This unit provides you with the knowledge on the neurology of dementia including the causes, difficulties and needs of the person with dementia. This will help to support your understanding of how people may experience dementia.

With the development of improved health care and healthier lifestyles, people are living longer. With an increase in an ageing population come age-related conditions such as dementia. Age is not the only cause of dementia as you will discover within this unit.

**In this unit you will learn about:**

- the neurology of dementia
- the impact of recognition and diagnosis of dementia
- how dementia care must be underpinned by a person-centred approach.
1. Understand the neurology of dementia

1.1 Causes of dementia

The word ‘dementia’ is a term which describes a serious deterioration in mental functions, such as memory, language, orientation and judgement. However, the causes are still not yet fully understood. Research in this area is ongoing and to date a number of types of dementia and their causes have been identified.

The brain is a complex organ and is divided up into different areas that control different functions within the body. The brain contains around 100 billion cells. In dementia some of these cells stop working properly. The part of the brain that this occurs in will affect how that person thinks, remembers and communicates.

Senile dementia is a term that refers to dementia in people aged over 65. It is not uncommon for people under the age of 65 to develop dementia. This is known as early onset dementia.

Dementia is a major health condition which affects over 820,000 people in the UK. Worldwide, more than 35 million people are estimated to have dementia, with 4.6 million new cases being diagnosed every year.

Types and causes of dementia

Alzheimer’s disease

Many people ask if dementia and Alzheimer’s disease are the same thing. The short answer is no. Alzheimer’s disease is the most common cause of dementia. It is responsible for approximately two-thirds of dementia in older people. Alzheimer’s is caused by nerve cells dying in certain areas of the brain. In addition to this, the connections between affected nerve cells deteriorate. As the disease progresses, it spreads and affects cells in other parts of the brain. The cause of the brain cells dying and the deterioration of the connectors is not fully known.

Vascular dementia

Vascular dementia is a form of dementia caused by damage to the brain through deprivation of oxygenated blood. Oxygenated blood is carried around your body and brain through arteries. Deoxygenated blood is carried through your body in veins. It is these arteries and veins that make up part of your vascular system. When an organ in your body is deprived of blood, that organ (or part of it) will die. This is what happens to the brain in vascular dementia. The conditions which can cause these problems are preventable and include high blood pressure, heart problems, diabetes and high cholesterol. When supporting people into leading a healthy lifestyle, it is important to bear this condition in mind, in the hopes of preventing the onset of vascular dementia.
Rarer forms of dementia

Creutzfeldt-Jakob disease (CJD)

CJD is a form of dementia caused by prion disease. Prions are proteins which are found in mammals. When these proteins cluster together in the brain, they cause brain cells to die. When these cells die they leave holes in the brain called spongiosis. Examining the brain under a microscope reveals the cells to appear sponge-like. This damage to the brain causes neurological difficulties and dementia.

There are four forms of CJD:
- sporadic
- familial
- iatrogenic
- variant.

Although each of these conditions is very rare, their prognosis is extremely poor. The affected person’s life expectancy is radically reduced, with death occurring usually within 6 to 24 months from early diagnosis. The disease can take many years from the time it infects a person to it causing recognisable symptoms.

The cause of Sporadic CJD is unknown and its onset is very fast. It affects people over the age of 50 and can cause death within a matter of months.

Familial CJD is an inherited form of the disease. Its symptoms usually affect the person at an early age from 20 to 60 years. Death occurs between two and ten years of symptoms beginning.

Iatrogenic CJD occurs as a result of contaminated blood or tissue entering the healthy person’s body. This can take place with corneal transplants, grafts or the use of growth hormones. To prevent the risk of contamination, transplants are no longer taken from people known to have the disease and growth hormones are now developed artificially. Because prions cannot be destroyed using normal sterilisation procedures, any surgical instruments used on people with CJD are not used on other patients.

The last form of CJD is known as Variant CJD. This form affects people at a younger age with the average age of death being 29 years. The average time the person is affected by this disease is 14 months. Variant CJD is caused by bovine spongiform encephalopathy (BSE) – a form of prion disease which affects cattle. The person contracts this disease by eating infected beef products.

To reduce the risk greatly of infected beef products reaching the market, manufacturers now remove the animal’s brain and spinal cord from general sale.

**Functional skills**

**Maths: Recording data**

This information can be used to record data in a chart and shows the use of working out averages for statistical purposes.

**Biswanger’s disease**

This is a form of vascular dementia in which damage occurs to the blood vessels in the deep white matter of the brain. It affects people over the age of 60 and is often as a result of long-term hypertension or high blood pressure.

**Dementia and learning disabilities**

Some people with learning disabilities are at risk of developing dementia in adult life. People with Down’s syndrome are at risk of developing Alzheimer’s disease. The risk of Alzheimer’s increases as the person gets older. It is estimated that over half of the people with Down’s syndrome will develop Alzheimer’s disease when they are in their 60s.

**Fronto-temporal dementia**

Fronto-temporal dementia is a rare form of dementia. It tends to affect younger people and is more common within men. The condition is caused by damage to the frontal lobe and/or the temporal parts of the brain. These areas are responsible for the person’s behaviour, emotional responses and language skills. The condition includes those known as Pick’s disease, Frontal Lobe Degeneration and dementia associated with motor neurone disease.

**Dementia with Lewy Bodies (DLB)**

Lewy Bodies are tiny protein deposits which are found inside the nerve cells of the brain. These deposits alter the way the brain functions and can be found in people with either dementia or Parkinson’s disease. Approximately four per cent of the older population who have dementia are affected by DLB. This form of dementia has characteristics of both Alzheimer’s and Parkinson’s disease.
1.2 Types of memory impairment commonly experienced with dementia

Within humans, the term ‘memory’ refers to information stored in the brain. Apart from storage, it also includes the retention or keeping and recalling of that information. A person’s brain is extremely complex and can store, retain and recall many, many pieces of information for many, many years. The ease with which the person can remember information will vary depending on the subject, the person and their state of mind. If the information is unusual or interesting, they may remember this more so than information which is uninteresting or mundane.

