**Unit Standard 23920**

Dementia – Describe and Support

**Script**

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# Segment1 - What is dementia?

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There is a lot of misunderstanding about what dementia is so in this segment I will discuss what is dementia, how it affects a person, behaviour and activity of the brain, what happens to the brain, and the stages of dementia

Slide 3 What is dementia

Many people think that dementia is a condition in itself. That is not correct. Dementia is an overarching term used to describe a chronic disorder of mental functioning caused by physical changes in the brain as a result of disease or injury. These physical changes can lead to a loss of the functions controlled by specific sections of the brain.

The damage caused by all types of dementia leads to the progressive loss of brain tissue and the symptoms will gradually get worse over time.

Slide 4 What are the symptoms

There is a wide variety of physical symptoms associated with the decline in memory or cognition that directly impacts a person’s ability to perform everyday tasks.

Memory impairment, especially short-term memory, is often the first symptom to be noticed. Someone living with dementia may be unable to remember ordinary information, such as their birth date and/or their address and may be unable to recognise friends and family members or remember recent events. However, while memory loss is a common symptom of dementia, memory loss by itself does not mean that a person has dementia.

The ability to think and reason (called cognitive ability) also declines.

Slide 5 How does loss of cognitive function affect a person

Loss of cognitive function can affect a person’s decision-making ability. This can be they have difficulty or can’t make a decision to making really bad decisions that put them at risk.

It also can affect their judgement. This may mean they cannot judge if it is safe to cross the road and walk out in front of a care. It can also mean they are discerning as to who they trust and can easily give all their money away along with many other things.

They can also lose their ability to orientate in time and space. This may mean they may get lost in familiar surroundings or cannot differentiate between night and day. This could mean they sleep during the day and wander at night.

Slide 6 How does loss of cognitive function affect a person

Their speed of reaction time can be altered to making them slower to react to something. For example, they may trip and their reactions to stop the fall are so slow, they just fall flat on their face. This can make them more at risk of injury.

The lose their ability to problem solve meaning they cannot work out how to get out of situation. Now you and I know how to get out of a corner, and they have no idea how to get out. They may totally misunderstand what you are saying and become angry as a result.

They could have verbal communication issues. For example, the person may have difficulty with finding words. They may be trying to tell you something and the words just don’t come out or are all completely wrong.

Slide 7 How Behaviour and activity may affect a person

It is not only cognition that is affected with dementia. Behaviour or activity may also be affected. So, the person may show changes in personality. For example, have inappropriate responses or lack of emotional control.

The person may experience problems with eating. This could be forgetting they have eaten and keeping asking for food, to not remembering how to hold a utensil to feed themselves and just look at their food. They could also have problems with dressing by not knowing the correct order for clothes to go on, how to put a garment on to putting multiples garments on. I had a lady who used to do this and one day, I discovered she had 10 pair panties on. We made a game out of it and I managed to remove the other 9 pair. They could also have problems with toileting by either not knowing what a toilet looks like any more or where to find the toilet. They may also lose the ability to recognise their urge to go to the toilet and become incontinent.

They may have a change in interest level. For example, they may lose interest in their surroundings and just sit and stair into space. They may also lose interest hobbies they used to enjoy. They can also lose ability to perform routine household tasks, so they are no longer able to tidy their close, take their dishes to the sink and wash them or sweep the floor.

Now a change in behaviour is a major factor for a person with dementia which makes it very difficult both the person and their caregiver. For example, the person may become agitated and perform repetitive actions, or experience delusions and hallucinations. This has discussed extensively in Having Knowledge and understanding behaviour topic.

Slide 8 What happens in the brain

To understand dementia and the brain you need to understand more about what happens in the brain with dementia. Firstly, dementia is a progressive neurological disorder, with increasing brain dysfunction. Physical changes occur within the brain cells, disrupting the electrical charges in the cells and the cells’ ability to connect or ‘communicate’ with other cells. The destruction or changes in the cells causes a loss of the brain function controlled by those cells.

Slide 10 How does it affect the person

Well with the loss of the cells, so they can’t communicate to other cells, means that the person’s memory, thinking, behaviour, emotion and physical functioning will all be affected.

Now a person living with dementia experiences it in their own individual way. Not everyone is the same. However, there are some common features. The way a person develops dementia and the signs and symptoms they experience are closely linked to the area of the person’s brain that is affected.

Slide 11 What are the types of dementia

So, there are many forms of dementia and while there may be some commonalities between them, they are not all the same. Therefor the term dementia is actually an overarching term or often referred to and umbrella term, for various forms of dementias., including Alzheimer’s disease, vascular dementia, fronto-temporal dementias, which used to be called Picks disease and may still be referred to as such. However, there are 3 stages of dementia. These are early/mild, moderate and advanced/severe. These will be discussed in more depth in Segment 7

Slide 12 What are the types of dementia

There is also Lewy Body dementias and alcohol-related dementias as well a dementia from Parkinson’s disease and head injuries can also result in a form of dementia.

There are also some key differences in the symptoms of the different types of dementia. In advanced Alzheimer’s disease the cortex shrinks dramatically. This is especially so in the hippocampus, which is the part of the brain that deals with new memories.

You can find out more about the different types of dementia in the Dementia Topic in the list of topics on Care Training Online.

# Segment 2 - Understanding the brain

Slide 1 Index

In this segment I will discuss the healthy brain, what happens to the brain, the lobes of the brain and their functions

Slide 2 About the healthy brain

The healthy brain has over 100 billion nerve cells called neurons, that communicate with each other and many other nerve cells in the body to form interlinking networks. These networks are ‘organised’ to do special things, such as thinking, learning, remembering, seeing, hearing, smelling and controlling muscle movements.

Brain function is carried out by the network of nerve cells or neurons, and connections throughout the brain.

Electrical charges or ‘messages’ travel through these networks to ‘control’ our actions, behaviours, memories, thoughts and feelings.

Slide 3 What happens to the brain in dementia

With dementia, physical changes within the brain cells disrupt the electrical charges and the cells’ ability to connect or ‘communicate’ with other cells. The destruction or changes in the cells causes a loss of the brain function that is controlled by those cells.

The signs and symptoms of dementia are closely linked to the area of the person’s brain that is affected. With Alzheimer’s disease, the most common form of dementia, nerve cells in the area of the brain that deals with thinking and memory become damaged and die off. As the disease progresses, the parts of the brain that are affected begin to lose tissue causing the brain to shrinks.

Slide 4 Parts of the brain

The brain is made up of different parts that all need to function together.

The cerebrum is the part that fills most of the bony skull. It is the part involved in remembering, problem solving, thinking and feeling. It also controls movement. The cerebellum which is part of the cerebrum, sits at the back of the head, underneath the cerebrum and it controls coordination and balance.

The brain stem sits underneath the cerebrum in front of the cerebellum. It connects the brain to the spinal cord and controls automatic functions such as breathing, digestion, heart rate and blood pressure.

The brain also has a wrinkled surface. This is a specialised outer layer of the cerebrum called the cortex which is tightly packed with neurons and is responsible for higher thought processes including speech and decision making. These “bumps” and “grooves” are tightly packed in the brain and allow more cerebral cortex matter to fit inside the skull.

Slide 5 Sides of the brain - Hemispheres

The brain is also divided into two halves that are separated by a groove in a middle. The left side controls the right body of the body and is responsible for logic, that is science and mathematics. The right half controls the left side of the body and is responsible for creativity and arts.

Slide 6 How do the hemispheres communicate

Well there is a groove between the two hemispheres that is a thick band of dense neural fibres. This is called the corpus colosseum. This is the area that allows the two hemispheres to communicate with each other and to share information from one side of the brain to the other because they don’t work in isolation from each other.

Slide 7 Lobes of the brain

Now each hemisphere is divided into 4 parts called lobes. These are the frontal lobe, the occipital lobe, the parietal lobe and the temporal lobe. It is important to remember though that the brain is very complex, so it is not possible to truly localise specific functions of the brain to just one lobe. So while the frontal lobe is responsible for cognition, you will see the other lobes will contribute as well.

Slide 8 What is cognition?

Well cognition means the mental processes involved in gaining and applying knowledge and comprehension which is understanding. These processes include thinking, knowing, remembering, judging and problem solving, and encompass language, imagination, sensory perception, planning and the initiation or inhibition of behaviour

Slide 9 What are the functions of the frontal lobe

The frontal lobe is responsible for the motor function. This means it generates the nerve impulses that controls movement of the body. The ability for attention and concentration is also situated here. It is also where the person is able to plan is situated.

Slide 10 What are the functions of the frontal lobe

Abstract thinking takes place here and is where the person can think about concepts. For example, think about a group of animals as opposed to one particular animal. Motivation is the get up and go in a person comes from here also. It is where the person has a reason for an action. Your motivation for getting up and going to work maybe so you can earn an income. If this part of the brain is damaged, the person may just sit and do nothing. Problem solving is here too and enables a person to work out why something is happening or has happened. So, it is the ability to analyse what has happened and create a way to fix, change or make something.

Slide 11 What are the functions of the frontal lobe

Reasoning and judgement comes from the frontal lobe too and is about working through what you want to do and assess whether it is right or appropriate. Insight, which means to understand the consequences of your actions, is here too. For example, you know that if you walk out in front of a car, the likelihood of being hit by the care is pretty high so you wouldn’t do it. A person with lack of insight will just walk out in front of a car without thinking. Spontaneity and initiation, which is about having the get up and go or to start something. For example, you might have the impulse to start a course and initiate it by finding out how to go about it and do it. If this part of your brain is damaged, you might sign up for a course but don’t do anything about getting started.

Slide 12 What are the functions of the frontal lobe

It is also about memory which is being able to recall what you have done, what has happened or what you have learned. Now language is about being able to communicate so people understand you. It can be either written or spoken but it is the way you make yourself understood. Impulse control/social and sexual behaviour is also in the frontal lobe. This is about being able to know and understand what you are doing appropriately. Like knowing how to behave in a socially acceptable manner at a gathering. For example, not laughing outrageously at a funeral or when or with whom sexual behaviour occurs. For example, not masturbating in the lounge in front of people or telling dirty jokes to people you don’t know.

Slide 13 Functions of the occipital lobe

This is where vision or what you see is located. Vison is also shared with the parietal lobe as well. It where what you see is processed and all the information you see with your eyes are sent to the brain. It helps you to make sense of visual information and understand it. It is also where we recognise colours and can see and track movement. This all comes from the occipital lobe

Slide 14 What are the functions of the Parietal Lobe

Now the functions of the parietal lobe are all about how we make sense of our environment and regulates and processes our five senses which are vision, hearing, smell, touch and feeling. So, it helps you feel sensations of pressure, touch, temperature and pain and help process the taste of food and drink. It is where the feeling and sensing of movement occurs as well and helps you with orientation which keeps you in alignment with your environment. It is your compass so to speak.

Slide 15 What are the functions of the parietal lobe

This is where you recognise objects and also where speech and language comes from. This function is shared with the temporal lobe. Tit is responsible for visuo-spatial tasks which is how we “identify, integrate, and analyse space and visual form, details, structure and spatial relations" in more than one dimension. Visuospatial skills are needed for movement, depth and distance perception, and spatial navigation.

Slide 16 What are the functions of the temporal Lobe

Functions of the temporal lobe are about processing auditory information. It is also about receiving sensory information from the ears and helping you comprehend and understand meaningful speech.

Slide 17 What are the functions of the temporal lobe

It helps you differentiate sounds and pitches transmitted from the sensory receptors to your ears. Like you can tell the difference between a child and an adult voice, a male or a female voice and many other sounds you hear to help you make sense of your world.

It is where speech and language is too and is about processing new information.

Slide 18 What are the functions of the temporal lobe

It is also about forming long-terms memories especially visual and verbal memory. It also helps you to interpret smells like the smells you grew up with. For example the smell of home cooking, or the smell of the farmyard.

So, as you can see, each lobe has some particular functions but also some functions are shared with other lobes as well. As I said earlier, the brain is a very complex organ, and it is not always easy to say one lobe will have just one function. They all have to work together.

# Segment 3 - Fundamental brain differences

Slide 1 Index

In this segment I will discuss the differences in the brain between a person with dementia and someone who does not have dementia. So, I will look at nerve cells or neurons, plaques and tangles, and memory changes. I will also look at normal aging verses dementia

Slide 2 Neuron in a normal person

Well firstly, the neurons do not suffer any damage if a person does not have dementia. This means the neurons do not die off or diminish. While older people may think they are getting dementia because they may be a little slower or forget some things, in actual fact there is nothing wrong with their brain and the same thing can and does happen to a younger person.

Slide 3 Neurons in person with dementia

Well many nerve cells cease to function properly. This means they lose connections with other nerve cells and eventually die. As more neurons die, the person progressively loses being able to function normally

Slide 4 Plaques and tangles without dementia

Now plaques and tangles are present in every brain from age 55 but that does not necessarily impair the function of the brain. Plaques and tangles are a special type of protein that assist in the normal functioning of the nerve cells and the movement of proteins within the nerve cells. There is no twisting or blockage that would result in the collapse of transport systems with the nerve cells meaning the messaged are uninterrupted.

Slide 5 Plaques and tangles in a person with dementia

However, in a person with dementia, plaques and tangles can accumulate between and within the nerve cells of the brain. These plaques contain clusters of an unusual protein within some damaged nerve cells. Tangles consist of clusters of twisted filaments within nerve cells that contain a particular protein.

So as these plaques and tangles accumulate in the brain, they cause other nerve cells to gradually wither and die.

Slide 6 Reactions and decision making without dementia

In a person without dementia there is a normal flow of information and messages, and there are no marked changes to normal behaviour and mental functioning.

Slide 7 Reactions and decision making with dementia

In a person with dementia, messages between brain cells are disrupted, preventing the brain from working efficiently. This leads to the characteristic symptoms of dementia such as loss of memory, impaired judgement and behaviour that is out of character for the person.

Slide 8 Memory changes without dementia

In a person without dementia, memory loss is not an inevitable part of the aging process. The person is able to function independently and carry out activities of daily living. The person is able to recall and describe incidents of forgetfulness given time. They may occasionally not be able to find the right word but can carry on a conversation perfectly normally. Judgement and decision making are not affected either.

Slide 9 Memory changes with dementia

However, in a person with dementia, symptoms that indicate dementia could be an inability to perform simple tasks, unable to recall or describe specific instances. The person may get lost or disoriented.

