

# 15 | Understand the process and experience of dementia (DEM 301)



## Assessment of this unit

Developing knowledge of the neurology of dementia will help you to understand how individuals experience the disease. It will give you an insight into the causes of this long-term condition, the types of memory impairment that can occur and the way it can impact on people's information-processing systems. Receiving a prompt diagnosis can ameliorate an individual's fears and apprehensions about what is happening to them, thus leading to a more satisfying life.

The aim of this unit is to enable you to gain knowledge and understanding of neurology of dementia. It provides you with an appreciation of the importance of an early diagnosis and explores the impact on this of recording possible signs and symptoms of the condition. The unit also discusses how dementia care is underpinned by a person-centred approach and considers ways in which individuals and carers can be supported.

The assessment of this unit is entirely knowledge-based (things that you need to know). You will need to:

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

In order to successfully complete the unit, you will be required to produce evidence of your knowledge of dementia, as shown in the table opposite. Your tutor or assessor will help you to prepare for your assessment; the tasks suggested in the chapter will help you to create the evidence that you need.

## AC What you need to know

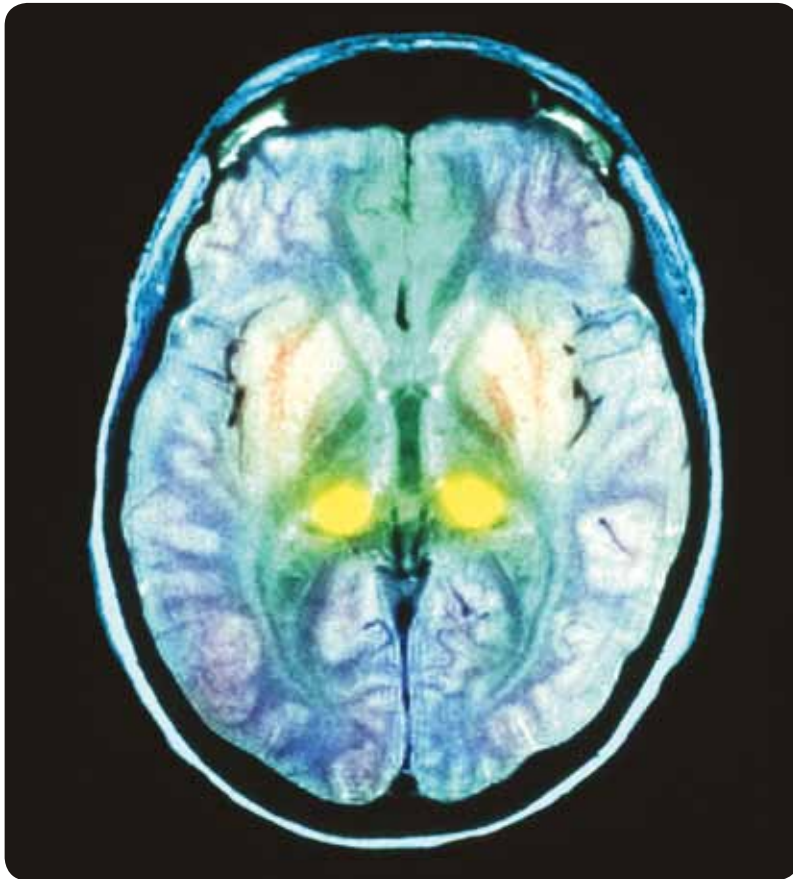
- |     |   |
|-----|---|
| 1.1 | Describe a range of causes of dementia syndrome   |
| 1.2 | Describe the types of memory impairment commonly experienced by individuals with dementia   |
| 1.3 | Explain the way that individuals process information with reference to the abilities and limitations of individuals with dementia     |
| 1.4 | Explain how other factors can cause changes in an individual's condition that may not be attributable to dementia                     |
| 1.5 | Explain why the abilities and needs of an individual with dementia may fluctuate  |
| 2.1 | Describe the impact of early diagnosis and follow-up to diagnosis   |
| 2.2 | Explain the importance of recording possible signs or symptoms of dementia in an individual in line with agreed ways of working       |
| 2.3 | Explain the process of reporting possible signs of dementia within agreed ways of working   |
| 2.4 | Describe the possible impact of receiving a diagnosis of dementia on: the individual, their family and friends                        |
| 3.1 | Compare a person-centred and a non-person-centred approach to dementia care   |
| 3.2 | Describe a range of different techniques that can be used to meet the fluctuating abilities and needs of the individual with dementia |
| 3.3 | Describe how myths and stereotypes related to dementia may affect the individuals and their carers                                    |
| 3.4 | Describe ways in which individuals and carers can be supported to overcome their fears  |

This unit also links to the following units:

- |                |  |
|----------------|--|
| <b>CMH 302</b> | Understand mental health problems  |
| <b>DEM 312</b> | Understand and enable interaction and communication with individuals who have dementia |
| <b>DEM 304</b> | Enable rights and choices of individuals with dementia whilst minimising risk          |

Some of your learning will be repeated in these units and will give you the chance to review your knowledge and understanding.

# Understand the neurology of dementia



A brain scan can show changes in the brain caused by dementia

## Your assessment criteria:

- 1.1 Describe a range of causes of dementia syndrome.

## Key terms

**Syndrome:** a set of signs and symptoms that is characteristic of a disease or condition

**Irreversible:** impossible to reverse or undo, as in a condition that cannot be improved

**Cognitive:** to do with thought processes

**Gene:** genetic coding in DNA that determines an inherited characteristic within an individual

**Neurotransmitters:** chemicals that transmit impulses from nerve to nerve

**Acetylcholine:** a neurotransmitter or chemical messenger that transmits impulses between nerve cells, including those in the brain

**Hippocampus:** part of the brain that stores long-term memories of personal events

## The causes of dementia syndrome

Dementia **syndrome** is a group of signs and symptoms that is characteristic of the condition. In dementia, **irreversible** changes occur in the brain of the individual leading to:

- ▶ death of nerve cells or loss of communication between nerve cells
- ▶ multiple **cognitive** deficits, including memory impairment
- ▶ problems with language
- ▶ failure to recognise people
- ▶ decline in overall mental function.

There can also be significant changes in the individual's personality and the way the person interacts in a social situation. Initially, the individual is able to care for themselves but as the condition progresses the ability to self-care is affected, usually resulting in admission as an inpatient to a care organisation. Progression of the condition varies from one individual to another and depends on the type of dementia. **Genes**

can play a role in some kinds of dementia, but the condition has not been linked to the inheritance of one particular gene.

