is saves time and cuts stress. Make to-do lists and cross off items as you accomplish them. Plan your day and stick to the schedule—you'll feel less overwhelmed.

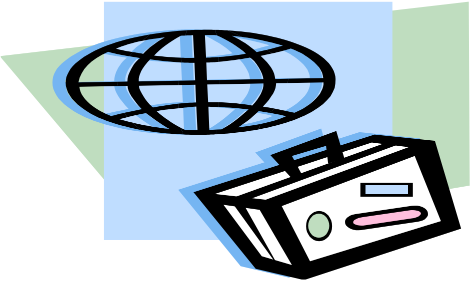
Flip your negative thinking:

If you see the downside of every situation and interaction, you'll find yourself drained of energy and motivation. Try to think positively about your work, avoid negative-thinking co-workers, and pat yourself on the back about small accomplishments, even if no one else does.

Don't try to control the uncontrollable:

Many things at work are beyond our control —particularly the behavior of other people. Rather than stressing out over them, focus on the things you can control such as the way you choose to react to problems.

Take time away:



When stress is mounting at work, try to take a quick break and move away from the stressful situation. Take a stroll outside the workplace if possible, or spend a few minutes meditating in the break room. Physical movement or finding a quiet place to regain your balance can quickly reduce stress.

Talk it over with someone:

In some situations, simply sharing your thoughts and feelings with someone you trust can help reduce stress. Talking over a problem with someone who is both supportive and empathetic can be a great way to let off steam and relieve stress.

Connect with others at work:

Developing friendships with some of your co-workers can help buffer you from the negative effects of stress. Remember to listen to them and offer support when they are in need as well.

Look for humour in the situation:

When used appropriately, humour is a great way to relieve stress in the workplace. When you or those around you start taking things too seriously, find a way to lighten the mood by sharing a joke or funny story.

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http://www.caregiver.org

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