Slide 10 Memory changes with dementia

They are unable to follow directions. In a conversation if words are forgotten or misused and it is difficult for them to find them so holding a conversation can be hard. Judgement and decision making are affected.

Slide 11 Normal ageing versus dementia

Dementia is not a normal part of the ageing process. As we grow older we do become more forgetful and our brains just don’t work as sharply or as well as they did when we were younger, but that doesn’t mean we have Alzheimer’s disease or any other sort of dementia.

Slide 12 What is ‘Normal’ cognitive ageing

When you make a cup of tea, use the internet, or read a book, you're using your cognitive abilities. Cognitive abilities are the mental skills you need to carry out a task. These mental skills include attention, the ability to handle information, memory, and reasoning.

Throughout adulthood our cognitive abilities do gradually change. A certain amount of cognitive decline is a normal part of ageing. Some people will have more cognitive decline as they age than others and some people will start to show cognitive decline at a younger age than others.

One of the major changes is that we process information more slowly as we age. This table shows some of the things that change with age and some that stay the same.

Slide 13 What normally does not change

There are certain things that do not normally change as one gets older like being able to focus on one task for example reading a handout. A person with dementia can be given a brochure and will still read it but they usually will not be able to recall it.

If they have learnt general factual information like general knowledge and word, they will be able to recall it quite easily.

We all do things automatically in our life. Things we have learnt while quite young. Because they are well cemented in our long-term memory, they will be able to remember how to do the without thinking. An example may be riding a bike. While they may not be able to actually get on a bike and ride it, they will not have forgotten how. All of these are habits of a lifetime for many can be recalled with ease.

Slide 14 What normally becomes more difficult with age

So as a person gets older, it does become more difficult to focus on one task while ignoring something else. For example, watching a movie while the people behind you are talking to each other or being able to focus on more than one thing at a time such as getting tea ready while talking on the phone. This is commonly called multitasking.

It may also be difficult to remember personal experiences such as whether they have taken Their medication this morning.

Being able to do complex tasks that require taking in complex information then analysing it can be more difficult too. An example is adding the cost of some grocery items and subtracting the discount. Now these things do not happen to everyone, but they are more likely to become more difficult as a person gets older.

So, as you can see, there are clear distinctions between a person with dementia and a person with normal aging.

# Segment 4 - Conditions that are not dementia

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Dementia is not a part of normal ageing as I said in the last segment. However, dementia is a group of symptoms affecting cognition, behaviour, and social abilities severely enough to interfere with a person’s daily functioning. Dementia indicates problems with at least two brain functions.

So, a person may show signs of what can appear to be dementia without actually having dementia. For this reason, you need to check what else is going on for the person without jumping to conclusions. For example, they may have moved home. This change of environment can lead to confusion for the person.

There can be other reasons why a person’s ability to perform daily activities can decline. Therefore, a diagnosis of dementia would not be made before other possible conditions were ruled out.

So, in this segment I will discuss what other things could be affecting the persons behaviour that you might think is dementia, but it isn’t. It includes acute confusion or delirium, depression, side effects of medications, taking longer to process information, and attention seeking with examples of why the behaviour has changed. –

Slide 2 What causes acute confusion or delirium

This refers to a sudden change in cognition and is usually related to illness like a heart attack or stroke, infection, injury or other medical reasons. The cognitive change tends to be dramatic and sudden. You can find out more about delirium in the delirium topic.

Slide 3 How depression affects a person

If a person has depression it can cause some changes in cognition. In particular, it can affect the person’s concentration or their ability to focus their attention on something. They lack motivation to do anything and their ability to recall information is impaired.

Slide 4 How depression affects a person

Depression is also accompanied by negative thoughts which makes it very difficult for a person to climb out of this state. They are likely to more irritable as well. Changes in appetite is also not uncommon. This could be to overeat or not even eat at all. Frequently their sleep patterns are affected as well. Doctors will often wish to rule out a depression before diagnosing dementia.

Slide 5 Side effects of medication affect a person

Many medications that are given to relieve symptoms of one condition can actually create other problems for people. For example, they can interfere with cognitive function that can mimic dementia and lead you down a path of thinking they have a dementia when they don’t. So never discount that medications can have a negative effect on a person’s cognition. Always check to find out if someone has begun a new medication recently and try to relate the commencement of the medication and the appearance of symptoms. Likewise, a person may have been on a medication for a long time and become toxic to it which can affect their cognitive ability and behaviour. So always keep this in mind if a person shows increasing signs of cognitive impairment that is unusual for them maybe medications can be the cause. Always keep a good record of any change in a person’s behaviour including dates and times. Makes it much easier to eliminate possible causes.

Slide 6 Taking a longer time to process information

Now you may find that someone is taking longer to process some information and think the person is getting dementia. While this could be a sign of dementia, it could also a result of normal aging. So, this symptom needs to be accompanied by another sign or symptom before it could be considered as suggestive of a dementia. Pace the task more slowly for the person. Tie it in with their past experience, as older people have years of accumulated knowledge and experience. This is where documentation is really important. You need to write down when you first notice any symptoms and what happened. This information is valuable in a diagnosis of dementia or not dementia.

Slide 7 How attention-seeking behaviour is displayed

Now sometimes when a person is aggressive, resisting care and reverting to childhood are labels often used to describe a person’s behaviours. Such labels represent some of the stigmatisation that can occur for people living with dementia. It is important to recognise that there are always reasons why a person behaves in a particular way so don’t jump to conclusions.

Slide 8 What may these behaviours mean

So how can these behaviours be explained? Well attention seeking may be loneliness, aggression may be fear and resistance to care may be to hold on to their independence

Reverting to childhood may mean responding to the care you are giving. Are you using a parental approach that they are responding too? Always look to what you might be doing that could be influencing the behaviour of the person.

Slide 9 What other factors can influence behaviour

Maybe the behaviour is not intentional? When we observe a fluctuation in a person’s functional abilities, we can make the mistake of believing that certain behaviour is intentional or being ‘put on’. It is important to recognise that other factors that can influence behaviour. Maybe the person is tired, anxiety, or hunger.

Slide 10 What other factors can influence behaviour

Maybe they are dehydrated or in pain. All of these can affect the brain’s ability to function. What may look like intentional behaviour can be a reflection of the type of dementia the person has, or of other factors that may be affecting them.

Slide 11 How to help a person maintain function

It is important to recognise and promote a person’s ability to maintain function.

A common mistake is that a diagnosis of dementia means a complete loss of function, when in actual fact we can ‘de-skill’ by not providing them with opportunities to use the skills they do have. So always encourage them to do things for themselves, never assume that can’t do something, break tasks down to what they can do to give them a sense of achievement.

Slide 12 How to improve the outlook for a person with dementia

The outlook for a person with dementia is not hopeless so always reinforce the message that people living with dementia can indeed continue to live full and productive lives. The role we have in supporting them can enhance their quality of life by helping them feel safe and comfortable and providing emotional support. Provide meaningful and fun activities they can do. Spend time with them relaxing and talking. All of these things will increase the person’s ability to function. Celebrate the fact that this work can be extremely satisfying and rewarding.

In the next few slides, I will give examples of scenarios of people living with dementia

Slide 13 Decision making (poor judgement) Scenario

It is not uncommon for a person to make really poor judgements too. For example, Alan woke up in the middle of the night and left the house. He was not able to discern what time of day it was, so he got out of bed and started wandering. He was found at 4 a.m. wandering along the banks of the Avon River in his pyjamas. He was cold and confused. He couldn’t tell the policeman where he lived or why he was there. So, his judgement was impaired, and he made a poor decision to get up and go outside.

Slide 14 Decision making (slower reactions) Scenario

Making decisions become slower too because it takes longer for the messages to get to the neuron to enable them to make the choice, so they need time to respond. For example, Jeremy lives on his own in a small flat. His support workers have noticed Jeremy seems to have difficulty in deciding what daily tasks need doing. Some legal documents require his signature, but he seems to keep putting this off. They have also noticed that some of his reactions are slower. For example, when the phone rings Jeremy seems bewildered by the sound and takes a few moments to realise that he needs to answer it.

Slide 15 Being lost in familiar surroundings (disorientation) Scenario

Getting lost in familiar surroundings is common too. For example, Jim knows he lives in a street called Puhara, and even the house number, 41. But when he goes out for a walk on his street, he often can’t remember which house is his. So, Jim cannot remember the street number or what the house looks like. Nothing registers as familiar. So, when a person gets lost in familiar surroundings, they can be at risk to their safety so require more supervision.

Slide 16 Carrying out everyday tasks Scenario

Being able to remember the order that tasks get done also become scrambled as well. For example, Alison often confuses the order in which she does things and her usual daily routine has been forgotten. She usually gets up and gets herself dressed. Today you notice that she has put her underwear on over her trousers and her socks over her shoes. So, she gets the order of putting on clothes confused or puts on too many pieces of the same piece of clothing. I remember a resident I had who kept putting on panties. One day, she had 10 pair of panties on. I made a game out of it and we managed to get them all off really easily.

Slide 17 Performing familiar tasks Scenario

Performing familiar tasks can become scrambled too. For example, Wiremu used to keep in contact with his whānau by phone. Now when he uses the phone, he often rings the wrong number and gets frustrated when he doesn’t recognise the voice on the other end. He just doesn’t know what he has done, and whanau get concerned they are not hearing from him as usual

Slide 18 Memory Changes Scenario

There will be changes in a person’s memory too. For example, Bill is in a residential dementia unit and is 78 years old. Recently Bill has started to get up and dressed at 5 a.m. He gets distressed when he can’t find his gumboots as he thinks he needs them to go and milk his cows. The long-term memory is still very clear to Bill and he thinks he still has to milk the cows so he is back in a different time in his life and because it had been a routine for so long, he is unable to understand why his usual attire is not available.

Slide 19 Memory loss Scenario

Memory loss is probably what people expect for people with dementia. It can come in many forms. For example, Ted mistook his grandson for his son when his son brought him to visit his grandfather in the dementia unit. He no doubt even realised he was in a residential facility either. This upset his family because Ted did not recognise his grandchild.

Slide 20 Personality Changes

Personality changes occur too. A normally mild-mannered person can become angry and aggressive very quickly without any provocation. An example is, Jenny gets ready to go to the supermarket. She puts on her dressing gown and slippers instead of her clothes. When her husband told her to put something more appropriate, she yelled at her husband which visibly shocked him, because this was not the Jenny he knew.

Slide 21 Ability to solve problems

Some people who have solved problems all their life, find it very difficult when they have dementia. For example, Mereana who used to be an accountant now finds it hard to do any maths in her head. Even when she is out shopping, she can’t to work out what change she will get. This can be very distressing for them.

# Segment 5 - Reversable dementia

Slide Index

It is very easy to assume someone has dementia if they become confused or suffer memory or behaviour symptoms however before a definitive diagnosis can be made, it is important to rule out any reversable conditions. In this segment I will discuss reversable causes that need to be eliminated before a diagnosis of dementia can be made so I will discuss medications, depression, vitamin deficiencies, infections, and other causes.

Slide 2 How medication cause symptoms

Now medications can interact in such a way that they cause unwanted or sometimes unexpected reactions in some people that produce symptoms like dementia. The sort of symptoms you could see are confusion, memory loss or hallucinations.

Slide 3 What medications can cause symptoms

Well these are common drugs that are used regularly with older people. For instance, a common medication used for people with continence issues, like Ditropan that works on the smooth muscle of the bladder to help the bladder contract is one drug that can cause confusion and memory loss.

Also sleeping pills, cough syrups, antiallergy medications all can cause symptoms of dementia.

Slide 4 What causes medication toxicity

Sometimes when a person has been on a medication for a long time, the body can become toxic to it and they become seriously unwell and cause symptoms of dementia or delirium. It essentially means the drugs builds up in the body to such an extent it doesn’t work for them but works against them. Now some medications are known to do this, and a person will have regular blood tests to check out their levels. For example, dilantin, an anti-epileptic drug so a person on this mediation is monitored. So, these are known side effects. Now some drugs side effects are unknown until a person presents with and adverse event and become extremely unwell so regular monitoring of medication is not carried out. So, there are known, and unknown side effects to medications. Known you can predict and monitor. Unknown you can’t predict or monitor...

I had a man in my care once who was displaying really strange behaviour and was suffering from a raft of strange symptoms. I took him into hospital on several occasions where they did a CT Scan and told me there was nothing wrong with him. All his blood tests were normal too. However, the symptoms kept escalating to such an extent he ended up running around the facility naked. Finally, I managed to get the Mental Health team in to assess him, after many tries, and it was found that he was having a reaction to a medication he had been on for a long time. It had become toxic to his body. He was finally admitted to hospital where he was taken off the drug and carefully monitored over this period and started on a new medication. It took 6 weeks to get him stabilised again before he was able to come back to us. So never disregard the effects of not only recently commenced medications but also medications a person has been on for a long time.

Slide 5 How depression symptoms mimic dementia

Whenever a person undergoes a major life stress it can affect the chemical balance in the brain and therefor produce symptoms like those in dementia. The type of things you could see are low mood and low energy levels. Forgetfulness is another common symptom as well. Again, once the depression is managed, the person’s mood and energy levels increase their memory returns as well.

Slide 6 What vitamin deficiencies can cause dementia symptoms

Insufficient B vitamins such as folate, niacin, riboflavin, thiamine and B12 or Cobalamin need to be available for good brain function. So, when the body does not have enough of these vitamins, then confusion and changes in mental state can occur. Once the deficiency is remedied, the symptoms disappear as well,

Slide 7 What hormone abnormalities can affect a person

Low levels of thyroid hormones as in hypothyroidism or high thyroid levels as in hyperthyroidism can mimic dementia. Also, Cushing’s Disease where a person has high levels of the hormone cortisol or Addison’s disease where there are increasing lower levels of cortisol can cause confusion or memory loss. Other endocrine abnormalities such continued frequent attacks of hypoglycaemia cause effects a person can result in confusion and lead you to think the person is getting dementia.

Slide 8 Common infections that affect a person brain function

Infections like cellulitis from skin infections or ulcers, urinary tract infections and chest infections can affect a person’s brain.

Slide 9 How do infection affect a person

The changes you will likely see are confusion and the rapid change in alertness, attention, memory, and orientation. When a person has this collection of symptoms it is called delirium. So, it is important treat a person’s infection because once the infection is taken care of, the delirium is reversed. This is why it is important to identify the cause and treat the problem. You can see more on delirium in the delirium topic.