Memory loss can be defined in different ways depending on the situation it is being used for and the type of memory which is lost. Memory loss can be the inability to retrieve information from the long-term memory. This type of memory loss usually happens when the person is distracted or is not fully concentrating when the memory is formed. Another form of memory loss is when new memories are stored within the brain replacing older memories. Think of your brain as a filing cabinet; there is only so much information you can store in it at any one time. To make room for new information, you will need to take out or discard some old information. This type of memory loss is normal and is experienced by everyone.

Memory loss can also be described as the fading away of memories. This sort of memory loss can occur with telephone numbers, facts or people’s names if you have not used them for a while. Think back to when you were at school. You would have known the names of many of the students and teachers. Can you recall all of the students’ and teachers’ names now? You may barely remember what their faces looked like and you may be struggling to remember everyone’s names. This could be because you have not had any reason to remember this information. It is not something you have had to use on a regular basis. Memory loss due to the ageing process can be defined as being the shrinking of the hippocampus, which is responsible for the storage of long-term memories. The hippocampus is usually the first part of the brain which suffers damage, leading to Alzheimer’s disease.

**Case study**

Recognising normal memory loss

Christine is 43 years old and is concerned about her memory. She is a very busy lady with a stressful job. Christine is walking down the corridor at work heading to yet another meeting. She is going over in her mind what she needs to raise in the meeting and checking through her diary to see what time she needs to leave to get into town for her third meeting of the day. Carol, one of Christine’s colleagues, bumps into her and tells her that Mark has telephoned and would like to see Christine later today at 3.15pm in the staff canteen. Christine says, ‘OK,’ and carries on to her meeting.

At 3.30pm Christine is sat at her desk writing up the minutes from a meeting last week when the telephone rings. It is Mark; he is in the staff canteen waiting for Christine and he is not very happy. He asks if she had received his message. This jogs her memory and she realises she should be in the staff canteen. She apologises and tells him she is on her way.

1. Explain in detail why you think Christine forgot about meeting Mark.
2. Why is it that Christine is able to remember what was discussed in a meeting a week ago, yet cannot remember what she was told earlier that day?
Within psychology, memory loss is usually defined as the inability to retrieve declarative memories from the long-term memory. An example of this could be amnesia. The person experiencing amnesia may not be able to remember facts or declarative memories, but they retain their procedural memory which is responsible for remembering skills such as riding a bicycle, reading or talking.

People with dementia may experience short-term memory loss. Their ability to store, retain and recall information may be affected due to the damage of the cells within their brain.

**Short-term memory loss**

Short-term memory can differ from one person to another. Research has been carried out on this by asking subjects to remember numbers. A list of numbers is read out at approximately one per second. The subject is then asked to recall these numbers and on average it has shown that a person can remember seven consecutive numbers.

A person with dementia may have difficulties remembering things that happened only a short while ago. However, the same person may be able to remember things that happened many years ago. Other memory difficulties could include:

- difficulty in recognising people or remembering their names
- the inability to find the right words for things or objects
- repeating conversations that they have already had
- asking the same question in a short space of time
- forgetting appointments or recent events
- misplacing items, forgetting where they have put things or where they are usually kept
- the inability to recall what they have had to eat or even forgetting they had eaten
- the loss of skills such as self-care, washing, dressing, putting clothes on in the wrong order, shopping and cooking
- the inability to judge time, thinking it is time to get up when it is the middle of the night
- forgetting where they live
- becoming unaware of their surroundings
- forgetting to take medication, possibly thinking they have already taken it
- forgetting their disabilities such as getting up to walk even though they are not able, which results in their falling
- an inability to have empathy which could make the person appear selfish
- personality changes — if previously extrovert, they could become introverted and vice versa
- the loss of social etiquette including making thoughtless comments, being rude or exhibiting sexual behaviours in public.

Initially people experiencing these memory losses may feel frustrated or angry with themselves. They are angry because they know that they have forgotten, and frustrated because they are unable to remember as they used to.

**Activity 1**

**Memory impairments**

Think about the people you support. What types of memory difficulties do they experience and how do you know about this?

**Functional skills**

**English: Speaking and listening**

Have a discussion with colleagues about the types of memory difficulties that people you are working with have. Ensure you take an active part in the discussion and that you show effective listening skills.

It is important to keep in mind that no two people’s memories will be affected by dementia in the same way. The inappropriateness of their behaviours is caused by a physical change to the brain and therefore the person has no control over it.
1.3 How individuals process information with reference to the abilities and limitations of individuals with dementia

The workings of the brain are very complex. As stated previously, the human brain is made up of around 100 billion cells. In the main these cells are called neurons. It may be easier to think of these neurons as switches which are either switched on or switched off. If the neuron is switched off it is resting; when it is switched on it fires electrical impulses along its body known as the axon. At the end of this axon there is a small part which releases a chemical. The chemical travels over a gap known as the synapse where it turns on another neuron. These chemicals are known as neurotransmitters. There are 60 identified chemicals involved in the brain’s activity. The following are some important neurotransmitters relating to the process of memory and associated functions.

Dopamine

The chemical dopamine is critical for controlling your body’s movements. If you do not have enough dopamine, you will not be able to move or control your movements very well. Dopamine also controls the flow of information from other areas of the brain, especially memory, attention and problem-solving tasks.

Serotonin

The chemical serotonin is the neurotransmitter enhanced by many antidepressants, such as Prozac, and has become known as the ‘feel-good’ neurotransmitter. It has a profound effect on mood, anxiety and aggression.

Acetylcholine (ACh)

ACh controls activity in the areas of the brain that are connected with attention, learning and memory. People with Alzheimer’s tend to have low levels of ACh in their brain.