Dementia syndrome covers the following diseases:

- ▶ Alzheimer disease
- ▶ Vascular dementia or multi-infarct dementia
- ▶ Pick disease
- ▶ Dementia with Lewy bodies (frontotemporal dementia)
- ▶ Creutzfeldt–Jakob Disease (CJD)
- ▶ Huntington disease.

Figure 15.1 below presents the brain changes that occur for each of these diseases.

**Figure 15.1** Brain changes occurring in different types of dementia.

**Investigate**

Using online and library sources, investigate the six different types of dementia shown in Figure 15.1. Try to find out which parts of the brain are affected by each disease.

**Key terms**

**Stroke:** common name for the loss of brain function that occurs when the flow of blood to part of the brain is prevented, either by blockage or haemorrhage of a blood vessel

Type of dementia	Changes observed in the brain
Alzheimer disease	Alzheimer’s disease is one of the most common causes of dementia. It kills brain cells and nerves, causing changes in the chemistry and structure of the brain. The brain shrinks (atrophies) as the number of nerves gradually reduces.  Brain chemicals ( <b>neurotransmitters</b> ) are reduced, in particular levels of <b>acetylcholine</b> fall. Gaps develop in the temporal lobe and in the <b>hippocampus</b> , both of which are responsible for storing and retrieving information. These gaps affect the individual’s ability to remember, speak, think and make decisions.
Vascular dementia (multi-infarct dementia)	Tiny <b>strokes</b> (infarcts) occur within the small blood vessels of the brain; these are often so small that they are not recognised. However, oxygen supply to the brain is diminished and brain cells die. After each infarct, brain tissue dies so the individual’s mental ability declines, eventually leaving them quite confused.
Dementia with Lewy bodies	Lewy bodies are distinct deposits of protein in the brain. These deposits damage brain cells and disrupt the brain’s capacity to function normally, leading to degeneration of brain tissue and dementia.
Pick disease	Damage occurs in the temporal and frontal lobes of the brain when individuals develop Pick bodies, another type of protein deposit. This disease is rare but has a genetic component and occurs in individuals below the age of 65.
Creutzfeldt–Jakob Disease (CJD)	Also known as ‘Mad Cow Disease’ due to the links between a variant form of CJD and a bovine degenerative brain condition. In all forms of CJD the brain develops holes and a sponge-like texture. This is caused by a protein called a prion, which is also an infectious particle. The build up of these abnormal proteins spreads causing nerve cells to die in the brain and spinal cord. The method of transmission is still the subject of on-going research but is thought to involve direct contact with infected material.
Huntington disease	This is an inherited disease, linked to defects in a single gene, which causes damage to nerve cells in areas of the brain called the basal ganglia and cerebral cortex. Damage to these parts of the brain affects the motor system.

## Types of memory impairment

Mild memory loss, characterised by episodes of forgetfulness, is considered to be a part of the normal ageing process. However, for those with dementia, memory loss becomes a problem when it disrupts daily life. There are several different types of **memory impairment** experienced by individuals with dementia:

- ▶ a decline in memory function results in the loss of memories of recent events
- ▶ loss of memory means that the ability to communicate is reduced as individuals tend to ask the same question over and over again or lose the thread of the conversation
- ▶ problem solving can become a major issue as individuals find it increasingly difficult to learn new skills
- ▶ loss of skills is particularly noticeable, for example cooking, managing a household budget, remembering the rules of a familiar game
- ▶ intermittent moments of lucidity mean that certain abilities fluctuate, for example individuals may be able to hold a conversation for a very short time
- ▶ mobility can be affected as a result of short-term memory deficit; individuals can feel lost and wander away from their known surroundings.

## Other signs and symptoms of dementia

Other characteristic signs and symptoms, in addition to memory problems, are movement difficulties – the individual can become unsteady on their feet and may develop a shuffling gait. Challenging behaviour may occur as a result of mood and personality changes. The individual can also become anxious, confused, suspicious or depressed.

## Ways of enhancing the memory at early stages of dementia

Some individuals with early stages of dementia can manage well in their familiar home environment because they become used to where things are. Many also live with family members, spouses or partners, or have professional carers supporting them at home. Simple measures can therefore be used to enhance their memory in the early stages of dementia, such as ensuring a daily routine that includes reminders or written notes. These can inform the individual, for example:

- ▶ when to get up and get dressed in the morning
- ▶ when to put the rubbish out
- ▶ to remember to lock the door at night

### Your assessment criteria:

- 1.2** Describe the types of memory impairment commonly experienced by individuals with dementia.

### Key terms

**Memory impairment:** memory loss, partial or total

### Reflect

Identify an older person in your practice placement (or relative, friend or neighbour) who has dementia. Try to engage them in a conversation with you, perhaps asking the individual to talk about their experiences. Reflect on this and write 100 words.

- ▶ about specific objects that are used regularly, through labelling items such as mugs, kettle, television, cooker
- ▶ when to go to bed.

Measures such as these can keep the memory active before it begins to disrupt the individual's life.

### Case study

Elizabeth, 70 years old, lives in Wales with her son, Joe. Until recently, Elizabeth has been coping well at home, even when Joe is at work during the day.

However, several times over the last few weeks on returning home from work, Joe has found Elizabeth wandering in the garden looking lost. When he questions her, Elizabeth does not know where she is and occasionally fails to recognise him. Once or twice Joe has found that Elizabeth has left the cooker on.

1. What symptoms is Elizabeth exhibiting?
2. Which type of dementia is Elizabeth probably experiencing?
3. Identify which part of the brain is affected.
4. Make a list of different types of memory impairment that Elizabeth may exhibit.



**Memory impairment can make the person feel lost in familiar surroundings**

## Processing information

Individuals with dementia experience difficulties interpreting the world due to incorrect processing of information in the brain. This can result in significant problems with perception and communication, including the ability to articulate feelings. Frustration, stress and fear may result.

### Processing visual information

The Thomas Pockington Trust (2005) suggests there is increasing evidence of significant disturbances in visual function in Alzheimer disease and other types of dementia. These deficits are believed to be more reflective of disturbances in the brain than of any problem with the eyes. Loss of vision profoundly affects communication. Problems with vision include loss of:

- ▶ **visual acuity**
- ▶ **contrast sensitivity**
- ▶ **colour vision**
- ▶ **depth perception.**

It has been suggested that hearing loss could be an early warning sign of dementia. It is known that the hearing loss in individuals with dementia exaggerates the effects of their poor cognitive function.

