

the **skills** network

NCFE Level 3 Certificate in Understanding the Principles of Dementia Care





These learning resources and assessment questions have been approved and endorsed by ncfe as meeting the requirements of the Level 3 Certificate in Understanding the Principles of Dementia Care.



Disclaimer:

This resource uses real life case studies where specifically stated and referenced. All other references to individuals, groups and companies contained within these resources are fictitious.

Unit 1: Understanding dementia

Welcome to unit one.

This unit is split into three sections. These are:

Section 1: Common types, causes and effects of dementia

Section 2: The importance of early diagnosis of dementia

Section 3: The effects and experience of dementia

Introduction

As you start to read through each page you will be able to make notes and comments on things you have learnt or may want to revisit at a later stage. At the end of each section, you will be asked to go to your assessment booklet and answer the relevant questions.

Once you have answered the relevant questions go to the next section and continue studying until all of the assessments have been completed.

Please make sure that you set aside enough time to read each section carefully, making notes and completing all of the activities. This will allow you to gain a better understanding of the subject content and will help you to answer all of the assessment questions accurately.

Good luck with your study. Now let's begin!



Section 1: Common types, causes and effects of dementia

This section will explore the following:

- The most common types of dementia
- The causes and risk factors of common types of dementia
- The signs and symptoms of common types of dementia
- A range of other types of dementia that may occur.

The most common types of dementia



STOP AND THINK!

What do you understand by the term 'dementia'? Consider who it might affect, the signs and symptoms and how it can be managed or treated.

Note down your thoughts in the space below. You can add to your notes as you learn more throughout this section.

Currently, research identifies the four most common types of dementia as:

- Alzheimer's disease
- Vascular dementia
- Dementia with Lewy bodies (DLB)
- Frontotemporal dementia.

Alzheimer's disease

Arguably the best known of all types of dementia, Alzheimer's disease is diagnosed in 62% of all known cases of dementia within the UK. It is a neurodegenerative disease, which gets worse over time and which has similar characteristics to other types of dementia, for example, memory loss, difficulties with cognitive processes like thinking and reasoning, and problems with disorientation where an individual gets lost easily, even on routes with which they were previously very familiar.

Definition: Neurodegenerative

Degeneration of the nervous system, especially the neurons in the brain.

Alzheimer's disease is caused by the formation of protein plaques within the brain. These tangles of protein are called 'tau' and are most commonly found in the temporal lobe, which is the area of the brain in which memories are formed. These plaques and tangles lead to an insufficient supply of blood to brain cells and as a consequence, these will eventually die off. As Alzheimer's progresses, the size of the area in which the brain is affected becomes larger and so the individual's symptoms worsen.

It is also believed that this disease could be caused by a lack of vitamin B in an individual's diet or because of an underactive thyroid gland (hypothyroidism). Although the real cause of Alzheimer's disease is currently unknown, many researchers argue that as many as 70% of cases are caused by a person's genes.

Definition: Genes

A unit of heredity which is transferred from a parent to their offspring and is held to determine some characteristic of the offspring.

Activity 1: Genetic make-up

Genes are something, which will be referred to often when discussing dementia, so it is important to know what aspects of a human can be affected in this way. Have a look at the list below and highlight the items which can be affected by someone's genetic make-up:

• Eye colour

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- Intelligence
- Disposition to certain diseases
- Height
- Social skills
- Ability to cope with stress.

Check your answers at the back of this workbook.

Vascular dementia

With less than half of the amount of diagnoses as Alzheimer's disease, vascular dementia, however is still quite prevalent among people who have dementia, being diagnosed in 17% of all known cases in the UK.

This type of dementia is caused by a reduction in blood supply to the brain due to the individual having diseased blood vessels. In order to function at their optimum level, brain cells need a consistent supply of oxygen and nutrients and blood is supplied to those cells by the vascular system by a network of blood vessels. If damage to the brain occurs, it is quite possible that some blood vessels will leak or become blocked and when this happens, the blood cannot reach brain cells effectively and so they eventually die.

There are several different types of vascular dementia dependent upon what has caused the damage to the brain and what area of the brain the damage is located in. All types of vascular dementia will have some symptoms in common but some are specific to an individual type and in these latter cases, the symptoms will progress in different ways.