Glutamate

Glutamate is vital for making the links between neurons that are the centre of learning and long-term memory.

Reading about these chemicals and what they do can help towards explaining how the person with dementia, who has damage to these neurons, has difficulty with their memory. Because the neurons are damaged or destroyed, they are not able to produce or transmit important chemicals which are required for the person to function fully.

Left-sided and right-sided brain

The collection of 100 billion cells or neurons in the brain is divided into two halves, known as hemispheres. The right side of the brain is responsible for putting information together — for example, information received from eyes. If you see a lady the information goes from your eyes to the right side of your brain, firing neurons, putting the information together so you are able to say, ‘I can see a lady.’ The left side of the brain analyses information which is collected by the right side of the brain. It enables you to expand on what you see so you are able to say, ‘I know who that lady is, it’s my sister Michelle.’

People with dementia who have damage to the neurons on the right side of the brain will have difficulty putting information together. They will be able to ‘see’ things, items or people, but will not be able to make the connection of what those things, items or people are. People who have damage to the neurons on the left side of the brain tend to be affected by depression. They will have more organisational problems and will have problems using language.
1.4 How other factors can cause changes in an individual’s condition that may not be attributable to dementia

Experiencing a loss or reduction in memory does not always indicate a form of dementia. There are other health conditions which could affect somebody’s level of memory. These are often referred to as reversible dementias. The part of the brain that has become damaged will determine how the person will be affected.

Conditions affecting memory

Brain injury

Injuries to the brain can be caused by external trauma such as a blow to the head, or internal factors such as a result of a stroke or aneurism. The level of brain injury can be anything from mild to severe. This can result in both short-term and long-term or permanent difficulties.

Brain tumour

A tumour of the brain can be benign (slow-growing, non-cancerous) or malignant (invasive, often growing rapidly and cancerous).

Diet

Some foods can have an effect on a person’s memory. It is believed foods such as those containing vitamin C and sugars can have an effect on memory.

Drug and alcohol induced memory loss

The effects of drug misuse including excess alcohol can cause damage to the neurons in the brain, resulting in neurological difficulties including memory disruptions.

Myalgic Encephalomyelitis (ME)

ME, otherwise known as Chronic Fatigue Syndrome (CFS) or Post-Viral Fatigue Syndrome (PVFS) is a chronic, disabling neurological disorder. It is characterised by persistent fatigue and muscle pain. Symptoms can include cognitive problems such as loss of memory and concentration, recurrent sore throat and enlarged neck glands, disturbed sleep patterns and persistent headaches.

Medication

Some prescription medications can have side effects which can affect somebody’s memory.

Encephalitis

Encephalitis is an inflammation of the brain, usually occurring as a result of viral infection.

Huntington’s disease

Huntington’s disease is a hereditary, neurodegenerative disorder of the central nervous system. It can cause emotional, intellectual and movement problems. The course of Huntington’s is characterised by involuntary movement of the limbs, trunk and face, progressive loss of mental abilities, and the development of psychiatric problems.

Huntington’s disease usually appears in middle age (30–50 years) but can develop in younger and older people.

Hydrocephalus

Hydrocephalus is usually associated with Spina Bifida and is caused by a build-up of cerebro-spinal fluid (CSF) in the brain. This condition can also be caused by infections such as meningitis, premature birth, head injury or stroke. Hydrocephalus can lead to problems with concentration, short-term memory, organisation and coordination.

Lack of sleep/insomnia

People who have difficulty sleeping may experience various health problems including memory difficulties.
Lyme disease
Lyme disease is an infectious disease caused by the bacterium *Borrelia Burgdorferi*. The disease is transmitted to humans through the bite of an infected tick. If left untreated, Lyme disease may affect a person’s memory.

Multiple sclerosis (MS)
MS occurs as the result of damage to myelin — the protective sheath surrounding nerve fibres of the central nervous system. This damage interferes with messages between the brain and other parts of the body.

Parkinson’s disease
This is a progressive neurological condition, which can affect the person’s ability in talking, walking, swallowing, writing and memory.

Stress
Stress is the emotional and physical strain caused by your response to pressure from the outside world. Stress can affect your health in many ways, including memory difficulties.

Stroke
A stroke occurs because of a disruption to the blood supply to a particular area of the brain, causing damage to that area of the brain.

1.5 Why the abilities and needs of an individual with dementia may fluctuate

Each person may experience dementia in different ways. There is no definitive direction or path that the condition will follow and there are no exact timescales in which the condition may progress. You have examined how the person’s condition will deteriorate over time, but during that time it can also fluctuate or come and go.

Fluctuation of needs and abilities
It is not fully known why somebody with dementia can have ‘good days’ and ‘bad days’. Part of the answer for this could be because we all have good and bad days. This very much depends on how we are feeling, how much sleep we have had, what activity we are doing and how much we want to do that activity.

When you are having a bad day, everything you do seems to go wrong. Could this be simply because you are feeling so negative? Can your attitude have an effect on the outcome? Think about this for a while. If you do not like doing something, it seems to take forever to get it over and done with. The time drags and your level of boredom or uninterest rises. On the other hand, when you are doing something you enjoy, the time rushes by so that before you know it the activity comes to an end. This theory could also relate to the person with dementia. If the person is doing something that is familiar to them, something that they have done many times and have developed a routine for, the person may appear very confident and able to do it with ease. They may appear to show no signs of dementia. However, take the person out of their familiar surroundings and out of their routine, and their confusion will grow, causing their symptoms to be more obvious.

Stress has been identified to have an effect on our memory. In the early stages of dementia, the person may be fully aware that they have forgotten where they have put things. This can cause their stress levels to rise, resulting in added memory difficulties, frustration and confusion. In these earlier stages it is important for you as a care worker to give the person emotional support. Do not be tempted to take over what they are having difficulty with. Help them to calm down and think about what they are doing. The more the person becomes agitated, the greater their difficulties will become.