### Memory

We all have two types of memory:

- ▶ Short-term memories of events that have just occurred in the last few minutes.
- ▶ Long-term memory is associated with past memories.

Individuals with dementia have short-term memory deficit and forget recent information, for example the date, time and year, or a relative who has just visited. Long-term memories, for example events from childhood, are normally recalled by those with dementia.

### Your assessment criteria:

- 1.3** Explain the way that individuals process information with reference to the abilities and limitations of individuals with dementia.

### Key terms

**Visual acuity:** clarity of vision

**Contrast sensitivity:** ability to discern different light levels

**Colour vision:** ability to see in colour

**Depth perception:** ability to see the world in three dimensions

### Information processing problems

Individuals with dementia experience different information-processing problems depending on the type of dementia (see Figure 15.2).

**Figure 15.2** Information-processing problems in different forms of dementia.

Dementia-related disease	Difficulties in processing information
Alzheimer disease	<ul style="list-style-type: none"> <li>• disturbances in visual function, including impaired contrast sensitivity and depth perception</li> <li>• persistent and frequent difficulties recalling recent events</li> </ul>
Vascular dementia	<ul style="list-style-type: none"> <li>• <b>hallucinations</b> and <b>delusions</b></li> <li>• blurred vision</li> </ul>
Pick disease	<ul style="list-style-type: none"> <li>• easily distracted with limited attention span</li> <li>• problems with sight and hearing</li> </ul>
Dementia with Lewy bodies	<ul style="list-style-type: none"> <li>• visual hallucinations of people and animals</li> <li>• spatial disorientation</li> <li>• difficulties with attention span</li> <li>• extreme confusion</li> </ul>
Creutzfeldt–Jakob Disease	<ul style="list-style-type: none"> <li>• impaired vision leading to blindness</li> <li>• other visual symptoms similar to Alzheimer disease</li> </ul>
Huntington disease	<ul style="list-style-type: none"> <li>• hallucinations</li> <li>• head-turning to replace eye movement</li> </ul>

### Investigate

Using online and library sources, investigate the ways individuals with different forms of dementia process information. Summarise your findings in about 100 words and file as evidence.

### Key terms

**Hallucinations:** seeing things that do not exist

**Delusions:** beliefs that cannot be challenged by reason



## Factors that can cause changes in an individual's condition

Depression and other confused states are sometimes mistaken for dementia. This is because these conditions all have similar effects on a person's behaviour and communication skills. It is important to be able to distinguish these conditions; although there are notable similarities in the symptoms there are also differences (see Figure 15.3).

### Your assessment criteria:

**1.4** Explain how other factors can cause changes in an individual's condition that may be attributable to dementia.



**Figure 15.3** The key differences between dementia, depression and confusional states.

	<b>Dementia</b>	<b>Depression</b>	<b>Confusional states</b>
<b>Mental performance</b>	slow decline	rapid decline	temporary mental incoherence
<b>Awareness of surroundings</b>	poor recognition of familiar surroundings	awareness of surroundings	disorientated
<b>Confusion</b>	progressive confusion and disorientation	not confused but can have memory problems	confusion with difficulty in maintaining concentration
<b>Motor skills</b>	impaired motor skills including loss of the ability to write and even speak	slow speech and movement	
<b>Memory</b>	short-term memory loss, including specific problems with time	no short-term memory loss	poor short-term memory but improves when confusion passes
<b>Other</b>		a negative view of life	

## Other conditions that may cause sensory changes

Be aware that there are other conditions that may cause sensory changes in the individual. These may not be attributable to dementia and could lead to a false diagnosis. Alternatively, they may present in an individual alongside dementia. These include:

- ▶ visual problems caused by age-related macular degeneration, **cataracts** and **glaucoma**
- ▶ age-related loss of hearing
- ▶ **tinnitus** which can affect hearing and balance
- ▶ **reduced metabolism** causing poor appetite
- ▶ **osteoporosis** and fear of falling.

All these conditions can have a tremendous impact on the extent to which an individual is able to carry out the activities of daily living, depending on the severity of the condition and the person's ability to adapt and manage their condition. These factors must be taken into account when conducting a holistic assessment of a person to ensure that the individual is not wrongly diagnosed with dementia.

## Case study

Pam, 65 years old, has just retired from her job as a nurse practitioner. She led a busy life until recently; now she is more or less confined to her home. She lives alone in an isolated, rural spot, a long way from her family, but has a few close friends nearby. Her job kept her busy and also gave her an active social life. Now Pam stays in bed, refuses to do anything, has a poor appetite, feels hopeless and can see no future. Stephanie, a friend who visits weekly, has become concerned and has taken Pam to see her GP.

1. Can you describe Pam's symptoms?
2. What do you think is wrong with Pam?
3. How can Pam's GP help her with her problems?

## Key terms

**Cataract:** opaqueness of the lens of the eye

**Glaucoma:** increased pressure within the eye

**Tinnitus:** ringing in the ears

**Reduced metabolism:** slowing of bodily processes, can be attributed to an underproduction of thyroxin in the thyroid gland

**Osteoporosis:** thinning of the bones

## The abilities and needs of an individual with dementia may fluctuate

### Environmental factors

The abilities and needs of an individual with dementia may fluctuate in response to changes in the individual's physical environment. One of the fundamental characteristics of the condition is the individual's inability to interpret the world around them. It follows, therefore, that any change in the environment can have a deleterious effect on the individual. The following changes may influence the individual's abilities and needs:

- ▶ moving house
- ▶ going into a care home
- ▶ going into hospital
- ▶ changes of personnel, such as a new carer
- ▶ death of a family member.

### Your assessment criteria:

- 1.5** Explain why the abilities and needs of an individual with dementia may fluctuate.



The care worker has an important role to play in helping the individual adjust to their new environment

## Changes in the individual's condition

Other factors that may disrupt the course of the condition include:

- ▶ changes in treatment, such as taking part in a new treatment for memory problems
- ▶ changes in medication, such as taking new drugs
- ▶ changes in the individual's physical condition, for example urinary tract **infections** are common in older people and can have far-reaching effects
- ▶ vascular changes, for example **transient ischemic attacks** are temporary but are implicated in the development of some forms of dementia
- ▶ a change in the rapidity of progression of dementia such that the individual suddenly becomes aggressive or agitated.