The three most common types of vascular dementia are:

- **Post-stroke dementia**: Strokes happen when blood supply to the brain is suddenly cut off. The severity of a stroke's consequences can vary, however, it is thought that up to 20% of individuals who have a stroke will develop vascular dementia within six months.
- **Single-infarct and multi-infarct dementia**: This type of dementia is caused by one or more smaller strokes. Sometimes a stroke can be so small that an individual does not even notice that they have had one, usually because the blockage in the blood vessel manages to clear itself. If, however, the blood supply is cut off for more than a few minutes, this can lead to the death of a large area of brain cells known as an 'infarct'. When this happens once, single-infarct dementia can occur. When several strokes happen after each other, the total damage caused by them all results in multi-infarct dementia.
- **Subcortical dementia**: This type of dementia is caused when blood vessels, which lie deep within the brain become stiff and twisted, causing blood supply to be reduced and for the vessels to then become diseased and for dementia of this kind to occur. Subcortical dementia is believed to be the most common type of vascular dementia.



Dementia with Lewy bodies (DLB)

DLB is a type of dementia that shares many characteristics with both Alzheimer's disease and Parkinson's disease. It is diagnosed in approximately 4% of all known dementia cases within the UK, but it is thought that this number is likely much higher, possibly up to 10%, because the disease is currently under-diagnosed.

Definition: Parkinson's disease

A progressive disease of the nervous system, characterised by tremors and muscular rigidity.

Lewy bodies, which are named after the doctor who identified them, are small deposits of protein that sit within a nerve cell. The link between Lewy bodies and dementia is not fully understood, but it is believed that there is an association with low levels of certain neurotransmitters, which send messages between nerve cells. When these nerve cells die, this leads to loss of brain tissue, which leads to DLB.

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Definition: Neurotransmitter

A chemical that is released from a nerve cell which then transmits an impulse from a nerve cell to another nerve, muscle, organ, or other tissue.

The way in which DLB affects someone, will depend upon where the Lewy bodies are located within the brain. For example, if they are at the base of the brain, then motor skills will be affected, if they are in the outer layers of the brain then this will affect cognitive functioning. Often these two symptoms occur together and sometimes people with Parkinson's disease will develop dementia as well. The symptoms of these two diseases become more similar as the disease progresses and one is often mistaken for the other. Together the two diseases are known as Lewy body dementias.

Frontotemporal dementia

This type of dementia is less common than the others, being diagnosed in approximately 2% of all known cases within the UK. It covers a range of specific conditions and is also known as 'Pick's disease' or 'frontal lobe dementia'.

Frontotemporal refers to areas of the brain which are damaged, causing the disease to occur. They are located behind the forebrain and are responsible for regulating an individual's behaviour, emotion and language.

Frontal Lobe

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Damage is caused by the death of nerve cells within these lobes, due to the lack of sufficient chemical messengers between them. When the nerve cells die, the lobes shrink in size and the individual with the condition is subject to changes in their personality and behaviour, they may also have difficulty with language. This form of dementia is believed to give people the shortest life expectancy after it is diagnosed.

Further Research: The brain

In order to understand the development of dementia, it is important to have some knowledge about the brain in general. Use the website below to research the brain's key areas and how these link to dementia. Make notes in the space below.

www.innerbody.com/image/nerv02.html

If the link does not work when you type it into a browser, simply search for 'innerbody brain' and the link will appear on the results page.

The causes and risk factors of common types of dementia

Dementia is increasingly common around the world; it is estimated that there are almost 36 million people who have dementia, of whom, up to 26 million do not have a formal diagnosis.

Understanding the Principles of Dementia Care

Key Fact

Within the UK, there are currently estimated to be 850,000 people with dementia but this figure is forecast to rise to over one million by 2025.

Source: www.alzheimers.org.uk

Given these figures, researchers are trying to identify possible causes and risk factors for dementia so that it can be prevented for those who do not have it and cured for those who do.

Causes and risk factors are sometimes thought to be the same thing and people use them interchangeably, however this is not the case. A cause is something that has made something happen, whereas a risk factor is something that increases the likelihood of something happening. For example, if a person walked along a high wall, then fell and broke their leg, the cause of the accident would be the fall. The risk factor was introduced when the person began walking on the wall. A person who did not walk along the wall would be less likely to fall, and therefore less likely to suffer an injury such as breaking their leg.

In terms of dementia, this would mean that a person whose mother had dementia might ultimately be the cause of them developing the disease too, but if they have smoked and had a poor diet, they have also increased the risk factors that might cause them to develop dementia. Alternatively, a person whose mother had dementia but who did not smoke and had a good diet, might still be diagnosed with the disease but they are reducing the risk factors.



Causes of dementia

The table below outlines some causes of dementia and how they contribute to the development of the disease.