Slide 10 other conditions that can affect a person

Other things you need to be aware of that can affect a person’s brain are things like dehydration, malnutrition or under nutrition and constipation. If a person doesn’t get sufficient water for the body, food to fuel the body or suffers a bowel blockage from constipation, then there can be a negative impact on the person. So, remember you need to be alert to any changes in the person and then work backwards. When did they last have a drink? Are they eating all their meals? If not, what are they leaving behind? You can find out more on tis in the nutrition and hydration topics. Also, when was the last decent bowel motion the person have? This is why it is important to record bowel motions and their descriptions. All these are contributing factors to other serious conditions.

# Segment 6 - Irreversible dementia

Slide 1 Index

In this segment I will talk about the dementia that are not able to be reversed and there are no known treatments for. This includes Alzheimer’s disease, vascular dementia, dementia with Lewy bodies, frontal lobe dementias as in Pick’s disease and Creutzfeldt Jakob disease.

Slide 2 About irreversible dementias

Now let’s talk about irreversible dementias. These are also known as degenerative dementias. The most common form of irreversible dementia, accounting for 50–60% of all diagnoses, is Alzheimer’s disease but there are many other conditions that cause dementia.

Slide 3 What happens in Alzheimers Disease

Alzheimer’s disease is the most common form of dementia and is where the nerve cells die, resulting in loss of brain tissue throughout the brain. With the cells dying over time, the brain shrinks dramatically, affecting nearly all its functions. The brains of people living with Alzheimer’s disease have fewer nerve cells and connections than a healthy brain does.

Slide 4 What happens in Alzheimer’s disease

As a result, people living with Alzheimer’s disease lose functional nerve cells in the areas of the brain that deal with thinking and memory. They also experience a build-up of abnormal proteins in some brain cells. So, when the never cells die, they cannot communicate with each other therefore a person’s ability to function normally is impaired. The way the nerve cells die, is different for each person so no two people will present with the same symptoms in the same order.

Physical changes in the structure of the brain develop because of cells dying which leads to the brain shrinking. Plaques and tangles develop in the brain tissue and disrupt the messages throughout the brain, especially in the areas that control memory and mental functions.

Slide 5 What are the symptoms of Alzheimer’s disease

Well there are a wide range of symptoms a person may have. As is said earlier, not everyone gets exactly the same symptoms in the same order. It depends where the brain cells start dying first. So, there is increasing difficulty in managing complex or new tasks. This might be the first indications a person living close to a loved one might have that there is something amiss. For example a person who has always been able to get themselves showered and dressed appropriately, may find that they cannot get the order of the clothes put on correctly and put their shoes on first and then try to put their legs into the shirt over their shoes.

They may start forgetting the names of people and places, appointments, and recent events. Now I am not talking about normal forgetfulness of people names, this is names of people they know well and do not even realise they have got their name wrong. They may have always been good at remembering appointments like going to see the doctor, but they suddenly just don’t turn up.

They could also show a lack of initiative or withdrawal from usual activities. For example, a normally active person now just stares into space with no inclination to get out of their chair.

Slide 6 What are the symptoms of Alzheimers Disease

The family may notice that they are more or even less emotional around things that would normally get a response or personality changes that now the family doesn’t know who the person is any more. They have become a quite different person.

They may become very frustrated when they can’t find something or remember how to do something, they used to be able to do. This may create an aggressive response from them which could be unusual for them.

They could be more anxious, sad, irritable, suspicious and lose confidence in their ability to do things.

It could be that they find it difficult to find the right words or understanding what has been said, say something totally outrageous or look at you in a confused way not knowing or understanding what you have said.

Slide 7 What is Vascular Dementia or multi-infarct dementia

The occurs when cells in the brain die due to the oxygen supply is being cut off. So, this is where they brain has been damaged from impaired blood flow. This happens because a blockage has occurred in the network of blood vessels that supply oxygen to the brain. This is the second most common form of dementia.

Related to multiple strokes also called multi-infarct dementia which are commonly known as TIA’s.

Slide 8 What are the symptoms of vascular dementia

The onset can be sudden caused by a major stroke. This means the person has one single event that causes severe memory loss. In this case they may not get their memory back. However, it may also occur gradually by a person having several small stokes. This can also coexist with Alzheimer’s disease as well so will show the characteristics like those of Alzheimer’s disease. However not everyone who has a stroke suffers vascular dementia.

Slide 9 What is Lewy Body dementia

Well Lewy Body dementia is when abnormal clumps of protein develop in the nerve cells in the brain. These deposits are called Lewy Bodies because there are many of them. They can occur on their own or in people living with other dementias or psychiatric disorders so is often difficult to diagnose. They affect many different regions of the brain and not just one area. These clumps disrupt normal functioning and act like a roadblock for messages travelling within the brain therefor the person is not able to receive or understand the message sent.

Slide 10 What are the symptoms Lewy body disease

Well there are many symptoms of Lewy body dementia. Firstly, there is a fluctuation in intellectual functioning, especially around their alertness and attention and they find it difficult to concentrate as well.

They can have poor hand–eye coordination. Now it is important to note that the symptoms of Lewy bodies disease are like Parkinson’s disease so can be easily misdiagnosed. These symptoms are slowness, muscle stiffness, trembling of the limbs, a tendency to shuffle when walking, loss of facial expression and changes in the strength and tone of voice.

Slide 11 What are the symptoms of Lewy body disease

They have balance issues and are prone to falls as well so you need to keep a close eye on them. Sometimes they have visual hallucinations and delusions meaning they can see things that are not there or think people are doing things to them which is not true. The person may also appear depressed and/or be aggressive. They are extremely sensitive to medications as well and can have adverse reactions to them meaning it can be difficult to establish a suitable medication regime making them difficult to manage.

Slide 12 What is Pick’s disease

Pick’s disease is a dementia where damage occurs to the frontal lobe and/or the temporal lobes of the brain. These areas are responsible for behavioural control, judgement, emotional responses, and language skills. Often affects younger people commonly between the ages of 40 and 64.

Slide 13 What are the symptoms of Pick’s disease

Well there can be personality changes such as apathy and indifference. So, a normally outgoing person becomes a different person with no interest in anything.

You may also notice inappropriate behaviour. For example, they may become very sexual which is not their normal personality or behaviour.

They can also have poor insight and social judgement and behave totally inappropriately or have no comprehension of what they are doing.

Slide 14 What are the symptoms of Pick’s Disease

Now unlike other dementia, they may not be forgetful in the early stages but may develop into accelerated memory loss. They lose the ability to initiate, organise and follow through on simple plans and familiar activities.

This makes it easy in the early stages to mis-diagnosed their condition as stress and/or depression.

You would also notice that they have difficulty with language where they may mimic or echo what you say, have difficulty speaking or understanding what is said

Slide 15 What is Creutzfeldt-Jakob disease (CJD)

Well this is a rare degenerative disease which occurs in later life that has a rapid progression with the person usually dying within a year of the onset. It affects people over 60 years of age. Now 85% of cases are sporadic which means a person has no known risk factors. Up to 10-15% of cases have hereditary factors and the third group are acquired where the disease is transmitted by exposure to brain or nervous system tissue.

Slide 16 What are the symptoms?

Well the early symptoms include failing memory, behavioural changes, lack of coordination, and visual disturbances.

Slide 17 What are the late symptoms?

However later symptoms include mental deterioration which becomes very pronounced. Also, involuntary movements, blindness, weakness of extremities, and finally coma may occur. However, this is a rare disease a I said in slide 16 but is good to have an understanding that it exists.

Now dementia can also occur with many other conditions like Parkinson’s Disease, Head injuries and Huntington’s Disease. However, these are not discussed in this segment, but you can find out more about these conditions in the Dementia topic in the list of topics.

# Segment 7 - Dementia, delirium, and depression

Slide 1 Index

In this segment we will discuss dementia, delirium, and depression. Although some of the features of dementia, delirium and depression are similar, there are some key differences between them that you need to know. It is not unusual for a person living with dementia to also experience either depression or a period of delirium.

Slide 2 How does dementia, delirium and depression differ

Well dementia is a progressive cognitive decline while delirium is a temporary state of confusion. However, a person with depression has changes in thinking and reasoning linked to their mood. Because signs and symptoms overlap, it can be difficult to decide what the problem is. Therefore, an accurate assessment is important to ensure the correct treatment is given.

Slide 3 What happens in dementia

Dementia has a slow onset that progresses over time. There may also be a period late in the day where they become increasingly agitated and have increased anxiety. This is known and ‘Sundown syndrome’

The condition has a time frame for progression from months to years. Now a person with dementia is generally alert and they do have a normal attention span especially in the early stages, but it will decrease over time. However, their recent and past memory are impaired meaning they may not remember what you just said or an instruction you give them. Over time, their long-term memory will be affected to the extent they may not even know people close to them.

Slide 4 What happens in dementia

The person will also have difficulty thinking and with words meaning they may look vague when you ask them something. They may have difficulty getting the right word when they want to say something too and spend considerable time trying to find the right word. They are also very likely to have poor judgement meaning they cannot discern things like what is safe and what is not. They may also have trouble with finances and give a lot of money away or keep drawing money out of the bank. Their sleep will be fragmented, and they may not be able to differentiate between night and daytime meaning they want to sleep more during the day and are up at night. They may also have personality changes leading people to think this is a completely different person in their midst. They may lack of insight into their condition and have no understanding that they have dementia and be totally in denial there is anything wrong with them.

Slide 5 What happens in delirium

Well with delirium there is a sudden onset. A person can be fine one day and the next are confused. This is more pronounced at night or on waking in the morning. It can last anything from days up to a month.

Slide 6 What happens in delirium

Their alertness fluctuates so it makes you think there maybe nothing wrong with them. Their attention is Impaired and can fluctuate as well and not be able to stay on one subject or get stuck in a particular subject. Sometimes you will get their attention and other times you will not be able to. Their memory is impaired with both recent and immediate. So, something that a person would usually remember like their daughter visited them the day before, they will have forgotten and they won’t believe you when you try to remind them she did come..

Slide 7 What happens in delirium

Their speech will be completely disorganised so you may find it difficult to understand what they are saying. Their sleep pattern is disturbed or their sleep– wake cycle is reversed. They may sleep during the day and be awake at night or keep waking up at night which is something new for the person. There is always an underlying cause too as it is associated with acute illness like an infection or heart attack

Slide 8 What happens in depression

So, the onset of depression can be usually gradual like over weeks or months. If it comes on suddenly it is usually a red flag for some other biological disease like vascular disease or a stroke. Depression can be bad at any time of the day but frequently worse in the morning or following certain situations. Depression can last for months to years especially without treatment.

Slide 9 What happens in depression.

The person’s alertness is normal meaning they understand what you are saying. They know what is going on and can hold a conversation, but their attention can be easily distracted with long periods of appearing to be deep in thought. So, you can be talking to them and they suddenly drift off somewhere else mentally. Their memory is patchy. Somethings they will remember and other times they will not. They can be so withdrawn that they completely forget they have an appointment to attend or remember what you have said to them the day before.

Slide 10 What happens in depression

Their thinking is very negative, and they put themselves down. They even show signs of hopelessness, do not see things changing at all, cannot see any future for themselves: they just give up. There are usually some sleep problems in depression from not being able to get to sleep, or they go to sleep but cannot stay asleep. Some people may feel like they have not slept at all when they have, or they just sleep all day. Other features maybe they neglect themselves not showering, shaving, getting into day clothes; just stay in the pyjamas all day. They can also spend long moments in deep personal thought. So, you can see there are some similarities and differences between the three conditions.

There is a table of these three conditions in the resources section as well.

# Segment 8 - Diagnosis of dementia

Slide 1 Index

Making a diagnosis can be difficult, especially in the early stages of the condition so in this segment I will talk about how to diagnose and support a person with dementia, how may a diagnosis affect a person and how to talk to them, and risk factors for dementia.

Slide 2 How to diagnose dementia

Sometimes a period of monitoring over several months is necessary before a diagnosis can be made. Early diagnosis is very important, as it will help rule out other conditions or illnesses that have similar symptoms and can help the person experiencing dementia to plan for the future.

Discussing concerns with a doctor is usually the first step. This can mean that illnesses such as depression are identified and treated. The doctor may refer the person being diagnosed to a specialist consultant.

Assessments can include conversations with the person being diagnosed and others close to them, a physical examination and memory tests and/or brain scans.

Slide 3 What types of scans are available

Well there are three common types of scans available to help decide if there are changes occurring in the brain. These are computerised tomography known as a CT scan or computerised axial tomography known as a CAT scan. Both these take pictures of the brain using X-rays and a computer. The other most common scan is magnetic resonance imaging or MRI scan. This uses a computer to create an image of the brain using radio signals produced by the body in response to the strong magnet in the machine.

Slide 4 How to support a person being diagnosed

If you are supporting the person being diagnosed, it is useful to write down any questions or worrying signs beforehand to ask the doctor, as it can be difficult to remember everything you want to ask during a consultation. So, write down any important points the doctor makes during the consultation. Do not rely on your memory to remember what they have said. By writing down these points you can then ask for clarification at a later stage once you have left the surgery.

Next ask for an explanation of medical terms, words, or phrases if you do not understand them. Doctors have a habit of talking in medical speak, thinking everyone understands what is being said. If there is anything you do not understand, ask for them to explain it to you.

Then find out what support is available in the community. While the doctor may not know, they should be able to direct you to organisations or places where you can get help.

It is important you do these things as you may have to relay what has been said in the consultation to other family or whanau members. While you may not think of everything, having a record of the visit is very helpful.

Slide 5 What else may be needed

Very likely there will be follow up appointments with other specialists. This may be with psychiatrists, neurologists, geriatricians, or a specialist team. Explaining the diagnosis is an important step and if you are the advocate for the person or their family/ whanau you may have to attend these appointments with the person.

It is also very likely that support from family or others may be needed to ensure that the person is fully but sensitively informed about the condition and its progress in language and terms they can understand. So, who else needs to be called in from the family / whanau to help? Part of your role may be to communicate with family members

While there is currently no cure for dementia, there are a number of drug treatments available for people living with mild dementia. These drugs can help lessen some of the common symptoms and may help improve general functioning for some people. If the person is to go on a drug regime, there may be things you need to know on what the drug is expected to do, how you will know there is an improvement, what are the side effects of the drug, how long the person can be on it to name just a few questions you should ask.