As the condition progresses, the more support the person will require. This will include support with day-to-day activities. You can give support through reminding the person what they need to do. Do not overload them as this will increase their stress and therefore their symptoms. If the person asks you a question and repeats it several times within a short space of time, answer it as though it is the first time you have heard the question. Do not show your frustrations as this will only cause them to become upset when they see how their behaviour is affecting you.

In the later stages, the person will become emotionally and physically frail. Their reliance on care will increase to the point where they are no longer able to care for themselves. They may lose their ability to eat, walk or speak, with only the occasional word being shouted or crying out.
2. Understand the impact of recognition and diagnosis of dementia

2.1 The impact of early diagnosis and follow-up to diagnosis

For most people, receiving the diagnosis of dementia is very distressing. It is also very upsetting for their family. Many people today still think of dementia as being a condition which causes people to go ‘mad’. It is these negative images that can add unnecessary distress to both the person and their family.

If you are supporting somebody who is exhibiting any signs or symptoms of forgetfulness, confusion or the inability to find the right words when communicating, it is important that they see their GP. Diagnosis can be difficult to make in the early stages as the symptoms of dementia can develop slowly. They can also be similar to symptoms of other health conditions. The GP or health professional will be able to monitor any pattern of symptoms and undertake tests over a period of time to measure any changes in the person’s mental ability. A brain scan can help with diagnosis; this could be a CT scan or MRI. If a diagnosis is made, the person may be referred to a specialist for further treatment.

**Early diagnosis**

The early diagnosis of dementia is essential in order to:

- rule out other conditions that may be treatable
- access advice, information and support
- allow the person with dementia and their family to plan and make arrangements for the future.

Receiving an early diagnosis of dementia can help the person and their family to plan and prepare for the future. Although there is no cure at present, there are various medications available which can help improve symptoms and, for some, slow down the progression of the disease. Early diagnosis can help the person to identify and access sources of advice and support for their condition.

The early education of the person and their family can help them to develop a better understanding of what the future may hold. The person will have time to put their finances in order and to make wishes for their funeral through the drawing up of a will. They can be encouraged and supported to sort out any bills and arrange for future bills to be paid for by direct debit so that important bills are not overlooked. The person may find comfort in keeping busy during the initial stages and they may feel reassured that their future has been planned to meet their needs.

Following diagnosis, the person may want to live as independently as they can for as long as they can. They may not appreciate someone taking over their life in these early stages where they are still able to care for themselves. To enable the person to remain as independent as possible, it may be an idea to encourage them to contact social services, if they have not already done so, to find out what support they could be entitled to. In order to aid their memory the person could place a list of important telephone numbers by their phone. This way they will always know where a telephone number is if they need it. Labels could be placed on cupboard doors to remind them of the contents. Notes could be placed on doors as a reminder to lock them. Lists could be put on a noticeboard of things to do and days to do them on, such as putting the rubbish out for the refuse collectors.
The most important thing to support the person with is in continuing to enjoy their life. Support them to continue with their hobbies or interests. One good activity which will help them in the future is the development of a life history book. Encourage and support them to collect together photographs of people who are important to them, events which hold important memories such as the birth of their first grandchild, their wedding day or family holidays. Encourage the person to label each photograph clearly in the book so that they can look back at it at any time and be reminded of good memories.

Early diagnosis can enable the early introduction of specialist services. The services may include:

- family GPs – referring the person for further tests, reviewing medication
- district nurses
- health visitors
- community psychiatric nurses
- consultants
- memory clinics
- neurologists
- geriatricians
- neuropsychiatrists
- physiotherapists
- dieticians
- clinical psychologists
- speech and language therapists.

In many cases, the earlier the diagnosis and follow-up, the sooner the person can start regaining their life again. This is not to say that they will receive a cure – at this moment in time the only option open to people is acceptance and treatment in slowing down the progress of the condition.

2.2 Recording possible signs or symptoms of dementia in line with agreed ways of working

The health and well-being of a person should be monitored on a regular basis to ensure any resulting needs can be actioned without delay. When monitoring somebody’s condition, it is important to record any findings in line with your organisation’s policies and procedures.

In the very early stages of dementia the person may have days or episodes of forgetfulness which could be put down to the person being off-colour or having an off day. These episodes may be masked by their ability to recall past events easily. They may be able to give a reason as to why they cannot remember what you have just said to them. They may say that the television was too loud and they did not hear you. They may even be adamant that you had not told them anything, giving rise to you questioning your own memory.

The person may have difficulty understanding or following new ideas or regimes. To cover these difficulties they may say that they preferred the old way, as it is not as confusing. They could hide occurrences of misplacing items, making out that someone has moved the item or someone has taken it. All of these events, happenings and reasons could be very genuine and indeed the person themselves may believe in what they are saying to be true. If they were all true, the person would be a very unlucky person to be experiencing all of these negative events. The likelihood of them all occurring to the same person in a short space of time would be rather remote.

Recording all of these occurrences would enable you and the team to build up a picture of the person’s mental and physical health. Recording times that they

Misplacing items can be one of the first symptoms of dementia.
needed reminding to do something or became confused or disorientated would enable you to look back and identify frequencies to ascertain if their memory is deteriorating.

**Involving the family**

When supporting somebody with dementia, it may be of immense benefit to involve the family. Encourage and support the family to keep a diary of the person’s symptoms. As a care worker, you may not see the person as much as their family do and therefore they can help to give you a better picture of the person and their needs. The diary that the family compiles could help them and you to identify changes in the person that may be otherwise missed. The diary could also aid in monitoring any current interventions and the resulting benefits to the person.

**Suggested monitoring and recording**

The person’s GP or neurologist may benefit from the information recorded in altering any medications or treatment the person receives. The following areas are those which it is important to monitor and record in the person, as these will show what changes have occurred and over what period:

- memory
- behaviour
- personality
- ability to cope with daily living skills
- care-giving strategies – have they worked?
- activities the person enjoys
- any medications they have taken that day (including prescriptions, over-the-counter and herbal remedies) with details of medication name, dosage, and when and how many taken daily.