Cause	How does this contribute to dementia?
Brain cell	If brain cells are not given a sufficient supply of oxygen and nutrients, they will decay and eventually die. When this happens, dementia will occur because the area in which the brain cells have died will not be able to function.
function and brain chemistry	Brain chemistry must also be adequate, which means that neurotransmitters, such as dopamine, must be able to send chemical messages from one area of the brain to the other. When this cannot happen, again, brain cells will decay and die, leaving specific areas of the brain unable to function properly.
Head trauma	A head trauma is anything that impacts the head and causes a disruption to normal brain functioning. Research currently indicates that older people who have suffered a moderate head trauma are twice as likely to develop dementia as those who have not suffered such an injury.
	The link between head trauma and dementia is not fully understood, but it is thought to be associated with a resulting change in brain chemistry, which may not become apparent for many years after the trauma occurs.
	A brain tumour is a growth of cells within the brain that multiply in an abnormal manner and which cannot be controlled.
Brain tumour	Tumours can grow so that they cause a blockage to brain cells. When this happens, the brain cells die and this is what is believed to be the link between brain tumours and dementia, although it is acknowledged that this is quite rare.
	A stroke occurs when the blood supply to an area of the brain is cut off temporarily. Strokes can be so slight as to not even be noticed by someone but can also be so severe as to be fatal.
Stroke	The link between a stroke and dementia is complex and dependent upon the type of stroke that has occurred and whereabouts in the brain it has taken place. Strokes can cause dementia because when brain cells in areas of the brain are eliminated, the function of that area becomes compromised. For example, if someone had a stroke that affected their temporal lobe then their memory would be compromised, as this is where new memories are formed.

Risk factors

The following tables outline some common risk factors, which may contribute to the development of dementia in some individuals, some of which are changeable and some of which are not.

	Risk factors that cannot be changed	Why is this a risk factor for dementia?
	Age	It is consistently documented that the risk of developing dementia increases as an individual gets older. After the age of 65, a person's risk of dementia doubles every five years. After the age of 80, it is estimated that 1 in 80 people are affected.
		Developing dementia before the age of 65, is known as 'early- onset dementia' and whilst this is rarer, it can affect people at any age dependent upon their associated risk factors.
	Family history	Having members of the family who have dementia increases the risk of development for some individuals, although research indicates that predicting this accurately is difficult. This is because some individuals who have family members with dementia will never have the disease, whilst others who do have it may have no family members who also have it.
		There are tests available for individuals to check if they have a genetic mutation, which makes them more susceptible to dementia but this will not give them a 100% accurate answer of whether they will develop the disease.
	Down's syndrome	Those individuals who have Down's syndrome are at particular risk of developing dementia. Figures indicate that by the age of 30, 1 in 50 people who have Down's syndrome will also have dementia and the figure rises sharply to more than half of people if they live to be 60 or over (life expectancy for Down's syndrome is around 60 years, though this is vastly improved since the age of 25, still prevalent in the 1980s).
		The reason that people with Down's syndrome are more likely to develop dementia is currently unknown. However it is believed to be linked to genetic abnormalities or a particular type of brain damage.
	Gender	Women are slightly more likely than men to develop Alzheimer's disease and men are slightly more likely to develop vascular dementia. The reasons for this are, as yet, unknown.

	Risk factors that can be changed	Why is this a risk factor for dementia?	
-	Heart health and diet	A good diet, which is rich in Mediterranean type foods such as fruits, vegetables and cereals is thought to be advantageous in staving off dementia. This is because this type of diet is likely to decrease the risk of type 2 diabetes and stroke, both of which increase the chances of dementia developing, due to damage, which may occur to the brain.	
		Heart health is linked to this because when someone has a good diet, their heart is healthier. This reduces the chances of an individual having high blood pressure, which can lead to stroke and there is less chance of arteries being blocked by fatty deposits.	
		Someone with heart problems such as coronary heart disease is therefore more likely to develop dementia because of the associated disease risk factors.	
	Alcohol misuse	Heavy use of alcohol has been associated with dementia due to the fact that it can cause neurological damage. Any damage to the brain can result in dementia as that part of the brain fails to function adequately.	
		Misuse of alcohol can also lead to Korsakoff's syndrome, which is a specific type of dementia linked to Alzheimer's disease.	
	Depression	Like many other risk factors, the reason that dementia and depression are linked is as yet unclear, but research has shown that late-life diagnosis of depression may indicate that someone is developing dementia.	
	Lack of vitamin B	A lack of vitamin B means that an individual's levels of an amino acid called homocysteine are increased. Although no one is really certain as to why, elevated levels of this substance within the body have been linked to the development of dementia.	
	Smoking	Smoking causes blood vessels to narrow and when this happens, there is more chance of a blockage occurring. Blocked blood vessels in the brain can lead to damage in specific areas, which can cause dementia, the symptoms of which will depend upon where the damage is located.	
		Smokers are twice as likely to develop dementia as non-smokers, with vascular dementia and Alzheimer's disease being the two most commonly diagnosed types within this group of people.	