## Emotional factors

Factors that affect the emotional wellbeing of the individual also influence the course of their condition.

- ▶ A change in the main carer, perhaps as a result of illness, can be upsetting, especially if the main carer is also the person's partner or close family member.
- ▶ Stressed carers may not support people with dementia to the best of their ability.
- ▶ The experience of any kind of abuse will have profound effects.

## Key terms

**Infection:** occurs when microorganisms proliferate inside the body

**Transient ischemic attack:** a temporary blockage in the blood supply to the brain caused by a blood clot and lasting about 10 minutes

## Reflect

Can you think of anybody, perhaps a member of your family, a family friend or a resident in your practice placement, whose needs and abilities are fluctuating due to dementia? Why does this fluctuation occur and how does it affect the carer? Keep your notes as evidence towards your assessment.

## Knowledge Assessment Task

1.1 1.2 1.3 1.4 1.5

Dementia-based conditions are brain or neurological disorders. They affect the structure and functioning of the individual's brain and can affect people in a variety of different ways. It is helpful for both care practitioners and the relatives of individuals diagnosed with dementia to understand the neurology of the condition. In this assessment activity you are asked to produce a poster or information leaflet that:

1. describes a range of causes of dementia syndrome
2. describes the types of memory impairment commonly experienced by individuals with dementia
3. explains the way that individuals process information with reference to the abilities and limitations of individuals with dementia
4. explains how other factors can cause changes in an individual's condition that may not be attributable to dementia
5. explains why the abilities and needs of an individual with dementia may fluctuate.

Keep the written work that you produce for this activity as evidence towards your assessment.

# Understand the impact of recognition and diagnosis of dementia



## Your assessment criteria:

- 2.1** Describe the impact of early diagnosis and follow up to diagnosis.

## Key terms

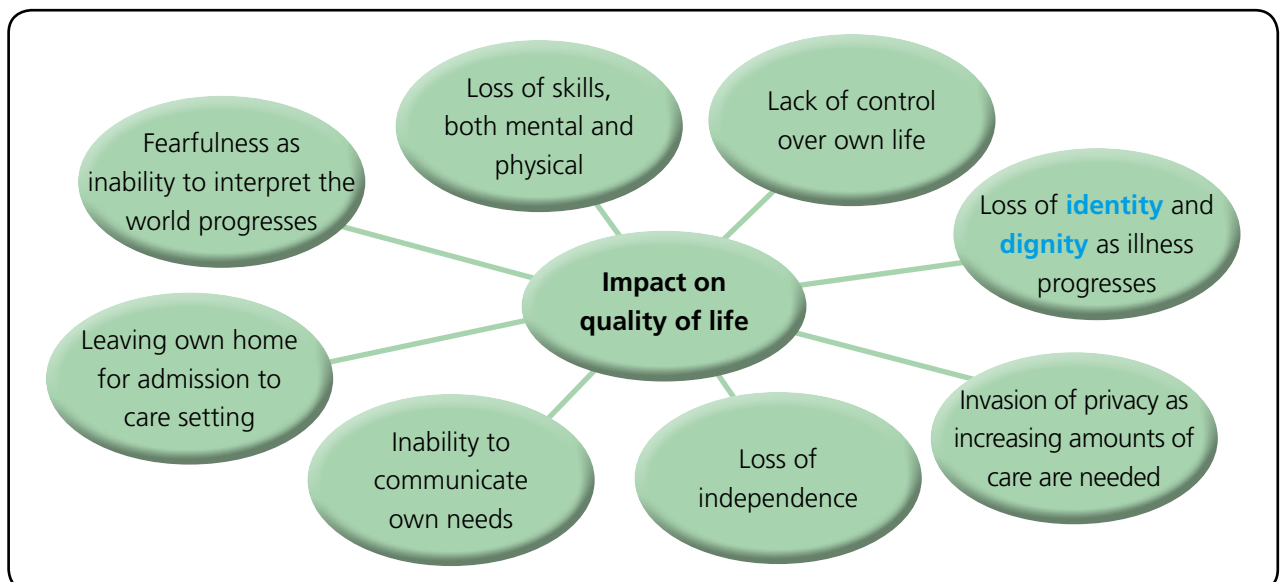
**Identity:** the characteristics that define the individual

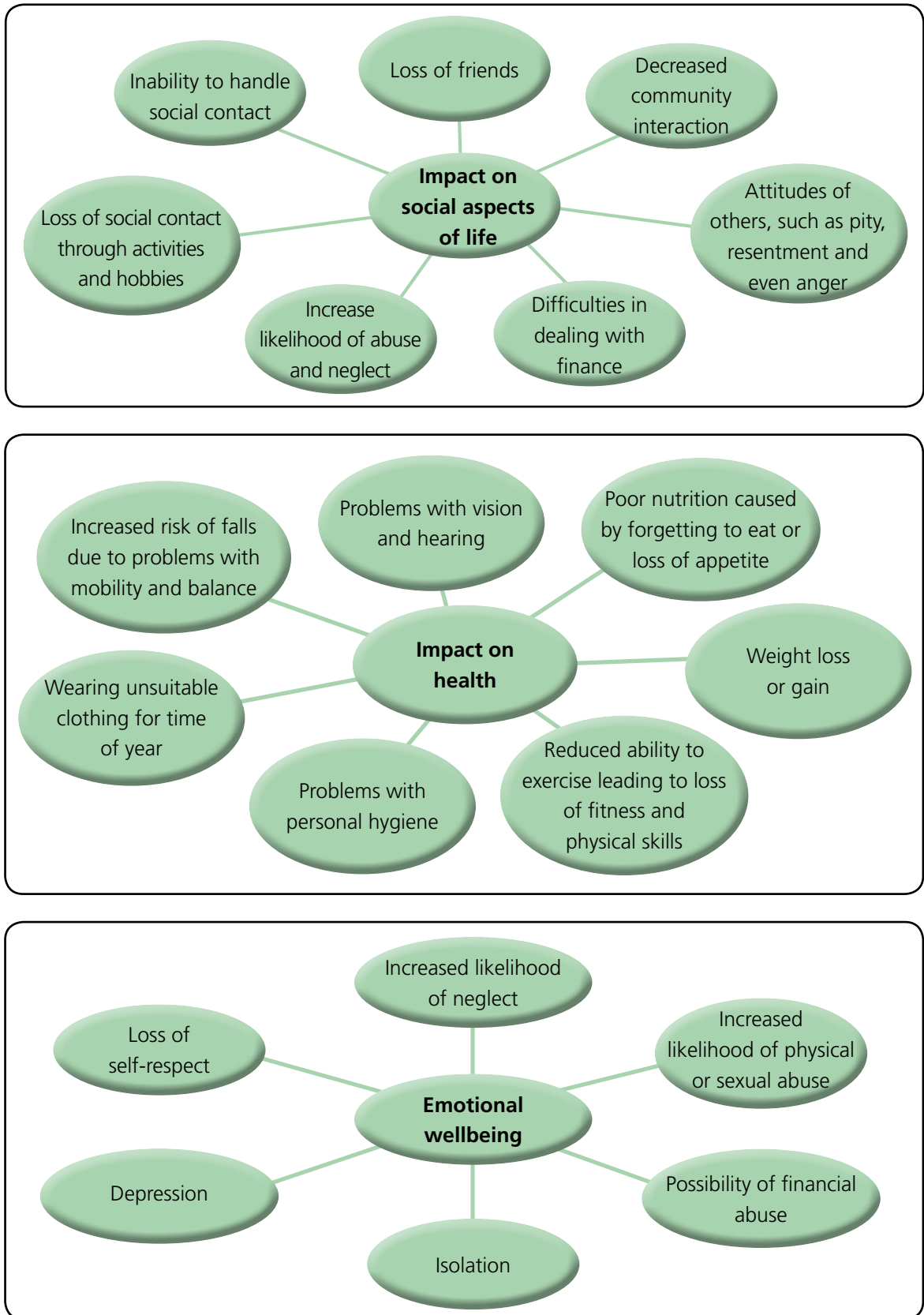
**Dignity:** preservation of self-respect