Slide 6 How will a diagnosis affect a person

A diagnosis of dementia can have a significant impact on a person’s wellbeing, and it is understandable they will experience a range of emotions including shock, disbelief, fear, shame, guilt, anger, and sadness. They will feel real concern about what the future holds for them as well as a sense of isolation and being cut off. For some, however, the diagnosis may bring a sense of relief there really is a reason behind their symptoms and behaviour. It is not being imagined. It is real so they can now get on with life.

Slide 7 How to talk to a person after diagnosis

So, for a person who is in shock there is no point in telling someone that there is no need to feel sad or there is nothing to worry about. It will not help, as they are likely to think that you simply don’t understand how they feel or what they are going through. This in fact is true. You don’t know how they are feeling.

So, what you need to do when talking with the person is to try to be sensitive to what they may be feeling. Just listen to what they are saying and don’t tell them everything will be alright. Reassure them and confirm that you are there for them whatever happens. Being abandoned may be a very real fear for them too. So, pay attention to non-verbal signs of emotion. Some people who are really frightened may just pass things off and laugh about it when in fact they are so afraid they don’t know how to express it while other people may become angry and aggressive.

Slide 8 How to talk to a person after diagnosis

Help the person to identify their emotions by commenting at an appropriate time on how you think they may be feeling. For example, by saying “You look quite sad” or “You seem worried” is showing you care and open the door for them to really talk about how they feel. You also need to allow time for your comment to sink in and for the person to react. Don’t expect an immediate answer. It may be that days later they say something like “Remember when you said to me, I looked sad? Well I was really feeling concerned for my family and that I may not be able to recognise them:” So, give them time to take in what you have said or asked. Don’t forget to confirm your impression by acknowledge the feeling. Saying something like “It’s a lot to take in isn’t it” or “I can understand you being sad”.

Slide 9 What is your role

It is not your role to diagnose a person living with dementia. The most important thing you can do is to report back any changes you notice in a person.

Usually the person to speak to would be your coordinator, district nurse, registered nurse or manager who may then contact the family/whānau and/or health professionals or GP to let them know about the changes.

Dementia doesn’t just affect the person living with it but also the lives of the family/whānau and friends who are close to that person as well.

A diagnosis of dementia can have a significant impact on a person’s wellbeing. It is understandable that they will experience a range of emotions, including shock, disbelief, fear, shame, guilt, anger and/or sadness.

They are likely to feel a real concern about what the future holds for them as well as a sense of isolation and being cut off.

For some, the diagnosis may bring a sense of relief because they now have a reason for their behaviour.

So, document what you see in their notes or keep a notebook record of the changes you notice with a date and time you notice it. This gives concrete evidence that there are changes happening for the person with a time frame. It could then be related to a specific event or even time of day. All these are critical pieces of information that will help with diagnosis.

Slide 10 What are the risk factors

The possibility of acquiring dementia increases with advancing age. Also, as are people living longer, dementia is becoming more common. Age is the greatest risk factor for developing dementia, but dementia is not a consequence of ageing. Dementia predominantly occurs in the second half of people’s lives, often after the age of 65.

Those who have a parent, brother, sister, or child with Alzheimer’s disease are more likely to develop it. The risk increases if more than one family member has the illness. When diseases tend to run in families, heredity or genetics, environmental factors, or both may play a role.

Segment 11 What is the incidence by age for severe dementia

Dementia affects more women than men and more European than other ethnicities. The incidence increases with age, but age is not the cause of dementia a I said in the last slide. It is estimated that around 2% of the population will develop dementia before age 70 while as high as 30% or more for those over 90. So, you can see how much it increases with age.

Slide 12 Other factors that increase the risk of dementia

Apart from the age and familial risks of dementia, researchers believe that most people develop dementia because of a combination of different risk factors rather than from a single cause. Factors that may increase the risks of developing dementia are a previous head injury. Dementia pugilistica can develop from a head injury. This is what happens to the brain by being repeatedly punched in the head as in boxing. It is also called “Punch Drunk Syndrome” By being repeatedly struck to the head, the brain degenerates. It can also result form other forms of head injury like repeated concussions.

Smoking.is also another factor that can contribute to dementia. Cigarette smoke increases oxidative stress and inflammation which is an imbalance between antioxidants and free radicals in the body. So, smoking can tighten and damage the blood vessels which restrict the blood flow to the brain. This can deprive the brain of essential nutrients and oxygen and increase the risk of blood clots in the brain as well that can lead to a stoke.

High blood pressure can also contribute to dementia as well because it can damage small blood vessels in the brain, affecting parts of the brain responsible for thinking and memory.

Slide 13 Other factors that increase the risk of dementia

Diabetes is a risk factor due to brain damage that is often caused by reduced or block blood flow to the brain.

High blood cholesterol means fatty deposits develop in the blood vessels. These fatty deposits eventually grow, blocking the blood vessel making it difficult for enough blood to flow through the arteries.

People who drink large amounts of alcohol over time are more likely to have a reduced volume of the brain’s white matter. The white matter in the brain helps to transmit signals between different brain regions. Alcohol-related dementia is known as Wernicke Korsakoff Syndrome. People with this syndrome have a particularly strange walking gait which is easy to see.

Slide 14 Other factors that increase the risk of dementia

While it is considered that other substance abuse can contribute to dementia, it has not been well studied so how it affects a person is not fully know yet.

People living with Downs syndrome are more at risk of developing dementia in adult life and this risk increases as they prematurely age. Research suggests that over half of the people living with Downs syndrome and who are in their 60s have Alzheimer’s disease.

Human Immunodeficiency Virus, or HIV as it is more commonly known, can cause healthy brain cells to break down, releasing damaging enzymes. These enzymes can then attack the healthy neurons, resulting in dementia symptoms. Over 20% of HIV patients develop some symptoms of dementia.

# Segment 9 - Stages of dementia

Slide 1 Index

Int his segment I will discuss what is dementia and how it affects a person. I will also discuss the types of dementia.

Slide 2 What are the stages of the disease

There are usually three stages of dementia that people go through although you may come across some information that says there up to seven stages but for this one, we will use the simple three stages. They are early/mild, moderate, and advanced/severe. In the next few slides, I will briefly describe each stage, but it is important to note that everyone is different, and these are a guide only. Because a person doesn’t display one of these symptoms doesn’t mean they do not have dementia. This are just to give you some idea of the signs and symptoms.

Slide 3 Early/Mild Dementia – Signs and Symptoms

In this stage of dementia, the person may still be able to work, drive a car or live alone but they are doing some things that are a little different for the person. It is a stage of awareness for those close to the person, not alarm so just be cautious and don’t jump to conclusions. Some of these signs and symptoms can be from stress, lack of stimulation or boredom. The difference with these conditions, if you give them time, they will be able to remember the right name for the person or the misplaced item.

So as a general rule the person may have difficulty coming up with the right word or name. You may need to prompt them to remind them and they could say “Of course it is. How silly of me to forget?”

They may also have difficulty remembering names when introduced to new people. Now many people, who don’t have dementia have this problem. I do for one, and I don’t have dementia. So, don’t get it confused with a normal behaviour but if it is an unusual behaviour for the person.

They may have difficulty performing tasks in social or work settings. For example, forget appointments. Things they normally had no problem with but now it is becoming difficult for them.

Slide 4 Early/Mild dementia signs and symptoms

They may forget material that was just read. Again is this something they normally can do and now can’t.

It could be they lose or misplace a valuable object. Now I’m sure that you have at times misplaced something like your keys. The difference here, is you have been able to track back where you have been and found them. A person with early to mild dementia is unable to do this. They just keep misplacing more and more items or they may even give away items or money to strangers. These people are at extreme risk and is a major alert for those close to them.

You may notice they are experiencing increased trouble with planning or organizing. You may find that their home surroundings are untidy which is unusual for them or they may shuffle papers around not know what to do with them. Now you may also find other strange things the person is doing that is unusual for them so keep a note of them.

An example of early/mild dementia may be a person is finding things normally done with ease. Like cooking a meal are becoming more difficult. The stove is being left on and taps left running. Going to the bank maybe difficult because of not remembering the PIN number. They may be on the road going to the supermarket and have to stop because they have forgotten how to get there or what they were going for i.e. the supermarket. They may also struggle once at the checkout working out how much money to hand over or become frustrated believing they have been short-changed. You can see on the image of the brain, the part of the brain that may be affected.

Slide 5 Moderate Dementia signs and symptoms

Now you might find some things a person is doing a little more unusual for them. They may have received a diagnosis of early dementia, but they are progressing into the next stage and are being forgetful of recent events or personal history. You may arrange to have a coffee with them, and they don’t turn up or they miss a family gathering.

You may find that they are often feel moody or withdrawn, especially in socially or mentally challenging situations. This may be an unusual situation for them especially if they are normally bright, cherry and very outgoing.

It could be that they are unable to recall information about themselves like their address or telephone number, and the high school or college they attended. Now some of this may relate to how often they meet up with old school chums, and now days with speed dials on phones, many people don’t remember phone numbers especially their own and they don’t need to call it so make sure what you are asking them is relevant to their situation.

Slide 6 Moderate dementia signs and symptoms

Maybe they are experiencing confusion about where they are or what day it is. Now again put that in perspective. I know many people during lock down for Covid-19 have had this trouble, including myself, because each day is the same. You are not going out or have appointments to keep so each day blends into another. The difference here is, that when you start asking questions and recalling conversations and go back through your memory bank or check the calendar then you have a prompt. People with dementia are more likely than not unable to do this.

You may notice the person is requiring help choosing proper clothing for the season or the occasion. They are unable to choose colours that match when they have usually been very coordinated with their clothing and style.

It could also be that you are noticing they are having trouble controlling their bladder and bowels. It could be that you notice a smell of urine in the house or that they are changing underclothes and hiding them, but the odour becomes overpowering. It could be embarrassment at this change or just not know what to do with the soiled underwear.

Slide 7 Moderate Dementia Signs and symptoms

Maybe they are experiencing changes in sleep patterns, such as sleeping during the day and becoming restless at night. They cannot discern the difference between day and night with the body clock being out of sync.

Maybe they are showing an increased tendency to wander and become lost. They may be someone who likes to walk a lot but you find they are now staying away longer than usual or don’t even come home so you need to get the police involved or may have a tracking device on them so you can find them if they get lost.

You may also pick up some personality and behavioural changes, including suspiciousness and delusions or compulsive, repetitive behaviour like handwringing or tissue shredding. These are all unusual behaviours for the person.

Slide 8 Moderate dementia signs and symptoms

It is at this stage that families become quite concerned at the behaviour of the person because they keep forgetting family names, not keeping themselves or their environment clean and tidy which is unusual for the person. It is possible that they may start wandering as well which is a major safety concern for the family.

Now an example of moderate dementia may be Mereana’s whānau has asked for some home support because they are worried about her safety and her ability to carry out everyday tasks for herself. Mereana often misplaces her house keys, her telephone and her purse. She puts things down in a logical place, but then can’t remember the logic she used to place the object, or even what she is looking for. This makes her frustrated and she often cries.

Mereana is avoiding seeing people and talking with her whānau. She has difficulty in finding the right words and even remembering what she was talking about is increasingly difficult. Mereana often repeats herself or becomes embarrassed when she uses the wrong word. She also finds that she is struggling to remember the names for things and people. She confuses family members and at times can’t remember who they are.

She finds shopping overwhelming, as she gets tired easily and can’t remember what she is shopping for, or often cannot remember where to get the item she needs.

Slide 9 Late stage dementia – signs and symptoms

Now at this stage it may become increasingly difficult for a person to be managed at home with a carer and are now requiring around-the-clock assistance with daily personal care. This is usually a very distressing time for the family facing the possibility they will have to relinquish the care of a loved one.

It I also possible for the person to lose awareness of recent experiences as well as of their surroundings. They just don’t know where they are. Now for some people this is very distressing, and they may look for familiar places or people they can’t find while others may be quite happy and content just being where they are.

They could also experience changes in physical abilities, including walking, sitting and, eventually, swallowing. You need to be aware of any of these situations occurring and adapt the care to suit the person.

Slide 9 Late-stage dementia – signs and symptoms

Some people have difficulty communicating. They either can’t get the words out to some people not even being able to speak so you have to anticipate what they want or are saying.

For others they may become vulnerable to infections, especially pneumonia which can result in their death.

Now the signs and symptoms described in the last few slides vary from person to person and there may also be signs and symptoms not described in these slides. However, a person with dementia can live with it for many years with the first changes taking place up to 20 years or more before a diagnosis is made. The onset of dementia is very gradual, and it is often impossible to identify the exact time it began. So, I guess here, don’t jump to conclusion but be aware and take note of changes in the person and date them so they have a history. This is information is very valuable in being able to get an accurate diagnosis.

# Segment 10 - Co-existing conditions

Slide 1 Index

The New Zealand Framework for Dementia Care is a response to the growing proportion of the elderly in the population and the increasing number of people living with dementia now and in future years.

Dementia has traditionally been treated as a medical issue. However, the medical model does not maximise a person’s overall wellbeing and independence, and so there has been a shift to a more integrated approach that includes both the health and social aspects of care.

Dementia is very often accompanied by one or more other serious medical condition. Healthcare professionals often struggle with complex interactions between dementia and other serious medical conditions, as medication and various other treatments can have an adverse effect on the cognitive status of the person. In the elderly in particular, it may be difficult to recognise the appearance of dementia and the co-existence of other medical conditions.

So, in this segment I will talk about other conditions that occur with a person who has dementia. These are called co-existing conditions. Plus, I will discuss other chronic, terminal or life-limiting as well as acute conditions.

Slide 2 What Chronic medical conditions may co-exist with dementia

Research has shown that many people affected by dementia also have the following chronic medical conditions. These are hypertension, which is high blood pressure. Part of your role may be to take regular blood pressures of those in your care. Typically, a blood pressure is taken on admission to a facility for a base line and monthly thereafter to monitor it.

Coronary artery disease is another common medical condition. This is where the blood flow is hindered flowing around the body due to plaques developing in the arteries. This is commonly caused by high cholesterol.