**Case study**

**Identifying dementia**

Geoffrey had been living in sheltered housing for a number of years following a stroke. His confidence in his own abilities since the stroke had been very low and he was often heard mumbling to himself. Geoffrey is visited every morning by the warden Leona to check that he is OK. Geoffrey always met Leona on his doorstep as he put out his empty milk bottle. One morning Geoffrey was not on his doorstep as usual, which concerned Leona. She rang his doorbell and waited. Geoffrey came to the door and greeted her with his usual smile. ‘Are you all right Geoff, you haven’t put out your empties?’ she asked. Geoffrey nodded, scratched his head and replied, ‘I’m fine, I haven’t finished the bottle yet as I didn’t drink much yesterday.’ ‘As long as you are all right then,’ Leona replied, waving goodbye as she turned and walked away.

The following day, once again Geoffrey was not on his doorstep. Leona rang the doorbell again and was greeted by Geoffrey still wearing the same clothes as he had on the previous day. ‘No milk bottles to put out again today?’ she asked. Geoffrey agreed, saying he had decided to drink more water: ‘I’m cutting down on my cups of tea, getting a bit of a beer belly,’ he joked. Leona was a little concerned but then shrugged it off, believing Geoffrey was always getting his words mixed up, due to his age.

As the weeks passed Geoffrey had days when he did not put out any empty bottles, and then he would put out three or four at a time. Some days Geoffrey looked unwashed or unshaven, which was unlike him. Leona was concerned but on talking to Geoffrey she felt she was worrying about nothing. Geoffrey’s behaviour had been up and down for over 12 months when Leona announced she was changing her job and a new male warden, Patrick, would be taking over. Geoffrey did not take this news very well and he became agitated, blaming Leona for the death of his wife. Leona was very shocked by this, especially as Geoffrey had never been married. She mentioned this to Patrick during her handover and explained she thought something was not quite right but she could not quite put her finger on it. Patrick asked how long had this been going on for and then said he would take care of it.

1. After visiting each resident in the sheltered housing, what actions should Leona have taken?
2. What concerns would you have had regarding Geoffrey?
3. How would records of Leona’s visits to Geoffrey have been of benefit?
4. What actions should Patrick take now, especially regarding Geoffrey?
2.3 Reporting possible signs of dementia within agreed ways of working

The diagnosis of dementia does not generally occur following the first visit to the GP. Generally there is a process in which the person goes through in order to receive a definitive diagnosis. During this process it is vital that any potential signs of dementia are reported following your organisation’s policies and procedures, and in line with government guidelines.

National Institute for Health and Clinical Excellence (NICE)

NICE has devised detailed guidelines in supporting people with dementia. This also includes the early diagnosis of dementia. Within this guide it states that primary health care staff should consider referring people who display any signs of mild cognitive impairment (MCI) for assessment. MCI is a relatively new term to describe those who show some difficulties with their memory but do not have dementia. Studies have shown that 50 per cent of people with MCI go on to develop dementia later in life. NICE also includes in its guidelines information regarding the diagnosis and assessment of dementia. It states that diagnosis should only be made following assessment to include:

- the person’s history
- a cognitive and mental state examination
- a physical examination
- a review of all medication including over-the-counter remedies.

As a care worker, your input in reporting possible signs of dementia would go towards the person’s history. Your input can help them receive the care that they need, when they need it. It is for this reason that you should ensure timely reporting of any observations you make or concerns you may have.

To report a concern, you must follow your organisation’s guidelines. If you are unsure of what these guidelines state, you should speak with your line manager as soon as possible to ensure your actions follow best practice for the person. In general terms, most reports are given to a designated member of staff. This may be your line manager, supervisor or manager. Your verbal report should be factual and to the point. Try to avoid giving your own opinions. Although opinions can help to look at and clarify various issues from differing viewpoints, they can also be unhelpful if used inappropriately. Once you have given a verbal report, you should back up what you have discussed with the appropriate person, by writing a written report. Again your written report should be factual and detail all of the actions you have taken.

Some reports will have an increased impact if they are delivered in a certain way. For example, you may have been asked to monitor somebody over a set period of time and report back your findings. Simply writing those findings down may not have the same effect as plotting your findings on a graph. A graph or chart will give a visual representation of your findings, which may give a better explanation as to the person’s mental state and any changes that have occurred.

Reporting occurrences such as wandering can have a greater impact if plotted on a graph.

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Activity 2

Process of reporting

Speak with your manager or line supervisor to identify your organisation’s policy and procedures on the process of reporting information.

Functional skills

English: Speaking and listening

This discussion can be either formal or informal and can give you the opportunity to practise taking part in a one-to-one discussion.
Reflect
Imagine you, or someone you love, had just been given the news that you or they had dementia. Being honest, what would be your initial thoughts or feelings? Do you feel it is OK to feel or think this way? Is there anything you feel that society can do to help with the acceptance or understanding of dementia?

2.4 The possible impact of receiving a diagnosis of dementia on the individual and their family and friends

Receiving news which you know will have a major impact on your future and those who are close to you can be very frightening and overwhelming. The person may feel very insecure at the time, despite possibly having family and friends around them. The impact on the person and their family and friends can vary; some may see it as a relief that the cause of their difficulties has been diagnosed, while others may be in disbelief, preferring not to acknowledge what they have been told.

Many older people fear becoming a burden on their family more than they fear death.
Feelings

The person may be shocked on first hearing the diagnosis; this can often turn to denial. One theory on loss or grief shows that the process usually goes through five stages including:

1. denial
2. anger
3. bargaining
4. depression
5. acceptance.