## The benefits of an early diagnosis of dementia

Being given a diagnosis of dementia is a significant event for many individuals and their families; they may be aware that life is changing in a way that they cannot control. A diagnosis can create feelings of bereavement in the individual as they feel the loss of the person they once were. These profound emotions can obviously affect a person's physical and emotional wellbeing, and their quality of life.

An alternative scenario is one in which having a diagnosis comes as a relief for some individuals and their families who have been fighting for recognition of a problem. It may initiate access to services that they require. Even if receiving a diagnosis has a positive impact for some individuals, it may still be a difficult and emotional experience. Figure 15.4 summarises the impact a diagnosis can have on the individual.





**Figure 15.4** Aspects of an individual's life that may be affected by a diagnosis of dementia



**Your assessment criteria:**

- 2.2** Explain the importance of recording possible signs or symptoms of dementia in an individual in line with agreed ways of working.

## Recording signs and symptoms of dementia

It is important to understand the reporting and recording systems in your organisation. Good record keeping is vital in providing care that is safe and effective. Increasingly information technology and electronic record keeping are being used, though it is still common for some records to be paper based.

### Agreed ways of working

When recording possible signs and symptoms of dementia in an individual it is important to adhere to the agreed policies of your organisation, whether they are written or electronic. It is very important:

- ▶ to record facts accurately
- ▶ to write legibly
- ▶ to date and sign the report
- ▶ to maintain confidentiality in line with recognised policies and procedures.

## Recording changes in condition

It is important to record accurately, not just the presence or absence of symptoms, but whether there is any *change* in the patient's condition, such as improvement or worsening of symptoms. This could highlight a pattern in the progress of the disease. The Data Protection Act 1998 covers health records and should be followed.

## Principles of good record keeping

There are recognised principles of good record keeping which include:

- ▶ legibility
- ▶ authenticity – records should be dated, the time specified if appropriate and signed
- ▶ accuracy – data should be factual, relevant and truthful
- ▶ completeness – full details of care and treatment should be included as appropriate and any identified risks should be specified
- ▶ compliance – records should adhere to any internal policies and procedures and to any relevant legislation such as the Data Protection Act
- ▶ protection – measures should be in place so that confidentiality is maintained
- ▶ originality – records must not be altered, destroyed or falsified; any necessary and permitted alterations must be signed and dated, and the original record should be clear and auditable.

## Investigate

Ask the person in charge of your practice placement whether you can look at the reporting and recording systems used within the organisation. Make notes on the different systems.

## Case study

Hilda, an 87-year-old lady, has recently moved into a care home. She had been used to living on her own in her flat with her cat but as her condition deteriorated Hilda reluctantly agreed to go into the home.

From the start, the care staff noticed that Hilda was getting lost and becoming quite hostile and aggressive with the other residents. It was obvious that she was feeling disorientated as she had moved from her familiar surroundings to a very different environment. She was finding it difficult to settle and communicate her feelings with the staff.

An assessment was conducted on admission and daily records were being maintained of her changing condition and worsening of symptoms. The GP was notified of these changes.

1. Why is it important to maintain good records in the care environment?
2. What changes in Hilda's condition should be reported and what actions taken?
3. Suggest how care staff should ensure that the principles of good record keeping are adhered to in the care environment.



## The process of recording possible signs or symptoms of dementia

The process of reporting possible signs of dementia should occur according to the procedures used within your own organisation, whether these procedures are verbal, written or electronic.

The process of recording should follow the principles of good record keeping (see page 17).



**Giving a diagnosis to an individual needs to be handled with sensitivity**

## The impact of a diagnosis of dementia

The person receiving a diagnosis of dementia may react in a number of different ways depending on the individual. There are mixed views about whether all individuals should be told about their condition as some may find the diagnosis very distressing. However, it is generally considered by GPs to be good practice to give a diagnosis because this helps with planning for the future and with understanding of what is happening.

Responses to a diagnosis can include:

- ▶ fear of losing one's home, friends, dignity and privacy, for example
- ▶ shock
- ▶ denial of the disease by refusing to acknowledge problems
- ▶ a need for more information – to know about the condition, symptoms, treatments and long-term outcome
- ▶ a need for emotional support
- ▶ a need for financial assistance
- ▶ a need for practical support, from family and the statutory and voluntary services.