Chronic obstructive pulmonary disease or COPD is an umbrella term used for people who suffer from emphysema, chronic bronchitis, and asthma. Like in coronary artery disease where the blood vessels narrow through plaque, in COPD the airways are permanently obstructed or restricted and the tissue inside the lungs is damaged, making it hard to breathe. While smoking is a contributor to emphysema, it is not necessarily a contributor to chronic bronchitis or asthma. You can find out more about COPD on the Asthma and Respiratory website https://www.asthmafoundation.org.nz/your-health/living-with-copd?gclid=CjwKCAjwm\_P5BRAhEiwAwRzSOzq-ygzQqh5YhZUFpdW1Z0h9GCY9J7sedRws7\_pRvk39O4hpPk4-GhoCvUQQAvD\_BwE.

Osteoarthritis is a very common form of arthritis that affect millions of people around the world. It can affect any joint though more commonly knees and hips. It is characterised by considerable pain. Many people will have a knee or hip replacement which does eliminate the pain usually. However, if a person has not had one, then they will remain in pain. If this is not managed, it can affect the behaviour of the person with dementia. Living with chronic pain is very distressing. You can find out more about bones by watching the Aging Process Bones, muscles, tendons, and ligaments.

A stroke which is also known as a brain attack is where there is a blockage from a brain clot or a haemorrhage occurring in the brain. It can be from a single major event to a series of minor events known as trans ischemic attack or TIA. Now not everyone will develop dementia from a major stroke, but it is certainly more likely for a person who has continual TIA’s. This is also known as vascular dementia.

Slide 3 Other chronic, terminal or life-limiting conditions

So apart from the conditions in Slide 2 there are some other conditions that may affect a person with dementia. Firstly, there is diabetes. This is considered a risk factor for vascular dementia because of the damage caused by blocked blood vessels to the brain. A person with diabetes will need some special monitoring by you to ensure their blood sugars stay stable.

Cancer is a terminal condition. Now there is interesting literature linking cancer and the effect it has on cognitive function. However, because a person has dementia, and cancer is diagnosed it does not preclude them from receiving the same treatment as other people without dementia. The deciding factor would be the ability to understand and comply with the treatment.

Now chronic renal problems are a terminal condition to. The kidneys and the brain are both susceptible to vascular damage because they are both broadly similar anatomically with blood flow features. So, because of abnormalities in the capillaries, which are the smallest blood vessels in the body, brains of people who die of dementia leads scientists to believe that increase albumin in the urine and vascular disease may go hand in hand.

Slide 4 Other chronic, terminal or life-limiting conditions

Multiple sclerosis, while not usually associated with dementia, a mild cognitive decline has been noted. Now multiple sclerosis can affect many parts of the brain so any cognitive function can be impaired making dementia mild to severe.

Research studies have indicated that people who are obese are 80% more likely to develop dementia however they also indicated that people underweight are at risk as well. So, obesity that triggers vascular dementia decreases not only the blood supply to the brain but also increased fat cells can damage the brain white matter. This can lead to loss of cognitive decline.

Parkinson’s disease is also a chronic disease. It is estimated that 50-80% of people with Parkinson’s Disease will experience dementia. However generally speaking where Alzheimer’s affects language and memory, Parkinson’s affects problem solving which is executive functions, speed of thinking, memory, and other cognitive functions as well as mood. However, there is a Lewy Body dementia that in the early stages is often confused with Parkinson’s disease, but the symptoms appear in a different order depending on where the Lewy bodies are in the brain.

A person with respiratory disease as well as dementia can cause multiple problems for a person. Because a person with respiratory disease has difficulty breathing, they often suffer from cerebral anoxia which is reduced oxygen to the brain which can exacerbate confusion. It is estimated that as many as 58% of people with COPD will develop dementia. Lung disease can be either restrictive where the lungs do not expand enough to get the air in or obstructive where something is obstructing the passage of air into the lung. Restrictive has a greater influence on cognitive decline because if the brain is starved of oxygen, it stands to reason, it will influence the brain and memory

# Segment 11 - End of life care

Slide 1 Index

In this segment I will talk about how to provide end of life care and things you need to be aware of when caring for a person. So, I will look at infections that may occur, eating issues, risk of aspiration pneumonia how to support a person with co-existing conditions and the impact and your role

Slide 2 End of life care – Infections

End of life care is a very important part of your job because most of the people in your care will require this. Infections are very common, and each will have its own set of challengers for you as a carer not to mention for the person with dementia. The most common infections in advanced or late-stage dementia involve the urinary tract, respiratory tract, skin, or eyes. Now because of a person’s immobility and incontinence this plays a major part in the UTI’s developing. Now women are more at risk than men purely because of their anatomy so it is important that good perineal care is undertaken to reduce the risk of bacteria entering the urinary tract. A reduced immune response will also make them at risk.

Respiratory Infections are also a possibility because of their immobility which makes it really important that you sit the person up and if possible, stand and walk them as well so that fluid does not settle in their lungs.

Skin and eye infections are also a risk for them so careful care to their eyes, cleaning regularly with a soft clean damp cloth is really important. Apart from keeping them clean and dry, it is for comfort as well. Skin infection should be avoided by ensuring the skin is clean especially in the skin folds and that pressure injuries are avoided. A person should be moved and turned at least 2 hourly. Now many of these conditions can be treated with antibiotics but it may be that the best thing you can do for a person is to keep them comfortable and pain free. This may be more appropriate. This is what palliative care is all about, keeping people comfortable and pain free. For an update on Pressure Injuries, go to Pressure injuries under navigation.

Slide 3 End of life care – eating issues

When we talk about eating issues it includes difficulties in chewing, swallowing, refusing food, and weight loss.

As the disease progresses the person with dementia may have difficulty with chewing or swallowing food. You need to be very considerate of people in this stage and give them food they can tolerate, like mashed, pureed, or thickened fluids. You find out more about providing these foods in Supporting a person to eat and drink and in the nutrition topics.

They may also be disinterested in food and unwilling to eat. It is not unusual for a person to refuse food. This is part of the dying process so do not force food on people. It is inevitable a person will lose weight, but it does not mean you do not offer people food. It means you offer food the person likes, for example, melted chocolate or ice cream. Even an ice block or ice cube can be very refreshing for them.

A person may not be able to eat and drink without assistance either, so you need to assist them if that is the case. Good oral hygiene and mouth care is another very important consideration. Follow the instructions from your registered nurse, palliative care team and know the policies and procedure in your facility for end-of-life care.

Slide 4 End of life care – aspiration pneumonia

Now a huge risk factor for a person at end of life, is aspiration pneumonia. This can occur when a person has difficulty swallowing and the food or fluid enters the lungs instead of going into the stomach and because a person is unable to swallow food or water safely. Now the challenge is that the family may think that the person is dying because they are not being cared for properly and are being starved. However, that is not the case. So, you need to be aware of the position the person is in when you are trying to give them food or fluid. Never attempt to feed while they are lying down. Only give small amounts of food or fluid at a time and wait till they have actually swallowed it before you attempt to give them anymore. It may be that all is required is for you to keep their mouth moist as it is natural in the dying process for a person not to want to eat or drink. This does not mean you do not do anything. You can try to alleviate their discomfort by keeping their lips moist with the recommended treatment in your facility and clean their mouth out with wet swabs that they may like to suck on. Avoid using mouth wash if they want to suck on the swab thought. The family need to be aware that the person is dying from the disease or the condition. The inability to eat or drink is a result of the advanced stage of the disease and not a sign of neglect on your part. You can find out more about aspiration pneumonia in Supporting a person to eat and drink topic

The content here has been adapted from Hospice New Zealand Fundamentals of palliate care programme.

Slide 5 How to support a person with co-existing conditions

People living with dementia generally need supervision and assistance. This is very often provided informally by family members, friends, or acquaintances. It is important to understand that you, as a support worker may not be able to provide the specific services their conditions need; and links to professional services that may be required.

As a support worker you need to be aware of the likelihood of dementia based on the risk factors. So, you need to know and recognise symptoms and the possibility of a chronic or an acute medical condition that could also be associated with the risk factors. For example, an older person who has been diagnosed with dementia is also a life-long smoker and has now developed respiratory disease.

As a support worker you need to ensure that all co-existing conditions are included in the assessments you conduct for the person you support. You also need to make sure their personal care plan documents the conditions. Your role is to also ensure any changes in any of the conditions, separately or together, are documented and reported immediately.

Slide 6 Impact of Co-Existing conditions

A co-existing medical condition could have a significant impact on the treatment, informal care and overall outcomes for a person living with dementia. This, in turn, may have a direct impact on you as a support worker, and your ability to manage stress and the burden of maintaining the health and safety of the person you support.

Slide 7 What is your role?

People living with dementia have diverse needs and require effective systems to link them to support services. As a support worker you may need to link systems to help by referring people living with dementia to service providers. For example, dementia specialists, psychiatrists, and other similar providers in the community.

As a support worker, your care is based on a holistic approach and you should consider the whole person, not just their dementia. It is for this reason that you must consider and include links to services or sources of information about services for co-existing medical conditions.

Family, friends, and others who support a person living with dementia may not understand or be aware of the treatment of problems associated with dementia and the impact of treatable co-existing conditions on the person’s cognitive and self-care abilities. Therefore, it is important to understand your role and responsibilities in the care of co-existing conditions

# Segment 12 - Impact of dementia on daily living

Slide 1 Index

Memory impairment, especially of short term memory is often the first symptom to be noticed. Someone living with dementia may be unable to remember ordinary information such as where they've put something like their keys, what they went into a room for and why they went to the shops. The key thing is though that even after time, they cannot recall any of these tasks as the disease progresses, that likely to remember the fifth date and all the trees,

It's the days we paid, it's such disease progresses. They are unlikely to remember their birth date and or their dress, and being able to recognize friends and family members repeat as the disease progresses. They're unlikely to remember the birth date and all their address, and being able to recognize friends and family members or recall recent events. However, while memory loss is a common symptom of dementia, memory loss by itself does not mean that a person has dementia.

The ability to think and reason which is cool, cognitive ability, also declines and cannot pick decision-making judgment, speed of reaction, time, problem solving, vehicle communication, including the ability to find words and orientation and time and space. For example, that person may get lost in familiar surroundings. When caring for someone living with dementia, you need to keep in mind that the care and sensitivity you use to interact and communicate with them can make a huge difference to their wellbeing and sense of self. The various characteristics of dementia can affect the activities of daily living and will have a direct impact on the type of support that is provided by the support worker and the family whanau.

So in this segment, I will discuss cognitive functional behavioral and psychological effects of dementia and the impact it has on how this affects that everyday living.

Slide 2 What are the cognitive effects?

So we paid, well, this is when the person with dementia has deficits with cognition, which is the understanding and reasoning. So the person may not recognize familiar people and places, numbers, dates, or even pen numbers. This means the person living with dementia will be at an increased risk of harm and falls because they can develop problems with the posture and how they walk. They may wander and have difficulties with nutrition as well. So in order to support them, they may require a plan for facility support, home services or services to help manage finances. These requirements may change with time and will depend on this stage of dementia. People living with dementia may also have difficulty communicating as well.

Slide 3 What is the impact of cognitive effects?

With as I mentioned in the last slide with cognitive impairment, they may have difficulty in recognizing people. This can be devastating for a person for they cannot remember the people closest to them like this spouse or children thinking they are strangers, not being able to remember places may mean they get lost and can't find the way home or even know what the house looks like. Even though they've lived in the area and in the same house for many years, it could also mean that they do not recognize a toilet or way to find it, but they still know that they need to urinate or defecate. So they do it in all sorts of funny places

Being unable to remember numbers like pin numbers or phone numbers is common to this can mean they have to entrust the number to someone else to get money out for them. This exposes them to risk of financial abuse. As a person can just help themselves to the money if there are no checks on them, also not being able to remove the phone numbers may mean they ring random people who may be rude to them, or could even exploit them.

Slide 4 What is the impact of cognitive effects?

Having a poor short term memory may lead them to forget appointments who has visited them and what you have just told them to do. They become easily confused and muddled, which can lead to frustration and agitation because they just have no idea what to do or what they are doing. Poor concentration it tension and being easily distracted means it is difficult for you to get them to concentrate on something like an activity. It can become hard to do an activity with them as they can concentrate on that and become easily distracted.

Slide 5 What is the impact of cognitive effects?

They are unable to think clearly or solve problems so there’s no good asking them to do a complex task. They just don't able to do it. They have difficulty in learning new things as well so don't have any expectation of them being able to learn something, you know, just stick to what is in their long-term memory.

Slide 6 What are the impact of functional effects?

Well, the person living with dementia may find it difficult to carry out routine Haas, household tasks and managing their hygiene, which may in turn lead to unsafe living conditions and health issues caused by a lack of proper hygiene and sanitation. Dressing and basic needs, including housing meals and physical kit, maybe necessary for a person progresses through the stages of dementia,

Slide 7 What are the impact of functional effects?

They will have difficulty completing everyday tasks and activities of independent living. This makes it difficult for them to live at home, especially on their own. It could be that they have difficultly hinting in managing, running this could mean they may not understand what money is continually grow app money and keep stitching it away. And then the house, or even give it away. This makes him open to exploitation by as crippled as people who have no moral compass safety could be a risk factor as keeping safe with appliances becomes more and more difficult for them to manage. For example, they don't turn gas off or leave it on filling the house with poisonous gas. They cannot manage cooking with electricity and leave a apart on an element for a long time. And it may catch on fire. If they do any ironing, they may leave the iron on or lying flat to the Boone's, the ironing board. It does not uncommon for people to leave a kettle on till the bowl is dry and burns out the element. So, fire is a big risk for them.

Slide 8.

They had difficulty knowing what to do next, especially out of routine and you've environment or routine totally flat maxims. They can have problems following social clues, repeat. They can have problems following social cues, which means they may laugh at a funeral or sob uncontrollably at a wedding and may jump up and dance to a solemn home. They are no longer able to understand the social norms of their customs. It could be that they have difficulty finding the right word or lose the ability to communicate verbally. For example, it may be raining outside, but they say, look at the fog or they no longer know what to say. So, they are saying nothing or mumble unintelligibly their reactions may become slower. So, it takes them twice or three times as long to do something. They may just stand aimlessly, folding, or unfolding something or doing everything. And [inaudible] motion repeat. They may just stand aimless, folding, or unfolding something or doing everything in slow motion. I hit a man who had been a tailor who would go around all day fitting the material of the curtains.

Slide 9 What about the behavioral effects?