The signs and symptoms of common types of dementia

As dementia is a progressive disease, its signs and symptoms are commonly grouped into three stages and these can be used to identify how far someone's condition is advanced. However, even before a formal diagnosis of dementia is made, researchers have shown that there are ten common 'warning signs' of all types of dementia, which are:

- **1.** Short-term memory loss
- 2. Difficulty planning ahead
- **3.** Forgetting how to carry out routine tasks
- 4. Forgetting the time
- 5. Difficulty with reading or with seeing objects

- 6. Social withdrawal
- 7. Poor judgement
- 8. Consistently losing things
- 9. Problems with coherent speech
- **10.** Sudden changes in personality.

Source: www.alz.org

This stage is sometimes referred to as pre-dementia and is often mistaken for what would be normal aspects of ageing.

STOP AND THINK!

Choose one or more signs from the list above and consider the effects that these might have on an individual's daily life. You should also consider how these might affect an individual's family and friends.

Note down your thoughts in the space below.

Once a formal diagnosis of dementia has been made, the individual will be assessed to ascertain which stage they are at:

- Stage one mild
- Stage two moderate
- Stage three severe.

Stage one

At this stage, those who have dementia may be struggling to come to terms with any changes that they have noticed about themselves. They may try to hide signs and symptoms from loved ones because they are embarrassed, afraid or in denial about the changes that are happening to them. Individuals may also try to isolate themselves from others so that no one else notices, which might make their symptoms worse.

At this stage, individuals may strongly resist any changes to their lifestyle, which might result in further confusion and they may exhibit noticeable changes to those closet to them.

The most common signs and symptoms at stage one are:

- Memory lapses; problems in retaining new information and recalling recent incidents.
- Changes in mood with frequent bouts of frustration or irritability.
- Loss of interest in hobbies and other activities, which were previously enjoyable.
- Consistently losing items around the house, such as keys or glasses.
- Forgetting names and the word for common items.
- Getting lost or disorientated on journeys, which were previously familiar.
- Following instructions this is especially prevalent in the early stages of vascular dementia.
- Visual and auditory hallucinations only prevalent in those individuals with dementia with Lewy bodies and which can prove extremely distressing.

Stage two

By this stage, there has usually been a dramatic decline in memory and individuals will no longer be able to hide this from others. There may be an element of care involved, usually from a voluntary carer, who will often be a family member. This stage is often very stressful for those close to the individual with dementia because they may appear to be very different to the person they were before dementia, although there can still be some lengthy periods of lucidity.

The most common signs and symptoms at stage two are:

- Severe lapses in memory.
- Confusion about the time period in which they are living
- Mistaking family members for other people, for example believing that their grandchild is their own son or daughter.
- Reading and writing skills are almost fully lost.
- Hallucinations these can be frightening to an individual.
- Paranoia, with many individuals believing that family members are stealing from them.
- Problems with social norms and etiquette, for example trying to leave the house in pyjamas, or swearing inappropriately.
- There will be little or no understanding of written communication.
- Sleep disorders occur mainly with those individuals who have DLB.
- 'Sundowning' also occurs, which is where the individual's symptoms seem to worsen as the daylight fades, which can often lead to wandering in the middle of the night.



Stage three

By this severe and advanced stage, the individual will be wholly reliant on caregivers. At this stage, caregivers may find the individual difficult to manage and it is at this time when a transition to residential care is most likely. The individual is also more likely to display behaviour that challenges, which is often cited as one of the most common reasons that residential care is requested.

The most common signs and symptoms at stage three are:

- Speech has often been reduced to simple sentences or even sometimes, a single word. However many emotional responses remain despite an absence of speech.
- Incontinence.
- Individuals are unable to feed themselves, possibly due to physical issues or because they cannot understand when it is time to eat.
- Apathy, where the individual will simply sit for hours at a time.
- No personal hygiene routine at all, individuals may not be able to remember how to care for themselves.
- Muscle mass usually deteriorates causing individuals to spend a lot of time in bed.
- Individuals at this stage are likely to die from complications arising from dementia, rather than the condition itself, such as organs not functioning correctly or an infection.