### Your assessment criteria:

**2.3** Explain the process of reporting possible signs of dementia within agreed ways of working.

**2.4** Describe the possible impact of receiving a diagnosis of dementia on: the individual, their family and friends.

## Impact on others

As well as the impact of the diagnosis on the individual, there is also a significant effect on the caregiver, family and friends. Anticipating the behavioural and psychological effects of the disease can be a severe source of stress for the carer. Studies have shown that psychiatric symptoms due to distress are common amongst caregivers with family caregivers demonstrating more distress than professional care givers regarding the delusions, depression and agitation of individual sufferers. There is a strong relationship between the severity of disturbed behaviours and the distress of the caregiver (Lay Ling Tan *et al*, 2005). Possible responses of family and friends to a diagnosis are similar to those of the individual receiving the diagnosis:

- ▶ shock and fear
- ▶ denial
- ▶ need for information
- ▶ need for support.

## Case study

Brian, 79 years old, lives with his wife, Lucy, in a rural village. He lived an active life until about six months ago when Lucy noticed a change in his behaviour. He stopped wanting to go fishing and dropped his bridge class. He started to neglect his personal hygiene and seemed to be becoming increasingly forgetful. He even got lost once on his way home from the library. Lucy has made an appointment for them to see Brian's GP together. Lucy is secretly wondering if Brian has Alzheimer disease; she would like a diagnosis of his condition so she knows what is going on.

1. Do you think Brian has the right to know if he has Alzheimer disease?
2. How do you think the diagnosis might affect him?
3. How would Brian's diagnosis of Alzheimer disease affect Lucy?
4. How could Brian and Lucy be supported?

## Knowledge Assessment Task

2.1

2.2

2.3

2.4

Dementia is a condition that many people fear. Individuals, or their relatives, who suspect they have the symptoms of a dementia-related condition can respond in a variety of ways. In this assessment activity you are required to produce a handout that could be used in a teaching session for new care workers or students that:

1. describes the impact of early diagnosis and follow-up to diagnosis of dementia-related conditions
2. explains the importance of recording possible signs or symptoms of dementia in an individual in line with agreed ways of working in your care setting
3. explains the process of reporting possible signs of dementia within agreed ways of working in your care setting
4. describes the possible impact of receiving a diagnosis of dementia on: the individual, the family and friends.

Keep the written work that you produce for this activity as evidence towards your assessment.

# Understand how dementia care must be underpinned by a person-centred approach

## Two different models of care

There are two models of care, as shown in Figure 15.5: the person-centred or **holistic approach** and the non-person-centred or **biomedical approach**.



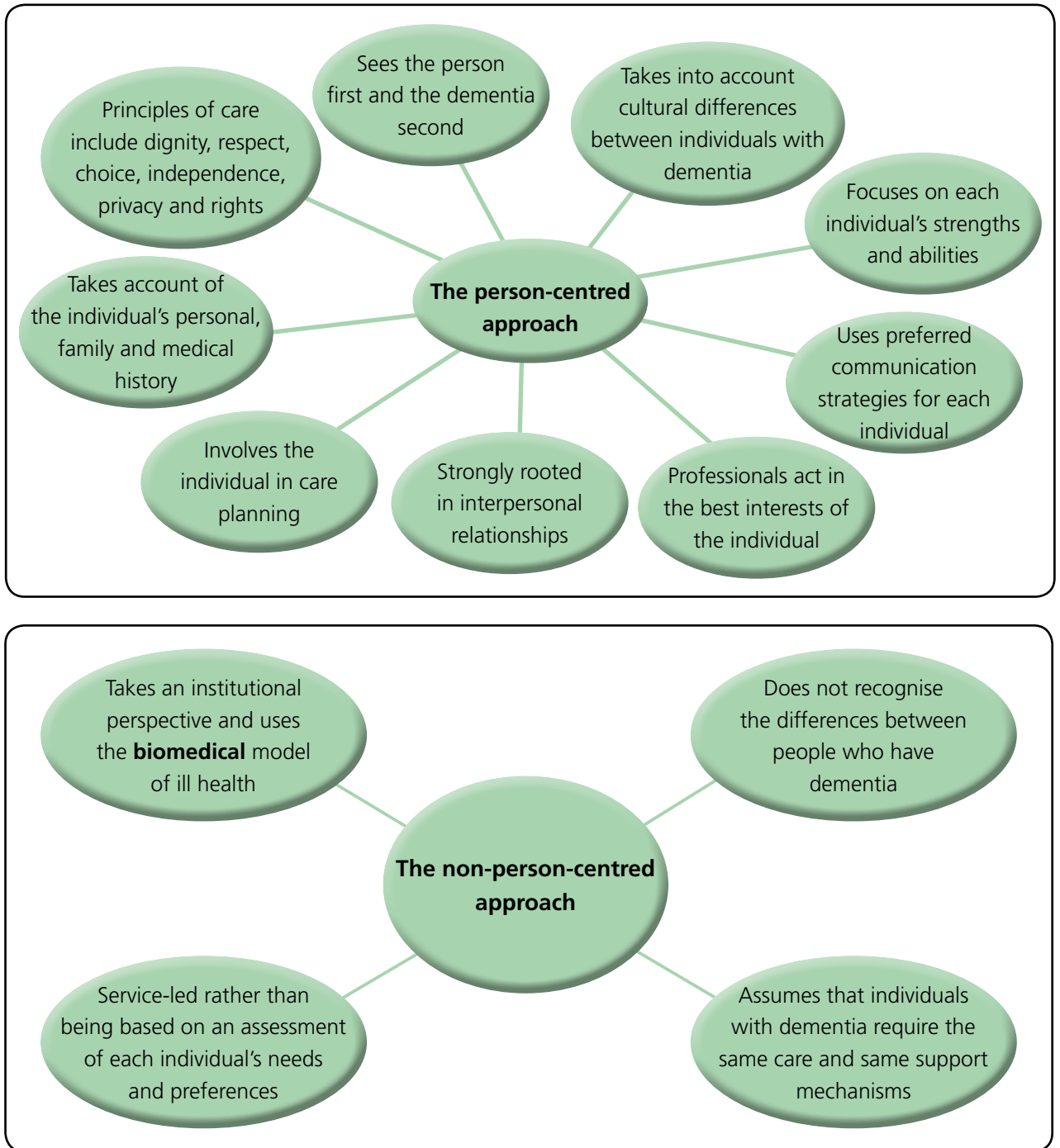
## Your assessment criteria:

- 3.1** Compare a person-centred and a non-person-centred approach to dementia care.