Well, people living with dementia may begin to change their behaviors. Like they may have been very calm person and now they are angry and aggressive. Then may find it difficult to adjust to their surroundings or the people around them. They may have previously enjoyed having the grandchildren round and now they are intolerant and shout at them. It confusion created by cognitive changes may make them restless or agitated. So, they can't sit still and not always on the move, or they sit wringing their hands or shouting out

Slide 10.

They may become suspicious of others and start accusing people of stealing their money or hiding things from them. They could act out to try and convey messages. They may also have difficulty in communicating as well. Behaviors may become increasingly challenging for the support worker and family whanau. And it's often that that leads to families to place a person in care. The stress becomes overwhelming for the carer.

Slide 11 So what is the impact of behavior issues?

Well, as result of the dementia, the person may lose social skills. This makes it more and more difficult for family to take them places. Their behavior can be. So, over the top that the embarrassment becomes too much for the carer. I had a lady who would comment very loudly. If she saw someone overweight, say, look at that fit lady pointing at them and laughing. They may have an overactive response to change it. So stimuli in the environment, the noise of grandchildren now causes some distress rather than joy, this upsets the children and the parents. So, they stop coming to visits. Groups of people are just too much for the person and they just want to run away from them displaying behavior that is both out of character for them, but also is the only way they can tell that this is something is not right for them. This of course may not make any sense to anyone. They may develop repetitive behavior patterns as well, like walking in circles around an area or asking the same question over and over again,

Slide 12

Because they find it difficult to understand what is happening with them or around them. They may become physically or verbally aggressive. This may mean they lash out with their fists or kick or bite anything to tell you they're not happy. They also may swear and call the carer dreadful names. Both of these actions are very distressing. So, you have to realize they are trying to tell you something at the only way that they know how their behavior could elicit an appropriate response, like taking their clothes off or picking their nose.

Also, the behaviors can be so bad, like running away or climbing on stairs and see they're sitting and listening, which was something they would have normally done.

Slide 13 What are the psychological effects?

Well, the person living was to meet. You may experience range of emotions. Loss of faculties, such as memory or clarity of thought may lead to emotional outbursts is psychologically. A person living with dementia may react to the loss of independence by losing confidence and having a low self-esteem, which could lead to depression and anxiety. The multidisciplinary team may need to discuss therapies or medicinal treatment to help support the person. In the next slides, I will discuss the impact of each of these effects. With examples, you may find

Slide 14 What is the impact of psychological effects?

Well, a person may become very irritable, and they shout when they can't understand what is happening to them or what is going on. Their mood may swing from being ultra-happy to sit and crying the next minute, this makes them unpredictable. So, the care is on tenterhooks. The whole time. They can become frustrated and angry with themselves and others. When things don't go their way or they cannot work out, how to do something. They previously found easy

Slide 15

They may undergo a complete personality change, which makes it difficult for their family or far new to understand this person, a mild man out calm person may become belligerent and very difficult. A person who has never worried about anything, much suddenly becomes anxious about knowing where the money is going or have they got enough food.

A previously very motivated person who used to do the garden, work in the workshop, or belong to clubs. Now there's no motivation to do anything. They just sit in the chair, watching television. They may be very depressed, which is something they never were. They were always upbeat and happy that now they are said and very insular.

So, while I have given you examples in each area, there are of course, many other ways people act or react with dementia. Each person is very individual and had their own set of responses to dementia. So look at each person with fresh eyes, don't compare them to others and let them be who they are or they have to be at this time and give them great compassionate care.

# Segment 13 - Meaningful activity

Slide 1 Index

In this segment I will talk about what are meaningful activities and what they should achieve, how to choose a meaningful activity and some examples of activities

Slide 2 What are activities?

Well activities are everything we do in our lives. These are the things we do from the time we get up in the morning till we go to bed at night.

Slide 3 What do activities include?

Well, they can include an occupation or role like being a parent or child. It also includes leisure activities such as sport, hobbies, and relaxation. Any self-care activity you do such as showering, dressing, and preparing and eating food.

Doing things that are enjoyable helps us to feel good about ourselves. Research has shown that while people living with dementia may not remember a particular activity, they have participated in they still retain the feelings created by doing the activity. You may have heard the saying “people won’t remember what you did or said but they will remember how you made them feel”

Meaningful activity is activity that is relevant to the person. It requires some detective work to build a picture of what was and is important to that person. Knowing the person really well is a big help in understanding what is meaningful for them.

Slide 4 What do meaningful activities do

Well meaningful activities can maintain existing skills. The more you do something the better you become and the more likely you are to remember it. Repetition is the mother of skill is a common saying

It can also stimulate the senses. Remember your senses are anything you do by touching or feeling, smelling, seeing, or hearing. These provoke long term memories and can be recalled at any time. Remember the man I talked about in the last slide who used to be a tailor. The feel of the material was important to him in his working life, and it remained even in advance stage of dementia.

Anything that provide pleasure for you stays with you. The more you like doing something the more likely you are to continuing doing it. If it is a chore, you won’t want to do it at all.

Slide 5 What do meaningful activities do

It calms the atmosphere. When people are happy with what they are doing, then the whole environment is calm even if it is noise around them.

They also provide a routine. When people know what to do when or there is a plan to the day, they are more likely to comply. Just think about yourself. When you plan your day, it goes smoother than when you don’t have a plan. People with dementia know when there is chaos around. They are much better when there is order.

They improve physical skills as well. The more you do something the better you become at it as I said earlier.

It provides a sense of success. If you feel you are good a something, it makes it more enjoyable. If you succeed at something, you are more likely to continue doing it than if you fail

Slide 6 How can activities be done

Activities can be by doing something actively. This means the person is ‘doing something like knitting, singing, playing bingo.

They can also be passive where the person may be just sitting watching or listening to music, the radio, TV, or movies.

Activity can be on their own, one on one, in small groups of two or three people, or in larger groups.

They can be unstructured that does not require the person to be closely supervised but enables them to participate as and when they choose.

Activities can also be structured which requires involvement from other people like other residents, staff, or family members.

Slide 7 How can activities be done

Some care facilities provide planned activities to satisfy people’s needs for enjoyable pastimes, either alone or with others so there is formal programme. In a home environment, activities are less formal and included throughout the day, but no less important. It is good to Include activities as part of the daily routine as it makes living more pleasant for people living with dementia. Showing them that others enjoy their company can build a person’s self-esteem.

Slide 8 How to support a person’s activity programme

You will need to be flexible around their ability to participate in activities. This is because people living with dementia can fluctuate in their abilities from day to day. Supporting them to function to their potential requires flexibility, patience, and the ability to change plans according to individual response. Often there is a need to balance safety and independence, using practical and sometimes clever solutions to minimise the risks. Whatever the activity, it will probably need to be broken down into simple, achievable steps but it also needs to be enjoyable for the person.

Slide 9 How to choose an activity

Select and modify activities to suit the person’s ability level. Remember, this is about them not about you. So, you need to give both visual and verbal instructions when getting them involved in an activity/

Use an activity the person can enjoy. It is hopeless to try and get them do something they don’t enjoy. It is too stressful for them and for you.

Use activities that get immediate results. For instance, playing bingo has an end to it and the possibility of getting some treat at the end.

Slide 10 How to choose and activity

Simplify activities and break them into smaller parts. If you are wanting them to do a collage with things like pasta, leaves, flowers etc, don’t give them all at the same time. It will confuse them. Just give them one at time to use.

Try to interact on a one-on-one basis where possible. This is likely to keep their attention rather than have a whole group of people sitting around talking and you trying to help them all. If an activity is successful take note and repeat it often. While there is no guarantee they will enjoy it the next time, it is worth a try.

Segment 11 Examples of activities

Ideas for activities that are meaningful and selected by the person themselves, if possible, can and will differ according to the time of the day and the person’s mood, their wellbeing, level of interest and energy. It is the ‘doing’ that is important.

Activities frequently involve social events, daily living activities and maintaining a person’s skills and interests. Different types of activity include things like arts and crafts. This could be handcrafts, making gifts or decorations or painting.

Hobbies like gardening, writing, music, singing are great to. Physical activity is another beneficial activity. It could be indoor or outdoor bowls, croquet, walks, exercise, dancing are all things that many residents not only enjoy but have a beneficial effect on their mobility. Many older and retired people join clubs to partake in physical activity not only to keep fit but for socialisation. Often these activities involve discussion, exploring and laughter which in itself is a great medicine.

Slide 12 Examples of activities

Stimulating mental activity is extremely useful as well. Don’t be put off because of their memory loss. Older people often used to playthings like board games, and this will be in their long-term memory so can still play. Pet therapy is valuable as well as many people will have had pets in their lifetime. Just sitting reading or being read to is also a great activity. It doesn’t matter if they don’t remember what has been said or done so long as they have enjoyed it.

Now quiet activities are great for keeping people balanced especially if they are upset by a lot of activity so put on some calm or classical music to calm down the environment. Use essential oils in an aromatherapy infuser or mix some oil blends in a carrier oil and massage their hands and feet. Even just looking at a pleasant view out the window or on the deck can be very calming and satisfying.

Sensory activity is really important. Being able to touch, smell or feel items can do wonders for a person. You might find a twiddle muff particularly useful for an agitated person. If you don’t know what they are, google it. It even tells you how to make one. Wool, pinecones, feathers, flowers, and leaves also provide a sensory experience for a person too and can keep them occupied for ages along with stimulating memories. Taking them into a garden area or giving them a musical instrument to play such as a piano, a triangle, rice in plastic bottles; anything that gives a person something to do that can not only be enjoyed but also stimulate memories.

Slide 13 Examples of activities

Don’t underestimate the power of reading books, magazines, or the morning paper. Just leave them open at interesting pictures for them to look at when it takes their fancy. It could be things like recipes or travel or sports pictures. In fact, anything really. It helps to find out what their interests have been and give them the type of reading they used to do. If they used to read books, then give them a book to hold and read. If they travelled a lot, give them travel magazines. Just make sure this type of activity has good light and comfortable and inviting chairs to sit in. Don’t focus on what they are taking in so much as the enjoyment they are getting out of the activity.

Often an activity will be started and left ‘half done’ where a carer leaves some part of a task unfinished. This provides an incentive for the person to complete something. Examples include clothes left to be folded and warm soapy water in the sink with cups and saucers stacked ready to wash. This can cue the person living with dementia to take the next step and helps the person retain the skills and abilities for familiar tasks.

If there are upcoming events or even events have been to a person with dementia can benefit by you talking to them about the events. Let them know what is involved in the activity and remind them about it frequently. Make sure people are prepared for the activity. You may also need to assist them when they are participating in the activity.

Music therapy is another fantastic activity that most people enjoy but I will expand on the benefits of music therapy and why in the next slides

Slide 14 Benefits of music therapy

Music is perceived by many in different ways and by different parts of the brain. For example, rhythm, pitch, and melody are all processed in different parts of the brain. This means that music can reach various functional sections of the person’s brain and may bring a response from even the most severely affected person. Even when all other modes of communication fail to make any impact, music can still bring some social, emotional, or cognitive connection.

Slide 15 Benefits of music therapy

Music and singing are ways of stimulating and encouraging social interaction. They can improve a person’s mood and enhance feelings of relaxation and confidence. It can also enable the person living with dementia to express their inner feelings more easily.

Slide 16 What does music do

Music and singing can enhance a person’s long-term memory. You will be surprised what memories surface with music that has particular reference to important areas of their life.

It can improve recall when familiar songs relating to special times in their life. For example, songs that were popular during the war will stimulate memories. This will give you another understanding of the person and their life. You may find a person with no verbal skills, will suddenly start singing using all the words to the song.

It also can maintain or even improve social or emotional functioning. By this we mean, get them to talk to people, laugh and lift their emotional state.

Slide 17 What does music do

Music and also help with mental processing and enable people to recall amazing events or times in their life, as I touched on in the last slide.

It can also improve physical health and motor skills. For example, if they used to dance to the music in their younger years, they may get up and start dancing again. When people are happy and laugh a lot, it improves their physical health as well.

It is important that the person providing the therapy knows the individual preferences of the person and significant events in their life story. How familiar the person is with the piece of music, whether they like it and the significance or memories it has for them are important factors for using music effectively.

Unfamiliar music does not have the same effect. Familiar music can bring positive responses such as tapping fingers and feet to the tune, humming, rhythmic movement of the body or a change of expression on the face. It also helps to retrieve both positive and negative memories from the past.

Therapy can be individual to the person, such as playing their preferred music as part of a night-time routine. Or it may be part of a wider quality-of-life programme used in a group setting – for example, wartime songs in reminiscence sessions, the music used in a strength and balance programme, or background recorded music.

So, don’t underestimate the power of music appropriate to the era of the people in your care that they can relate to. It is no use using modern music as it will have no positive effect and in fact may have a negative effect. Classical music is very soothing normally so pick the music carefully.

# Segment 14 - Restraint and the person’s rights

Slide 1 Index

Restraint reduces or removes the person’s rights to freedom of movement. It can be a stressful experience for many people, especially when it is associated with memory loss and confusion. Inability to communicate thoughts, feelings and emotions heightens a person’s anxiety and frustration. Therefore it is to be used with caution so in this segment I will discuss all the requirements that are necessary before a restraint can be applied which includes communication, organisational compliance, the approval process, which includes assessment, informed consent, care and monitoring, reporting and recording, review and evaluation and the legislation.

Slide 2 What does good communication do?

Positive communication during restraint is essential to reduce the person’s agitation and anxiety and to make them feel safe and secure. Depending on the kind of restraint, the person may feel more anxious or sometimes may feel greater security and safety through being restrained. Your body language will communicate your respect and care for the person, who may be feeling vulnerable.

Slide 3 How do you communicate

Remember the importance of the tone and pitch of your voice, rather than the words you say, that will help the person make sense of the world around them. So that means you must be calm and sensitive and show you care.

Touch can also be a useful way to communicate with the person, convey care and concern and provide reassurance in a confusing world. Make sure that touch is culturally acceptable for the person with dementia.

If it is decided that restraint is the best option, the person being restrained will need a full explanation about what is happening and why. The explanation should be within the person’s ability to understand. You may need to repeat the information several times so that they understand.

Slide 4 What do you and your organisation need to do

When talking to people about restraint, you and your organisation will need to involve them in discussion and all aspects of the restraint process as much as possible.