It is felt that the person may not necessarily go through each stage in this particular order, and indeed can go backwards and forwards, repeating various stages a number of times before reaching and remaining at acceptance.

The person may experience fear or the concern that they will lose control over their lives and their future. They may also fear becoming a burden on their family and friends. Some may feel guilty, blaming themselves, thinking that they could have prevented their condition happening.

Whatever feelings the diagnosis creates in the person, you should encourage and support them to talk about their feelings. Some may not feel comfortable voicing their feelings to their family and friends, preferring to talk with someone they do not know. The person’s family and friends should not be upset by this decision and should respect the wishes of their loved one.

Initially the person may simply want to curl up and lock out the world around them. Family and friends need to be supportive in these situations. Telling the person to ‘get a grip’ or that what they are doing is silly is not going to be of any benefit – in fact, it will often make things worse.

NICE requirements

NICE guidelines state that following a diagnosis of dementia, health and social care professionals should provide the person and their family with written information regarding:

- the signs and symptoms of dementia
- the course and prognosis of the condition
- treatments
- local care and support services
- support groups
- sources of financial and legal advice, and advocacy
- medico-legal issues, including driving
- local information sources, including libraries and voluntary organisations.

Any advice and information given to the person and their family should be recorded in the person’s care notes. The confidentiality of the person should be respected if they decide they do not wish any information to be given to their family.
3. Understand how dementia care must be underpinned by a person-centred approach

3.1 Person-centred and non-person-centred approaches to dementia care

It is important to remember that people with dementia are individuals first, with their condition of dementia coming second. They may also be mothers, fathers, brothers, sisters, sons or daughters. They may have led a fulfilling life before the condition of dementia took hold of their memories and personality. How could the care of any person be anything other than individual, specific to their needs, involving and respecting their views on how they want their care to be delivered?

Person-centred care is a way of providing care with the person at the centre of everything you do. Another way of describing it is individualised care — care that is given to the person according to their needs, wishes, beliefs and preferences. One would hope that gone are the days when everyone in a care home got up at the same time, ate their breakfast at the same time, got washed and dressed at the same time, even going to the toilet at the same time. These regimented routines of care homes were devised for the benefits of the staff, not the people being supported. The day revolved around tasks, duties that had to be met, more often than not putting the people’s specific needs at the end of the priority list. If you needed support, which type of care home would you choose?

Earlier on in this unit we looked at how dementia can affect people and identified that no two people would necessarily follow the same process through the condition of dementia. This being the case should automatically exclude all people with dementia being treated in the same way.

Studies have shown that a person-centred approach can help reduce agitation in the person with dementia. Agitation is often caused by the person’s frustration in not being able to express themselves. The expression could be one of sadness, pain, thirst, hunger or tiredness. Other studies on a person-centred approach have shown that the person often remains living in their own home for longer. A person-centred approach can also ensure that the person does not endure the degrading, discriminatory and abusive practices which could otherwise occur. People and all those involved in their care should feel safe, feeling that they are a part of what is going on, receive continuity of care, have purposeful goals which they are supported to progress towards and have a feeling that they do matter.

How does a person-centred approach benefit the person?

As a care worker, you should identify the specific needs of the person with dementia. These needs could arise from their gender, ethnicity, age, religion and personal care. Other needs could also arise from their physical health or physical disability, any sensory impairment, communication difficulties, problems resulting from poor nutrition, poor oral health or learning disabilities. The person’s needs should be identified with input from the person, their family, friends and any other persons that may be important in that person’s life.

Once the person’s care needs have been identified, plans should be made to draw up a support plan which will describe how those needs will be met. As with the assessing of needs, the person must be at the centre of the support planning process. Nothing should be planned for them without them.
3.2 Different techniques to meet the fluctuating abilities and needs of the individual with dementia

Many people with dementia are able to live in their own homes for most of their lives with care being given to them by their families. It is important that the person is supported to recognise that the condition that they have is not the fault of anyone, especially not their own. When supporting the fluctuating needs and abilities of the person, it is very important that you recognise that they are not responsible for the things that they do. It is not the person who is spitting out their food; it is the condition’s effects on the person’s ability to communicate which is preventing them from saying, ‘I don’t like that.’ It is not the person who is constantly wandering around the environment; it is the condition that has taken away their spatial awareness.

As a support worker, you must focus on the skills and abilities that the person has, rather than those that they have lost. Ensure that you are fully aware of and respect the person’s background, their history, likes and dislikes. Be prepared for changes and adapt a flexible approach. No two days may be the same in supporting people with dementia. Seize the challenge and look forward to the unexpected. As the saying goes, ‘variety is the spice of life’.

Knowing the person

By learning about each person’s history and background, you can design the care and support you provide around their specific needs. For example, the person may have been a sergeant major in the army, which could account for his shouting out his orders. The person may have experienced a traumatic event in their lives such as being trapped in a collapsed building, which could account for them becoming agitated and screaming when the lights are switched off in their bedroom at night. Without this background knowledge, and more importantly understanding, the person who shouts his orders may be wrongly labelled as being noisy and dictatorial. The person who screams in the dark may be wrongly labelled as disruptive and attention-seeking.

A person’s physical condition can be affected by their dementia. Their mobility may be reduced as may the person’s ability to maintain their own personal care or diet. Combining these factors can increase the person’s susceptibility to other illnesses such as chest infections or physical conditions such as pressure sores.
Ensure the person’s support plan is kept as up to date as possible and shows alternative methods to use for various fluctuations in their support needs. Support other care workers by sharing proven practices. As a support worker, you may have identified triggers to somebody’s behaviour. Do not keep this information to yourself; inform other care staff and have it recorded in the person’s support plan. This would be the same for identifying any new method or way of supporting the person to meet their fluctuating needs.