## Key terms

**Holistic approach:** person-centred care or care that focuses on the wellbeing of the whole person, not on treating the condition in isolation

**Biomedical approach:** medical model of care that addresses the biological aspects of the condition, the opposite of the **holistic approach**



**Figure 15.5** A comparison of the person-centred (holistic) approach and the non-person-centred (biomedical) approach

## Techniques to meet the fluctuating abilities and needs of the individual

Two different techniques are often used to meet the fluctuating abilities and needs of individuals with dementia:

- ▶ reality-orientation approach
- ▶ validation approach.

### The reality-orientation approach

Reality orientation is used to stimulate the memory of an individual with dementia and to facilitate orientation to the day of week, time, date and even weather. The aim is to keep the person in touch with reality and the present day. Carers use tools as a reminder of current life:

- ▶ recent family photos
- ▶ flash cards
- ▶ a frequently changing display board giving the day of the week, time of day, date and year.

### The validation approach

Naomi Feil developed validation therapy. It is based on a therapeutic conversation between the carer and the person with dementia. Whatever is happening in the here and now, the conversation is based on past events in that person's life; this is especially useful if they have a limited recent memory. The positive interaction encourages the individual to take control of the conversation and the therapy validates their feelings and emotions. These are some tips for using this approach:

- ▶ Try to understand why the individual behaves in a certain way in response to a particular trigger. Try to get to the root of the problem by using a therapeutic conversation about past events.
- ▶ Individuals with dementia may not make much sense when they try to communicate but they may still express emotions, for example being tearful. These emotions are still valid, so accept them even if the message is incoherent.
- ▶ Respond to what they say in a positive and encouraging way, even if you know that the events being described come from long ago in the past, or are not true at all.
- ▶ For example, the individual may talk about getting married. Offer congratulations rather than try to correct them.
- ▶ Ask specific questions during the conversation about feelings and validate their responses expressing your understanding. You could say, 'I would be upset too if that happened to me.'

### Your assessment criteria:

- 3.2** Describe a range of different techniques that can be used to meet the fluctuating abilities and needs of the individual with dementia.



### Investigate

Using online and library sources, investigate on validation therapy and the reality-orientation approach. Summarise your findings in about 100 words and file as evidence.

## Using the physical environment

Assistive technologies can be used to meet the individual's fluctuating abilities and needs. The following can all be used to help keep someone with dementia safe:

- ▶ pressure mats that detect when a person is treading on them
- ▶ door alarms
- ▶ key pads on doors
- ▶ personal alarms
- ▶ handrails, non-slip flooring, bathing aids and walking aids.

## Using the social environment

Use of the social environment can enable positive interactions with individuals with dementia. These techniques tend to form part of a holistic, responsive and flexible approach, and include:

- ▶ **reminiscence** about past events
- ▶ involvement of family and friends
- ▶ appreciation of the individual's personal beliefs
- ▶ a focus on their strengths and abilities
- ▶ effective communication using preferred strategies
- ▶ appropriate exercise
- ▶ social activities such as music
- ▶ Complementary and alternative therapies such as **aromatherapy** and **massage**.

## Maintaining health and wellbeing

It is important to maintain the health and wellbeing of an individual with dementia by encouraging them to:

- ▶ eat well
- ▶ maintain their fluid intake
- ▶ exercise, for example daily walks or a gentle programme that can be completed sitting in a chair
- ▶ engage in personal care, for example taking responsibility for their personal hygiene needs
- ▶ have regular checkups with the dentist
- ▶ have regular checkups with the optician and **audiologist**
- ▶ use both conventional and complementary medicines appropriately.

### Key terms

**Reminiscence:** recollection of past events in one's life

**Aromatherapy:** use of essential oils for therapeutic purposes, especially relaxation

**Massage:** manipulation of the body tissue to aid healing or bring about relaxation

**Audiologist:** professional who assesses hearing and advises on hearing problems



## Using complementary and alternative therapies

**Complementary and alternative medicine (CAM)** covers a wide range of therapies that include:

- ▶ **herbal medicine**
- ▶ aromatherapy
- ▶ massage
- ▶ **acupuncture.**

There is limited research into the treatment of dementia with CAM, however there are a number of therapies that can be beneficial. There is evidence to show that both aromatherapy and massage produce a reduction in agitated behaviour for those with dementia, helping bring about relaxation.

## Ensuring safety

Although most CAM therapies have a good safety profile, it is not correct to believe that they are completely safe. For example, there are concerns regarding some herbal preparations that may interact with conventional drugs. It is important for anyone caring for someone with dementia to check with a doctor before recommending any of these therapies.

### Investigate

Using online and library sources, investigate information on assistive technologies and the use of CAM in treating individuals with dementia. Summarise your findings in about 200 words and file as evidence.

### Your assessment criteria:

- 3.2** Describe a range of different techniques that can be used to meet the fluctuating abilities and needs of the individual with dementia.

### Key terms

**Complementary and alternative medicine (CAM):** a group of interventions not considered to be a part of conventional medicine

**Herbal medicine:** use of plants and plant extracts in the treatment of ill health

**Acupuncture:** therapy using fine needles at specific points on the body to restore function by unblocking energy pathways



## Effects of myths and stereotypes

Myths and stereotypes can cause significant distress for the individual with dementia, their family and their carers. The stigma of dementia can negatively affect relationships with others, leading to social isolation of the individual, and possibly the family and the carer too.

There is often an assumption that, following a diagnosis, the individual will lose their independence straight away. However, in the early stages of the disease many people with dementia are able to continue:

- ▶ making decisions about their own care
- ▶ driving a car
- ▶ caring for themselves
- ▶ communicating their needs.

## Challenging myths and stereotypes

If myths and stereotypes are allowed to prevail, people with the early stages of dementia may be put off interacting with the medical community leading to:

- ▶ delays in getting an early diagnosis
- ▶ a lack of knowledge of the availability of support services
- ▶ a lack of knowledge about appropriate treatments

Professionals who base their care on person-centred values should challenge myths and stereotypes by respecting the individual's rights, offering them real choice, giving them privacy and dignity, independence and autonomy. This approach is considered to be the essence of good practice and should be an integral part of the delivery of care.

### Your assessment criteria:

- 3.3** Describe how myths and stereotypes related to dementia may affect the individual and their carers.

### Reflect

Reflect on how myths and stereotypes can affect the relationship between individuals and carers. Make notes of about 100 words and keep as evidence.