This means they need to involve the person in the decision making as much as possible, within their level of understanding. So you have to explain in clear, simple language and use short sentences free from jargon that may confuse them.

You also need to involve family/whānau or their advocate in the consent process, with the persons consent of course. Family/whānau and advocates have an important part to play in ensuring that the person’s best interests are considered.

You also need to obtain informed consent. However, consent can only be obtained when full information is given and understood. Consent needs to be gained from the person, if they are able to give it, or from their representative. If you don’t understand what informed consent is, check out informed consent in the topic under navigation. Keeping the person informed throughout the restraint process is an important responsibility for the organisation.

Slide 5 How do organisations comply

When implementing restraint there is always a planned process. Your organisation will have policies and procedures about how restraint is used and what your responsibilities are in using it. These policies and procedures strictly follow the Health and Disability Services Restraint Minimisation and Safe Practice Standards*.* This means they need to review their organisation’s policies and procedures and the standards to understand the processes for the use of restraint in your workplace well before the process begins.

Slide 6 What has to be considered before approval will be given

Now before approval to implement a restraint will be gained by management of the organisation, there must be clear processes that has determined why restraint is the best option for the person. This is the way in which your organisation controls the use of restraint to comply with the Health and Disability Sector Restraint Minimisation and Safe Practice Standard. This must include why it is the best options, who is responsible for implementing and monitoring the person and the restraint. It must also include who has been consulted and agreed to the use of the restraint. All this must be documented before a restraint can be implemented.

Therefore, documentation is the only way of showing what care and support has been given to the person before the restraint was considered. It will also need to be shown how the person will be monitored during restraint. For example, each time you provide support you must record this in the manner your organisation requires. This may be by signing a record sheet, completing a progress report, or ticking boxes on a checklist to show that the person under restraint has been monitored. There must also be a review process because the restraint cannot be applied and left because it may not be needed long term, or it may not even work.

Slide 7 What must be assessed?

Assessment is always undertaken before any treatment is started. Restraint is a form of treatment that needs to be considered as one among a range of possible options and so the need for and risks of restraint must be assessed for each person.

Assessment will consider the person’s general health, the risk to others and what the end goal of restraint should be meaning what would restraint hope to achieve. Assessment will also look at the strategies that can be used, which may mean that other effective actions can be taken so that restraint is not required.

Slide 8 How to gain informed consent

Informed consent is always sought when treatments of this kind are used. If a person living with dementia is unable to understand the significance of restraint, then a welfare guardian is asked to sign the consent, after being given all the information. In an emergency, your organisation may permit the use of restraint before a signed consent is obtained but the decision must be fully documented.

Slide 9 How you provide care and monitor the person

Personal plans include all aspects of the person’s care, including restraint. Your organisation will decide how support during restraint should be described – it may be part of the main plan or in a separate document. You will need to know where to find the information about your responsibilities for providing care and support during restraint use.

Slide 10 What to report and record

Reporting and recording are an important part of a support worker’s role. Your organisation’s policies will describe what general observations you make like how the person is tolerating the restraint that may indicate it is working or not working. There will be a sheet provided listing what you need to monitor or check on a regular basis. You will also need to document any unexpected changes that has happened to the person while being restrained. The policy and procedure will tell you what recordings to make and how often this needs to be done. Therefore, you need to put the time and date you did the observations or recordings.

Slide 11 Evaluation and review

Evaluation and review is about determining the effectiveness of the restraint that has been used. Evaluation will look at the history of the restraint episode through the records that you and others have kept. It is the chance to look at whether restraint was the correct decision and achieved the result that was intended, or whether some other intervention would have been safer for the person.

For example, high bed sides may make the person more unsafe if the person tries to climb over the sides and then has a fall. This makes the risk of using a restraint greater than not using a restraint. A mattress on the floor may be a safer option for this person.

Evaluation also considers whether the restraint used was the least intrusive or restrictive option for the person. A review process decides whether there should be any changes in the process if restraint is required in the future or whether it will be discontinued. For more in-depth training on restraint, types of restraint go to Restraint Minimisation and Safe Practice under Navigation.

Slide 12 What Acts and Codes protect people by law

When wanting to apply a restraint on any person there are strict Acts that have to be complied with. New Zealand has legislation that recognises people’s basic rights to protect them so a person cannot be restrained without going through proper processes. It is important to note too, that people living with dementia have the same rights as other people residing in New Zealand.

So, there are core Acts, codes and regulations that have an impact on your work practice and how you interact with the people you support.

The main Acts and codes are the Human Rights Act 1993 which specifically promotes and protects human rights, the basic rights and freedoms that all people are entitled to. This includes freedom from discrimination. The intention of the Act is to ensure that all people in New Zealand are treated fairly and equally.

The Privacy Act 1993 and the Health Information Privacy Code 1994 have the same purpose – the promotion and protection of an individual’s privacy and personal information. The Health Information Privacy Code applies specifically to the area of health.

The Health and Disability Commissioner Act 1994 created the Office of the Commissioner of Health and Disability. One of the Commissioner’s first tasks was to find out what people expected from service providers in terms of quality of care and then to define these expectations by means of legally enforceable rights.

Out of the legislation or Act, a regulation established the Code of Health and Disability Services Consumers’ Rights (1996). It is often simply called ‘the Code of Rights’ or ‘the Code’. The Code was created to promote and protect the rights of health and disability service users. I will refer to this as the Health and Disability Code for short

Slide 13 How does the Health and Disability Code protect consumers

This is a very important document that you must adhere to. The Code tells consumers what their rights are when receiving treatment and how they can expect to be treated when they receive a health or disability service. It also sets out the procedure for a consumer to make a complaint if these rights were not being met among other rights.

Slide 14 How to find the Health and Disability Code

The Code is available in many different formats, including pamphlets and posters. You probably see them in your facility/organisation.

Ask you supervisor or manager for a copy or how to get one. It is important that you know where to get a copy of the Code as there may be times when the people you support want to check their rights, or when you need to check what your duties are in a particular situation. The way you behave at work must reflect the legal obligations set out in the Code of Rights.

You can also obtain a copy of the Code from the Health and Disability Commissioner’s office or website [(www.hdc.org.nz](http://www.hdc.org.nz/)).

To understand more on the Code of Rights Check out the Code of Rights topic in the Navigation list on Care Training Online.

# Segment 15 - Restraint

Slide 1 Index

Sometimes people’s behaviour or actions become so difficult or unsafe for them and those around them that special measures such as restraint are required to protect them. Restraints limit a person’s freedom of movement and are used to keep people safe. So, in this segment I will discuss when restraints would be considered, the guiding principles for using restraints, Implementation of restraint, types of restraints, and assessment process

Slide 2 When should restraint be considered

Restraints should only be used when all other interventions have been unsuccessful and there is risk of harm to people if restraints are not used.

The Health and Disability Services (Restraint Minimisation and Safe Practice) Standards (NZS 8134.2.2008) have been developed and revised to provide guidelines to the health and disability sector, so that the use of restraint is recognised and reduced. If restraint is necessary the standards recommend using the least restrictive kind, in a safe and respectful manner.

The use of restraint is a serious clinical decision. The situation must be fully assessed, and health professionals must decide that restraint is needed.

Slide 3 What ethical principles must be considered

The whole process of implementing a restraint, must be guided by ethical principles to guide the care given to people in health and disability settings. These principles remind us to consider all aspects of care for the person.

Firstly, the restraint must act in the person’s best interests. This means that the person will benefit from the restraint. It is not there for you but for the person. Nor cause any harm to the person in any way, as the aim is to keep the person safe. It must also respect the person’s dignity which means it must not be demeaning and harm their pride, and their rights under the code of rights.

Slide 4 What factors influence restraint use

So, when considering restraint use, there are other factors that influence its use; it is not just ethical principles. So, the person’s general physical and mental health must be taken into account. This means will it make their physical or mental health worse? Not being able to move may mean the person could damage their physical body that can really exacerbate an existing condition or create a whole new set of physical problems. Not being able to get out of a restraint could cause serious damage to their mental health and exacerbate or make worse their behavioural problems.

The person’s gender has to be considered as well as some restraints may not be suitable for a male but better for a female and visa versa. It has to suit the person.

Are there any cultural considerations that need to be accounted for and explored? It may be that there are restrictions within their culture that makes the type of restraint being considered not appropriate.

Slide 5 What factors influence restraint use

What is the risk to the person, those around them and to the environment? Will the restraint put the person at risk of injury or injuring others around them? Would the environment be damaged as a result of the person not accepting the restraint?

The person’s experiences during their life will influence how they react to the restraint. It is no good putting a person in a restraint if it has been used as a form of punishment for the person when they were a child or they were locked in a room somewhere where they couldn’t get out. It will bring back all those harmful and painful memories and they will fight against it.

By using a restraint now, will it have an effect on the way the person reacts in the future. Will it have harmful memories that they want to try and get away from. What is the likelihood of it making them worse rather than better?

What possible alternatives to restraint has been considered? Is there something better that will have a more positive effect on the person

Slide 6 How to keep the person safe

Your organisation will implement policies and procedures to keep the person safe during a restraint episode. You will need to follow the restraint policies and procedures of your organisation. These will include observing the person carefully. This means you keep an eye on the person and see how the restraint is affecting them. The person should not be put in their room where no one can see them or attend to them if they get into any difficulties

You also need to monitor the person’s condition and activity. Which means to check their condition and what they are doing and write it down any changes that may be affecting the person, so they are picked up early.

You must also record what you saw and what you did. This means each time you check or observe anything, no matter how small or insignificant you might think it is so there is a record of how the person is tolerating the restraint. A written record is the only proof of any untoward signs being noticed early so a remedy can be implemented. So, write everything down

Slide 7 How to keep the person safe

You also need to report the effect of the restraint and any other important thing you observe. While writing it down is essential and important, you cannot just leave it in the hopes the Registered Nurse will see what is recorded in a timely fashion to ensure the person doesn’t come to any harm. This means anything you notice and record, you tell someone about it so that can do something about it. You must also report it in the progress notes and at handover so that everyone knows what has been going on for the person.

Making sure the person is adequately supported while being restrained to is essential. This means you need to make sure they are supplied with food and fluids and their toileting needs and comfort is attended to. It is no good just leaving the person sitting in one place and forgetting about them. You also need to let them know you care and shift their position or take them for a walk if possible. Leaving a person in one place so they get a pressure injury is not good care nor is not making sure they get food, fluid or taking to the toilet.

Also communicate with the person. Talk to them, touch or stroke their arm or shoulders. Anything that makes them feel a real person and they matter: that they are safe, and you care about them. Tell them what is happening around them, sing along with them. So, something that will make them smile.

Maintain their dignity and privacy when you are providing care for them too. Make sure their body is not exposed, that any personal cares are done in the privacy of their own room and parts of their body are not exposed. Because they may not be able to move or they move around a lot and shift their clothes off them, does not mean you leave them exposed.

Slide 8 Types of restraint

There are many different types of restraint. Any use of restraint must be strictly in accordance with the Health and Disability Services (Restraint Minimisation and Safe Practice) Standards and your organisation’s policies and procedures. It must also be within your scope of responsibilities. Legal and ethical practice must be adhered to at all times.

The different types of restraint include personal restraint, environmental restraint, physical restraint, seclusion, and chemical restraint. So, in the next slides I will discuss each type of restraint.

Slide 9 What is person restraint

Well person restraint is when you use your own body to intentionally restrict the movement of a person.

Slide 10 Examples of person restraint

Well things like holding a person’s arm when a blood test is being taken is person restraint. Also, if two people are having an altercation and you have to physically separate them or even if you have to pull a person back from trying to cross a busy road. Even though these are for the benefit of the person, it is still person restraint because you are using your body in some way to restrain them.

Slide 11 What is physical restraint

Well this is when equipment or furniture is used to limit the person’s normal freedom of movement.

Slide 12 Examples of physical restraint

So, a physical restraint is when a person is unable to get out of a chair independently because of the design of the chair. A ‘fallout chair’ is an example or where a belt is used to keep the person seated or even a table or fixed tray is placed so that it prevents the person from leaving the seat. While these options may stop a person from falling, the other side is that they just cannot get up either so in some cases may actually increase their falls with them trying to get out of the restraint and falling harder.

Slide 12 What is environmental restraint

Environmental restraint intentionally restricts a person’s normal access to the environment. This means that the person is not able to get out of the environment they are in be it the facility or the grounds around the facility.

Slide 13 Examples of environmental restraint

So environmental restraint is where there is a means of locking devices on doors, windows, or gates so a person cannot get out of the building or property. Another form of environmental restraint is when a person is denied their normal means of independent mobility by putting them in a wheelchair. If a person cannot get out of the wheelchair, they will lose their ability to be able to get around. While it might save you a problem because they are no longer getting in your hair, it does nothing for the health and wellbeing of the person.

Slide 14 What is seclusion

Well seclusion is a kind of restraint that can be legally undertaken only under the Mental Health Act. A person may be placed for a period of time alone in a room or area from which they cannot leave. This is usually to prevent them from causing injury or harm to themselves or others or endangering other people or property. This is not used in Aged residential care and in fact, if it is it is against the law. DS you cannot ever confine a person to their room on your own volition. This is not the same as a person having time out in their room for them to calm down from an overactive environment. However, the door must always be able to open for them come out when they are ready.

Slide 15 What is Clinical restraint

Well, this is when a drug is given to ensure compliance to prevent a person harming themselves or others. It may restrict the freedom of movement of a person, make them incapable of resisting and, in some cases, sedate them. This type of restraint, like the others, is a clinical decision. Medication should only be used for the purpose it has been prescribed for and not as a form of chemical restraint, which would be against Restraint Minimisation and Safe Practice Standards.

Slide 16 What are enablers

Enablers are equipment, devices, or furniture that a person chooses to use. Use of enablers follows an assessment of a person’s needs and should be the least restrictive option for that person and should be voluntary.

Slide 17 Examples of enablers

The intention should always be to promote or maintain the person’s independence and safety – for example, a raised bed rail to assist mobility in bed, help position pillows for comfort or prevent the person falling from the bed.

Where equipment or furniture is used in the physical positioning of a person without limiting their normal freedom of movement. These interventions are not considered a form of restraint, but rather are a normal component of the person’s day-to-day life.

Slide 18 When do enablers become restraints

However, enablers *may* become restraints, if a person is confined to a bed unwillingly, or is unable to get out of bed because of the bed rails, then this becomes a restraint.