**Provide a stable environment and suitable surroundings**

One of the main triggers resulting in somebody with dementia becoming agitated and confused is a change in their routine. Any changes to the person’s life or daily routine can cause them to become unsettled, which could lead to inappropriate behaviours. To ensure stability it is important to:

- have consistent, regular staff. Unfamiliar faces can cause the person great upset. Ensure they know the staff and ensure the same staff member provides care to the person in their own home
- maintain a familiar environment. It is an eventuality in everyone’s life that their surroundings will change at some point. This could simply be through redecoration or changes in furniture. Where possible, if decoration needs to be undertaken within the person’s environment, try to make the new decor similar if not the same as it was previously. If relocation is required for the person, ensure this is minimised by confirming the suitability of the new location. This will save on the person needing to be relocated again due to the environment not being suitable for their needs
- ensure the person is in a non-stressful, constant and familiar environment
- establish a regular routine, regular physical activity and adequate exposure to light to improve any sleep disturbances.

**Specific strategic support**

People with dementia may behave in a way that is completely out of character. Some of these behaviours can be disturbing to onlookers and especially the person’s family, seeing their loved one behaving in a way they have never seen before. The following are examples of the types of behaviours people with dementia may display.

**Wandering**

People with dementia may tend to walk or wander apparently aimlessly for a variety of reasons. This could be because they are bored or they feel they need to escape or get out of the environment they are in. The person may simply need to use the bathroom but cannot remember where it is. On occasions this wandering may take them out of the house or even down the street. This could lead them into becoming ‘lost’ if they are unable to find their way back home. For most people, wandering may only be a short phase that they go through. And, although little comfort at the time, people with dementia often retain a good degree of road sense and are seldom involved in traffic accidents. To reduce incidents of wandering, promote physical activities to reduce the person’s boredom and to help use some pent-up energy.

**Incontinence**

Loss of bowel or bladder control usually occurs as the dementia progresses. Sometimes these accidents may happen because the person cannot remember where the bathroom is or cannot get there in time. If the person does become incontinent, you need to help them to maintain their dignity and respect by being understanding and reassuring. Incontinence pads, sheaths or catheters can be obtained to help keep the person free from unnecessary embarrassment and frustration.
Agitation

Agitation can include behaviours such as sleeplessness, verbal or physical aggression and irritability. These types of behaviour often increase with the stages of dementia and can become quite severe. Agitation may be triggered by a variety of factors including environmental factors, fear and tiredness. Most often agitation is triggered when the person feels as if they are no longer in control of the situation. You can help reduce episodes of agitation by reducing the intake of caffeine, sugar and processed foods. The reduction of noise or crowds can also help, as does the maintenance of the person’s routines.

Repetitive speech or actions

It is a common occurrence with those who have dementia to repeat a word, statement, question or activity more than once in a short amount of time. This repetition can be frustrating and stressful to the care giver and their family. Repetition is often as a result of the person becoming anxious, bored, fearful or agitated. One way of reducing this is to provide them with reassurance. Alternative strategies could include displaying reminders of activities around their home such as ‘Dinner is at 6:30pm’ or ‘Dave comes home at 5pm.’ This may assist with reducing anxiety and uncertainty about anticipated events.

Paranoia

People with dementia may suddenly become suspicious, jealous or start accusing others of things. When this happens, the person will believe in what they are saying and therefore you should not try to argue or disagree with them. Stay calm and encourage the person to calm down. Ask them what is wrong and let them know that you are there to help them.

Improve your knowledge and understanding

Many organisations have helpful information on understanding and supporting people with dementia. Set yourself a goal to develop your practices through research, talking to people who are in the early stages of dementia or family and friends of those who have it. Learning about dementia from those who have first-hand experience is often more beneficial than reading a book, although books have the benefit of being portable and accessible at any time. At the end of this unit there is a list for further reading which will help your knowledge and understanding further.

Doing it well

Meeting the needs of people with dementia

- Know the person well, including their history and background.
- Keep their support plan up to date.
- Provide a stable environment and suitable surroundings.
- Ensure specific strategic support.
- Improve your knowledge and understanding.

3.3 How myths and stereotypes related to dementia may affect the individual and their carers

Dealing with the difficulties that come with the diagnosis of dementia is not going to be made any easier with the myths and stereotypes that society has created. Within society, dementia is often seen as a condition that causes the person to require 24-hour care in a secure environment so they cannot get out and wander aimlessly. People who are newly diagnosed with the condition are sometimes disbelieved because they appear ‘normal’ and are dribbling or babbling. Some myths or falsehoods can create an unrealistic hope within the person or their family. Some of these untruths profess to offer cures or preventions. The following information can help you to identify fact from fiction.

Q – Can using aluminium saucepans affect the risk of developing Alzheimer’s?

A – No, there is no convincing evidence that cooking with aluminium saucepans increases the risk of developing Alzheimer’s.

Q – Is it true that people who follow a healthy lifestyle reduce the risk of developing dementia?

A – Yes. Research shows that people who enjoy a healthy lifestyle by eating a well-balanced diet, not smoking and taking regular exercise reduce their chances of developing dementia. Recent research has shown that being healthy in mid-life can help lower our risk of developing dementia as we age.
Q – Can Ginkgo Biloba help people with dementia?
A – No. Unfortunately, the latest evidence shows that Ginkgo Biloba has no benefit for people with dementia.

Q – Does eating meat have any connection with developing Alzheimer’s?
A – There is no convincing proof that eating meat is linked to developing Alzheimer’s.

Q – Do people who have dementia become childlike?
A – No; it is very important to remember that people with dementia are adults and should be treated with the dignity and respect other adults receive.

Many people, quite wrongly, have stereotypes when it comes to dementia. It is these stereotypes that can become the fear of reality for people newly diagnosed with dementia. Sometimes it is the person’s own stereotyping of dementia that they have to face. Facing and resolving this can only occur with education and acceptance.

3.4 Ways in which individuals and carers can be supported to overcome their fears

Research has shown that many people fear the thought of developing a form of dementia. The worry of losing one’s identity, independence and mind for some is a greater fear than the fear of death. Worrying about a condition that you may not develop seems futile. Worrying about a condition which you have developed will not do your health much good.