A range of other types of dementia that may occur

Dementia is a complex condition and can manifest itself in many different diseases and syndromes. As well as the four most common types, which were discussed earlier in this section, there are others with which individuals can be diagnosed. These include:

- Creutzfeldt-Jakob disease (CJD)
- Korsakoff's syndrome
- Huntington's disease
- Progressive supranuclear palsy (PSP).

CJD

CJD is a very rare disease, which is fatal due to the fact that it causes severe and rapid brain damage; most people will die from infection less than a year after being diagnosed with it.

CJD is caused by an abnormal and infectious protein, known as a 'prion' which then multiples and spreads rapidly, causing irreparable damage to nerve cells in the brain. CJD causes a massive amount of symptoms due to the fact that it directly impacts the nervous system. In some cases, emotional symptoms will be the first to appear but in other, more severe cases, physical symptoms will appear first and worsen dramatically.

Initial physical symptoms of CJD include:

- Balance and coordination difficulties, causing problems when walking
- Dizziness
- Numbness or pins and needles in various parts of the body
- Double vision
- Hallucinations.

Initial psychological symptoms of CJD include:

- Extreme depression
- Feelings of despair
- Withdrawal and isolation
- Insomnia
- Anxiety and irritability.

After these symptoms present, they are likely to worsen rapidly and result in the following more serious ones.

Advanced physical symptoms include:

- Muscle twitches and spasms
- Loss of bladder and bowel control
- Swallowing difficulties (dysphagia)
- Loss of speech and voluntary movement.

Advanced psychological symptoms:

- Severe memory loss
- Confusion
- Loss of appetite
- Paranoia
- Inappropriate emotional responses.

Source: www.nhs.uk

Korsakoff's syndrome

This syndrome is a form of alcohol related brain damage (ARBD) and is caused by excessive use of alcohol, which results in a chronic lack of thiamine (vitamin B1) in the brain and subsequently, produces severe and enduring problems with memory.

Vitamin B1 helps brain cells to produce energy from sugar and when levels of this vitamin are depleted, brains cells cannot produce enough energy to function and Korsakoff's syndrome develops as a result.

Approximately 12% of dependent drinkers will develop Korsakoff's syndrome, which can be very difficult to manage because misuse of alcohol can also cause cognitive functioning to be impaired in several other ways:

- Head trauma due to falling when inebriated
- Biological stress of repeated inebriation and then withdrawal
- The ongoing toxic effects of alcohol on brain cells caused by continual consumption of alcohol.

Symptoms of Korsakoff's syndrome include:

- Problems learning new information
- Long-term memory gaps
- Difficulty recalling recent events
- Easily distracted and difficulty with concentration
- Confabulation when an individual cannot remember information and instead makes something up
- Having a seemingly normal conversation only to be unable to remember when it took place or with whom only minutes later.

Huntington's disease

This condition is usually inherited and is characterised by damage in certain areas of the brain, which worsens over time; just 3% of people who have this disease do not have any family history of it. There is no cure for Huntington's and its progress cannot be slowed or reversed. Symptoms usually begin between the ages of 30 and 50 but the disease can develop at any age.

It is quite difficult to diagnose in the early stages because many of its symptoms are overlooked and attributed to something else, these early symptoms include:

- Very subtle changes in mood and behaviour
- Very subtle changes in mental ability
- Fidgety movements.

After the presentation of these early symptoms, the condition will deteriorate resulting in physical movements becoming jerkier and walking becoming very unsteady. Further deterioration will cause speech to become very laboured and eventually, the individual will be unable to speak altogether. Mental ability will decline and become dementia, although the length of time that this will take will vary depending on the individual.

PSP

PSP is a rare form of dementia that is characterised by problems with eye movements, balance and movement. Individuals who have this condition are susceptible to falls because cells in the area of their brain, which coordinates movement have decayed irreversibly. There is no cure for this condition so treatment must focus on managing signs and symptoms:

- Loss of balance whilst walking
- Inability to move the eyes properly
- Stiff and awkward movements
- Frequent falls
- Sleep disturbances, including insomnia
- Loss of interest in previously enjoyable activities
- Facial expressions, which appear constantly surprised or frightened because of rigidity of facial muscles.

PSP is thought to affect around 4,000 people within the UK but this figure may be higher due to rates of misdiagnosis. Most cases develop in people who are aged 60 or above. There have been links to genetic inheritance although there is no solid evidence of this.



Check your answers by looking back over this section.

CONGRATULATIONS, YOU HAVE NOW COMPLETED SECTION 1. PLEASE NOW GO TO YOUR ASSESSMENTS AND ANSWER QUESTIONS Q1 TO Q4.