If person is unable to get out of a chair independently because the position of a table or fixed tray prevents them from leaving the seat, then this becomes a restraint.

Bed rails may keep a person safe, to prevent them falling out of bed. But they can become a restraint if people are confined to bed unwillingly.

# Segment 16 - Making decisions - Advanced Care Planning

Slide 1 Index

Advanced dementia will decrease life expectancy that is a given. There is no recovery from dementia or indeed getting old and dying for that matter. The end result is the same which is death. So, it makes sense to plan for end-of-life care before it reaches a stage when the person can’t make decisions for themself.

J Chatterjee, in her book “End-of-life care for patients with dementia.’ Written in book

*Nursing Older People, which was written in 2008, ‘Specific needs of residents with end stage dementia seem to arise not only because they have a prolonged disease trajectory and uncertain prognosis but also because poor cognition impairs their ability to express their wishes, verbalise their feelings of pain, discomfort and emotional anguish.’*

So, in this segment I will look at how a person can plan for end-of-life care, well ahead of time. I will look at What is an advanced Care plan, what does an Advanced Care Plan do, and why have an advanced care plan

Slide 2 What is advance care planning

Well essentially it is the decisions about a persons end of life treatment and care that a person will need to make at the onset of dementia, whilst the person still has the mental capacity to make their wishes known before their health deteriorates further.

Advance care planning or ACP as it is known is a way to help a person think about, talk about, and share their thoughts and wishes about their future health care. It is focused on and involves both the person and the health care professionals responsible for their care. It may also involve whānau/ family and/or carers if that is the person’s wish. While this is not a legal document as such, it can be used as one

Slide 3 How can they make their wishes known

Well, there are several ways to do this. It will include and advanced care plan, enduring power of attorney which will be discussed in Segment 17. Also, an advance directive which is also called a ‘living will’ as well as end of life directive, which will be discussed in Segment 18

Slide 4 What is an advanced care plan

An Advanced Care Plan is a document where a person can write to include all the things that are important to the person, what worries them and why they are making an ACP.

Slide 5 What is in an advanced care plan

It outlines why you made the decisions, what you would like if you cannot make your decisions what you would like if you were dying.

Slide 6 what is in an advanced care plan

It also includes the care and treatment they would like and what they want to have happen after they die. It also includes Advanced Directive and Enduring power of attorney which I will discuss in more depth in the next slides.

This document is written by the person themselves and is like their own Care Plan. On the ACP website it states an Advanced Care Plan “*that shows loved ones they are thinking about their advance care plan and what are important, even if you never write down an actual plan. However, if the person does complete an advance care plan, it needs to be shared with their healthcare team and anyone else they want to have access to it. It is important their whānau and loved ones know they have a plan and where it is kept. It is also important it is reviewed on a regular basis – maybe every year around their birthday or some other significant date.”* Adapted directly from the ACP document that can be found on the by typing in Advanced Care Planning in the URL. While this document in itself is not a legal document, apart from EPA and Advanced Directive, it could be used in a court of law if any disputes ever arise within families as to the care the person has chosen.

Slide 7 What does an ACP do

So essentially it shows the family and health care professionals that they have thought about their end of life, care, what is important for them and who they trust as your advocate. It keeps everything together in one place so your chances of getting their wishes met are not left to chance because it is what they want.

Slide 8 Why have an ACP?

As I said in the last slide it outlines a person’s wishes but more importantly, it can deter families fighting over a person’s end of life care. By the person writing it themselves and discussing it with the health care team, and family, it will enable the team to provide for their wishes and not necessarily the wishes of their family. So, it gives more power to the person and to the health care team to provide what the person wants.

Slide 9 Example of how an ACP works

Now October 2020 New Zealand voted in the End-of-Life Choice bill. While what form it will take is unknown, what is known, is that a person can choose to have assisted dying under certain circumstances. Now a person may choose to have this option, but another family member be vehemently opposed to it. So, who is going to be listened to? Well, if you have it written down in your ACP then it is clear it is the person has considered this option. However, even though this may be their choice when they wrote the ACP, it will not automatically happen. This is because the person has to be deemed competent at endo of life and still choose this option and meet other criterions. So even though a person has written it down in the ACP, it does not mean when the time comes, they will choose it. They are always free to change their mind.

# Segment 17 - Making decisions – Enduring Power of Attorney

Slide 1 Index

In this segment I will discuss Enduring Power of Attorney. It is a requirement for all people who go into hospital or care have an Enduring Power of Attorney, referred to in this segment as an EPA. On admission this will be requested to be provided. The reason for this is so they know who the person has nominated to speak on their behalf if they are unable to do so. So, in this segment I will discuss who can set up and EPA, what is an EPA, Types of EPA’s and the decisions they can or cannot make, when can they make the decisions and what happens if there is no EPA in place

Slide 2 Who can set up an EPA

While anyone over the age of 18 can set up and Enduring Power of Attorney, it is more common for seniors to set one up for themselves. However younger people, especially if they go overseas, are more likely to set up a less prescriptive Power of Attorney and nominate a person to act on their instruction on their behalf if need be.

Slide 3 What is Enduring power of attorney

An EPA is a legal arrangement in where a person is nominated to make decision for the person when or if they are no longer able to do so. Generally, the person chooses someone they know and trust but on occasions, a person is appointed by the court to act for a person.

Slide 4 What are the types of attorneys

There are two types of EPA. One is for property and includes finance as well. The other is for personal care and welfare.

In your workplace it is likely that you have experienced supporting a person who has an EPA for their personal care and welfare. The person who has the power of attorney is usually a close family member or friend of the person living with dementia. Someone who knows the person really well and that they trust or for people who are not able to choose or know someone who can do it, a family court will appoint someone.

Slide 5 What decisions can a property and finance attorney make

Well, they can manage anything to do with finances and property. This means, they can pay the persons bills, sell property if needed or anything else and work with the welfare attorney to find a place for you to live. However, because a person sets up a property attorney it does not give them automatic right to take over the persons financial or property. They can have a single person but usually 2 or even 3.

Slide 6 When can EPA property and finance be actioned

Now as I said in the last slide, by setting up an EPA for finance/property the attorney does not have automatic right to take over the person’s property or money. The EPA when it is drawn up must state if it is to take effect immediately or when the person becomes incapacitated. So, this means the person can assign the attorney to be their agent immediately if they choose. There is a form at Work and Income that has to be completed along with a copy of the EPA document stating they wish to allow this person to act as their agent. This is to protect the person and ensure that the appointed person does not take over the persons finances or misappropriate their funds, especially if the person if capable of managing them themselves.

Slide 7 What are the requirements of property EPA

Now, even if the person assigns the attorney to act as their agent, they are required to keep the person informed. However, if a person is deemed incapacitated to operate their property/finance then the attorney does manage everything but again they have to keep accurate records of all transactions. They are not permitted to use any of the money for their own purposes, but they can take reasonable expenses incurred which of course have to be recorded. Sometimes more than one person is appointed as an attorney or two people to act jointly to protect the person or a professional trustee appointed or restrict the powers of the attorney. So, there are many safeguards in there for the person.

Slide 8 When can an EPA Personal Care and Welfare be actioned

When the person living with dementia can no longer make decisions for themselves and a medical practitioner has completed Form 5 certificate of mental incapacity, the person holding EPA will make decisions for the person.

Slide 9 What decisions can a Care and Welfare attorney make

Well, there are a whole range of things and can include where the person experiencing dementia will live, the diet they will be given because they know the person so well they know their likes and dislikes, and the types of clothing they will wear. They can also consent to surgery on your behalf. However, they cannot make any decisions for the person unless they have been deemed as not having the capacity to make these decisions for themselves. Now unlike the property EPA where more than one person can be assigned as the attorney, in a Care and Welfare order there is only one person assigned to this role. However, the person can list others that need to be consulted in regard to care and welfare.

Slide 10 What decisions can’t a welfare attorney make

They cannot consent for any surgery to the brain, ECT or any treatment that can alter behaviour.

Nor can they make decisions for you to get married, divorced, or separated They cannot make arrangement for the adoption of a person’s children or allow the person to take part in any medical experiment, unless it might save your life or prevent serious damage to your health

Slide 11 When does an EPA Welfare take effect

Now I mentioned this in slide 12 but I will elaborate more on when an EPA Care and Welfare can be actioned as it is imperative that you understand the following conditions of an EPA.

It does not take effect until a person ceases to have the ability to make decisions about their own health and welfare.

It does not take effect until the person is assessed by a qualified person – for example, a general practitioner, psychiatrist, or a member of a mental health team.

A form 5 must be completed before the person who has been appointed with EPA can take over any decision-making powers.

The appointed EPA cannot make decisions without the EPA being activated.

Slide 12 What is Form 5

Well, a Form 5 is the health practitioner’s certificate of mental incapacity to activate an EPA in relation to a person’s personal care and welfare.

Slide 13 When is a person incapable

To enable a person to be assessed as lacking capacity, there has to be some guidelines for the medical practitioner to follow. So, The Mental Health (Compulsory Assessment and Treatment) Act 1992 defines mentally incapable as when a person is lacking the capacity, which basically means ability or competence to do so, they are unable to make a decision about a matter relating to personal care and welfare. It is also considered they do not understand the nature of decisions about matters relating to personal care and welfare

Slide 14 When is a person incapable

They also lack to ability to foresee the consequences of decisions about matters relating to personal care and welfare or of any failure to make such decisions. Also, they are lacking the capacity to communicate decisions about matters relating to their personal care and welfare.

Slide 15 What happens if there is no EPA

If the person being supported has not appointed someone as EPA for them, the person can appoint someone if they have capacity. So, in the absence of the person being able to appoint one, the facility may apply to the Family Court appointed a Personal Care and Welfare and a Property Manager. Now the facility may be appointed as the Personal Care and Welfare guardian, but it won’t ever be appointed as a Property Attorney. The court will appoint a person to this role who is likely to be a professional person like a lawyer to do this. However, this process is complicated and can be quite costly and time consuming. It can take several months before it is granted.

# Segment 18 - Making decisions – Advanced Directives

Slide 1 Index

In this segment I will discuss Advanced Directives. So, I will discuss what is an advanced Directive, the requirements for an advance directive, what it includes how you will know their wishes, what are your boundaries and some special notes. However it is important to note that at the writing of this segment, as the result of an end of life referendum that has just been held whereby a majority of New Zealanders chose to have a choice on, some of the wishes discussed in this segment may be altered**.**

Slide 2 What Is an Advance directive?

An advance directive is another way in which people can make decisions about their care ahead of time. A person can use an advance directive to tell medical professionals what kind of medical care they would like to receive.

Slide 3 Are people required to have an advanced directive?

Currently all hospitals and residential care providers are required to ask if a person has an Advanced Directive in place. If one is not in place, then the person and their family are given the information to complete one. However, some people find it difficult to complete something like this as don’t wish to face the fact they will die.

Slide 4 What are the requirement for an Advance Directive?

That the person makes it of their own free will and that they are of sound mind when they make it, meaning they understand what they are putting in place. If neither of these are present when the person is admitted to hospital or residential care, then an advanced directive cannot be made and the person is automatically for resuscitation or any other life-saving measures as deemed necessary for the person, if the case arises. Remember, a doctor’s role is about saving lives, not shortening them.

Slide 5 What does an advance directive include?

Well, it includes whether a person wants to be resuscitated and have CPR which is cardiopulmonary resuscitation, to be performed if their heart stops beating. It also includes whether the person wishes to be kept alive on a ventilator if they are unable to breathe without assistance or whether they want to be kept alive by tube feeding.

Slide 6 What does, and advance directive include?

It also includes whether the person wants to be given fluids if they are dying. Some people just want to slowly die and not be forced to drink or eat. What kind of drug therapy the person wants? For example, they might choose to be given pain relief but not antibiotics to fight an infection. What the person wishes to happen about organ or tissue donation. Do they chose assisted dying?

Slide 7 How will people know a person Advanced directive wishes?

Now this is really important because if a person does not have something with them to state this, and the collapse in the community, or at home for that matter, they will be resuscitated whether they want to be or not. So, to ensure their wishes are adhered to the person can carry a card to tell medical professionals what they want. Note, it has to be specific too. The information will also be in their personal plan.

Slide 8 What do you need to know?

For each person you support, you need to know if they have an advance directive or they carry an advance directive card.

Although there is no standard format for advance directives, the New Zealand Medical Association’s website offers information and sample forms for use <http://nzma.org.nz/patients-guide/advance-directive>. It would be a good idea for you to check out the website to see what an advanced directive might look like for a GP>

Slide 9 What are your boundaries?

As a support worker you must know and understand your boundaries and the personal and professional limits to providing care. This is what you can or cannot do. You can only provide support you have been trained or are permitted to give.

Knowing your limits will help you to feel safe in your role. You should also know where your role ends and where someone else’s begins.

Working within the limits of your role may also be called your ‘scope of practice’. This means that you support a person in the way that’s set down in your job description and in the person’s personal plan. Your workplace will have policies and procedures about your scope of practice. They may also have a staff handbook that gives you important information about professional guidelines.

Slide 10 Special Note

If the person you support has an EPA that has been activated, you need to know the final decision rests with the person’s general practitioner. The GP will take into account the opinion of the appointed EPA but will make the final call. The GP need to be certain it is the wishes of the person, and the advanced directive was made by the person of their own free will and while they are mentally competent. Any doubt in the GP’s mind will necessitate the beginning of treatment.

Slide 11 When might an Advanced Directive be overturned

So, and example may be, if the person you support has a chest infection and the EPA says, “Don’t treat him.” The GP may consider that the person still has a good quality of life and therefor has the right to decide to treat the person with antibiotics and other medication. This is because the GP must always act in the best interests of the person, not the person’s EPA or family.

If you are ever faced with this situation, it is important for you to know that you must follow all medical orders, not the EPA’s direction.

Slide 12 What to do if family instructs not to treat?

For example, Mrs Smith’s family member (her appointed EPA) tells you not to give antibiotics. You must follow the GP’s orders at all times. However, you must notify your supervisor who is likely to arrange for the GP and EPA to speak to one another to resolve any conflict. Of course, you must also document all you did in the resident notes. This ensures you cover yourself and keep yourself safe. It is not up to you to resolve the conflict between the family and GP but to clearly document what happened in resident notes and complete an incident report would also be useful.