Simply telling somebody who has received a diagnosis of dementia or their family not to worry is insufficient. Advising the person and their family to talk about their fears will help towards them overcoming any uncertainties. Ignoring the condition or pretending it is not happening is simply denial. To help all those involved to overcome worries for the future, the person and their family should be supported to learn the truth, what they can expect from the future.

Understand the condition

The person and their family should be supported to develop a true understanding of the condition they are facing. Information can be obtained from GPs’ surgeries, health centres, libraries and the Internet. When obtaining information from books or the Internet, you need to ensure it is up to date and reliable. Internet sites run by organisations such as the Alzheimer’s Society or NHS Direct can be seen as reliable sites, as can educational sites such as those ending with .org. Some of the facts relating to dementia do not always make for easy reading; however, the person and family need to know what to expect. Skirting around these issues will not enable the preparation that may be required. This could lead to a bigger shock when it actually happens, which would not do anybody any favours.

Encourage future planning

Once the person and their family are aware of how dementia may affect the future, they should be supported to think ahead and be ready for the changes that will follow. The person and their family will need to prepare things not just materially but emotionally as well. At some point the person may require support with toileting and other personal care needs. They may not want their family attending to this sort of personal care,

People’s inappropriate views or opinions on dementia often arise from ignorance. For many, the only portrayal they have of dementia is that which they see on television. Storylines shown in films are often of people in the advanced stages of dementia. If this is the only perspective you have, then there is no wonder why society looks at this condition in the way it does. If the individual newly diagnosed with dementia or their family has only ever known of dementia in this way, then their fears will understandably be heightened.

Activity 3

What’s in a name?
Devise a simple questionnaire which you can either send out to colleagues or staff within your organisation, or give to your family and friends. Ask questions such as, ‘Give the first word that comes into your head when you hear the word “dementia”.’
Include a few questions that relate to the myths around dementia to see if your colleagues or family know the truth or not. Compile the results from your questionnaire and discuss these with your assessor.
preferring to have a care worker attend to their needs at home. There may come a point where the person is unable to stay in their own home due to the advancement of their condition. The fear of this eventuality can create a lot of worry for them. Supporting the person to plan for this can help allay those fears. They and their family could be supported to identify a care home which the person may move into in the future. Simply knowing that this step has been arranged can help them feel a little easier, knowing that they will not be placing a burden on their family.

Making life easier

The person may have received a diagnosis of dementia because of their current memory difficulties. The family may worry that the person will not be able to cope very well at home, forgetting to take their medication, forgetting to lock doors and windows when going out and so on. These sorts of worries for the family will not necessarily lessen. As each day passes they may worry. As each day passes the person’s condition may increase, making the family worry all the more until it becomes a vicious circle. To help reduce these fears, the person can be supported to remain as independent as possible at home with the use of notes, labels, lists – any memory joggers. The environment in which the person lives can be made safer – for example, installing grab rails or an emergency pull cord system. Making these minor changes to the person’s home may reduce the natural worries of the family with regards to their loved one’s safety.

Dealing with the diagnosis of dementia is never going to be easy. Some people and their families may benefit from receiving counselling. This can often be provided by the GP’s surgery. It is a confidential service which is there to help the person and their family to develop ways of dealing with their thoughts, fears and feelings.

Reflect

Think about the support you have offered people and their families to overcome their fears. Was it appropriate? Did it benefit the person and their family? Is there anything else you now feel you should have done or said differently?

Further reading and research

- [www.alzheimers.org.uk](http://www.alzheimers.org.uk) (Alzheimer’s Society: The UK’s leading care and research charity for people with dementia and those who care for them. The organisation provides information, support, guidance and referrals to other appropriate organisations)
- [www.bild.org.uk](http://www.bild.org.uk) (British Institute of Learning Disabilities: An organisation that works to improve the lives of people with disabilities. It provides a range of published and online information)
- [www.cjdsupport.net](http://www.cjdsupport.net) (An organisation which supports people with prion diseases, including forms of Creutzfeldt-Jakob disease (CJD). It provides a range of information on the various forms of prion disease, and works with professionals to improve the level of care provided for people with these conditions)
- [www.hda.org.uk](http://www.hda.org.uk) (Huntington’s Disease Association: An association that provides information, advice, support and useful publications for families affected by Huntington’s disease in England and Wales. It can put you in touch with a regional advisor and your nearest branch or support group)
- [www.mssociety.org.uk](http://www.mssociety.org.uk) (Multiple Sclerosis Society: A charity which provides information and support to anyone affected by multiple sclerosis. The society has a national helpline and a network of over 350 local branches)
- [Dementia – A NICE–SCIE Guideline on supporting people with dementia and their carers in health and social care – National Clinical Practice Guideline Number 42](http://http://guidance.nice.org.uk/CG42/Guidance/pdf/English)
Getting ready for assessment

You need to be able to demonstrate or show that you have the knowledge for each of the assessment criteria listed in the standards. You can demonstrate your knowledge with written or verbal explanations. This can be achieved by answering questions, either in written form or verbally, which have been set by your assessor.

Your knowledge can also be demonstrated using case studies or professional discussions. You may wish to undertake a written research project covering as many of the assessment criteria as possible. Your project could also include real-life case studies where you have examined what effects dementia has had on the people you work with. When using real-life case studies, you must be mindful of confidentiality and seek permission from the appropriate person. This could be your manager or a relative of the person concerned.

You may want to arrange to talk to relatives of people who have dementia; again, you will need to seek the support of your manager before doing this. Talking to relatives would be of benefit for outcomes 1.2, 2.1, 2.4, 3.3 and 3.4. When talking to relatives, you will need to be sensitive to their feelings, especially if the person has been diagnosed recently. This unit does not have any requirements for observations.
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