**In early stages of dementia many individuals continue living with independence and autonomy, and carers can support them in sustaining this**



## Overcoming fear

A person-centred approach that takes full account of the individual's needs and abilities can help address the individual's own fears and those of family and carers. When the best care, information and support are offered, fears generally subside. Individuals, families and carers can be assisted by:

- ▶ person-centred planning and case reviews in which both the individual and the carer are fully involved
- ▶ involving the individual, family and carer in decision making
- ▶ clear and accurate information about accessible and appropriate support services
- ▶ emotional support
- ▶ involvement with a support organisation such as the Alzheimer's Society, which works to improve the quality of life for individuals with dementia
- ▶ creating a balance between protecting the individual and maintaining their rights.

## Integrated service provision

Service provision should be integrated across private, statutory and third sectors:

- ▶ The private sector covers services that are provided by commercial and not-for-profit organisations.
- ▶ Statutory services are provided according to government legislation through the public sector (local authorities and primary care trusts). The role of statutory services is vital for people with dementia-related conditions. Increasingly health and social care practitioners provide support for the families and carers of people affected by dementia too. This is important as it helps to maintain the individual's social support networks and can be the factor that enables them to remain living in their own home.
- ▶ Third sector services complement statutory provision and are provided through voluntary organisations, for example, the Alzheimer's Society. Some specialist services provide drug and other treatments in specialist clinics for people showing early signs and symptoms of memory impairment, particularly Alzheimer disease.



### Your assessment criteria:

- 3.4** Describe ways in which individuals and carers can be supported to overcome their fears.

**Individuals and carers can be supported to overcome their fears with help from a range of health and social care practitioners**

## Dementia adviser service

The Alzheimer Society has developed a new Dementia Adviser Service – volunteer and staff advisers support people with dementia, their carers and families through their experience of Alzheimer disease. Access to a Dementia Advisor help to may allay fears. An adviser:

- ▶ is a named contact who develops a relationship with each family
- ▶ provides an impartial, quality information and advice service
- ▶ focuses on the individual by empowering them to access the information that they need
- ▶ collaborates with other health and care professionals, working in partnership
- ▶ enables those who are hard to reach to access appropriate services
- ▶ operates from a Dementia Adviser Centre that may be located in a memory clinic or GP centre.

## Your provision of person-centred care

As someone with responsibility for dementia care, you can help individuals overcome their fears by providing the person-centred care to the best of your ability. You can also help by being knowledgeable about the services that people with dementia can access. These include:

- ▶ hospitals and hospices
- ▶ residential care and nursing homes
- ▶ supported independent living
- ▶ sheltered housing
- ▶ day care
- ▶ domiciliary care
- ▶ GPs and pharmacists
- ▶ social services
- ▶ end-of-life support and urgent care response
- ▶ early intervention
- ▶ psychiatric services
- ▶ memory services
- ▶ **physiotherapists**
- ▶ **occupational therapists**
- ▶ **dieticians**
- ▶ other health and social care workers
- ▶ counsellors
- ▶ **dementia advisers**
- ▶ **advocates.**

### Key terms

**Physiotherapist:** treats individuals with physical difficulties resulting from illness

**Occupational therapist:** offers advice on specialist equipment to assist with daily living

**Dieticians:** offers advice regarding appropriate diet

**Dementia adviser:** enables those with dementia to access quality information

**Advocate:** speaks on behalf of another in a legal context



**Person-centred care provides access to a range of services from GPs and pharmacists to domestic help, supporting the individual through the experience of dementia**

### Case study

Frances and Fred have been happily married for 50 years. About 10 years ago Frances noticed a change in Fred's behaviour. He was a patient and mild-mannered man who was gradually becoming hostile and aggressive, with rapid changes in his mood. One moment he would be happy and laughing, and the next very tearful. He seemed confused at times, finding it difficult to hold a conversation and not be able to remember Frances's name. Fortunately, Frances was able to persuade Fred to see their GP. While conducting the assessment, Dr Long noticed significant memory loss and language difficulties. He informed Fred that he was going to refer him to the memory service for a specialist assessment.

1. Suggest how the memory service can help Fred.
2. Who will perform the assessment at the memory service?
3. What help and treatment could the statutory and voluntary sectors, for example social services and the Alzheimer's Society, offer Fred and Frances?
4. What other services could Fred and Frances access to help Fred live in the community for as long as possible?
5. How could complementary and alternative therapy (CAM) help Fred to feel less agitated?

### Your assessment criteria:

- 3.4 Describe ways in which individuals and carers can be supported to overcome their fears.



**Overcoming one's fears requires the care practitioner to show compassion, respect and sensitive handling**

### Knowledge Assessment Task

3.1

3.2

3.3

3.4

Compassionate, high quality dementia care is best delivered using a person-centred approach. This kind of approach whilst effective may need explaining to new care practitioners and the relatives of individuals diagnosed with dementia. In this activity you are required to produce an information leaflet that:

1. compares a person-centred and a non-person-centred approach to dementia care
2. describes a range of different techniques that can be used to meet the fluctuating abilities and needs of the individual with dementia
3. describes how the myths and stereotypes related to dementia may affect the individuals and their carers
4. describes ways in which individuals and carers can be supported to overcome their fears.

Keep the written work that you produce for this activity as evidence towards your assessment.

## Are you ready for assessment?

AC	What do you know now?	Assessment task	✓
1.1	Describe a range of causes of dementia syndrome	Page 13	
1.2	Describe the types of memory impairment commonly experienced by individuals with dementia	Page 13	
1.3	Explain the way that individuals process information with reference to the abilities and limitations of individuals with dementia	Page 13	
1.4	Explain how other factors can cause changes in an individual's condition that may not be attributable to dementia	Page 13	
1.5	Explain why the abilities and needs of an individual with dementia may fluctuate	Page 13	
2.1	Describe the impact of early diagnosis and follow-up to diagnosis	Page 19	
2.2	Explain the importance of recording possible signs or symptoms of dementia in an individual in line with agreed ways of working	Page 19	
2.3	Explain the process of reporting possible signs of dementia within agreed ways of working	Page 19	
2.4	Describe the possible impact of receiving a diagnosis of dementia on: the individual, their family and friends	Page 19	
3.1	Compare a person-centred and a non-person-centred approach to dementia care	Page 28	
3.2	Describe a range of different techniques that can be used to meet the fluctuating abilities and needs of the individual with dementia	Page 28	
3.3	Describe how myths and stereotypes related to dementia may affect the individuals and their carers	Page 28	
3.4	Describe ways in which individuals and carers can be supported to overcome their fears	Page 28	

### References:

The Thomas Pockington Trust, 2005

Lay Ling Tan *et al* 2005.