Module 1:
Understanding Dementia
Module 1 - Understanding Dementia

Introduction

As life expectancy rises in the developed world, more cases of dementia are being diagnosed. There are currently approximately 82,000 people with dementia in Scotland (overall, approximately 5% of people over the age of 65 years experience dementia, with the risk of developing dementia increasing with age).

In this module, we will look at some of the more common types of dementia and examine their prevalence, how they affect the brain, and what signs and symptoms are likely to occur as a result. There is no single cause of dementia and it can affect a diverse range of people. However, there are a number of factors that can increase or decrease the risk of developing dementia. We will look at some of these risk factors and consider what can be done to reduce the risk of developing dementia.

We will also consider the stages of the dementia journey. Key to understanding dementia is the recognition of the impact on people’s communication skills and the impact of the environment on people with dementia. Finally we consider the importance of equality and diversity in dementia care and support.

What is dementia?

Dementia is a term used to describe the symptoms that occur when the brain is affected by specific diseases and conditions. There are many types of dementia, each caused by a different disease affecting the brain. Among other things, these affect people’s memory, relationships and their ability to communicate.

There is currently no cure for dementia and although there are medicines that can improve some symptoms or temporarily slow progression, the condition is terminal. All types of dementia are progressive, though in some less common types the progression can be halted. Some symptoms are common to all types of dementia, while other symptoms are more likely to occur in one specific type.

It is important to understand that many people with dementia are able to live well with dementia, and lead active and fulfilling lives for a number of years after they first experience difficulties and receive a diagnosis. Health and social care workers can also take a lot of positive action to ensure people with dementia can have the best possible quality of life as their dementia progresses, and these are issues we will explore through out the other modules in this learning resource.

While there are many similarities experienced by people with different types of dementia, no two people will experience dementia in exactly the same way and the rate of progression of dementia also varies greatly between people.

Learning outcomes

By the end of this module you will be able to:

1. Identify and describe the different causes and types of dementia, and understand the symptoms and difficulties people will experience.
2. Understand the concept of the dementia journey and its different stages.
3. Understand the impact of a diagnosis of dementia on the person and their family.
4. Distinguish between dementia, depression and delirium.
5. Explain the risk factors relating to dementia.
6. Reflect on the factors that can influence communication with people who have dementia.
7. Understand the impact of the environment on people with dementia.
8. Recognise the importance of equality, diversity and inclusion when working with people with dementia.
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Types of dementia

<table>
<thead>
<tr>
<th>Alzheimer’s disease</th>
<th>Prevalence</th>
<th>Alzheimer’s disease is the most common cause of dementia, accounting for around 62% of those with a diagnosis and affecting around 465,000 people in the UK.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age groups affected</td>
<td>Approximately 98% of people with Alzheimer’s disease are over the age of 65 and the risk of developing Alzheimer’s disease increases with advancing age. Less commonly, Alzheimer’s disease can also develop in younger people, affecting approximately 5,000 people under the age of 65 in the UK.</td>
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<tr>
<td>Typical symptoms</td>
<td>Alzheimer’s disease involves a general decline in a range of cognitive abilities. Typical symptoms include poor memory for recent events, impaired concentration, decision-making difficulties, disorientation and difficulty in carrying out everyday tasks.</td>
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<tr>
<td>Progression</td>
<td>Alzheimer’s disease is progressive, but the rate of progression differs widely between individuals.</td>
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Vascular dementia

<table>
<thead>
<tr>
<th>Prevalence</th>
<th>Vascular dementia is the second most common type of dementia, affecting around 112,000 people in the UK.</th>
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<tbody>
<tr>
<td>Age groups affected</td>
<td>The risk of vascular dementia increases with age, but it is one of the most common types of dementia among the 15,000 younger people with dementia in the UK.</td>
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<tr>
<td>Typical symptoms</td>
<td>These include problems with concentration and verbal communication, memory problems (though this may not be the first symptom), periods of acute confusion, and epileptic seizures. People with vascular dementia may experience physical symptoms of stroke, such as physical weakness or paralysis. In this type of dementia, people often have good awareness of their difficulties and, partly due to this, depression can be quite common.</td>
</tr>
<tr>
<td>Progression</td>
<td>Vascular dementia can often involve a ‘stepped’ progression, with symptoms remaining at a constant level and then suddenly deteriorating.</td>
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Mixed dementia

Some people with dementia have a diagnosis which means that the progressive damage to the brain is being caused by both Alzheimer’s disease and vascular dementia.
Remember

Some people may be affected by more than one type of dementia – experiencing the difficulties associated with one type of dementia does not exclude the possibility that the person may also experience the difficulties associated with another type.

<table>
<thead>
<tr>
<th>Dementia with Lewy bodies</th>
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<tr>
<td><strong>Prevalence</strong></td>
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<tr>
<td><strong>Age groups affected</strong></td>
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<tr>
<td><strong>Typical symptoms</strong></td>
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<tr>
<td><strong>Progression</strong></td>
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For further information see the Alzheimer’s Society factsheet available at: www.alzheimers.org.uk/factsheets

<table>
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<tr>
<th>Fronto-temporal dementia</th>
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<tr>
<td><strong>Prevalence</strong></td>
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<tr>
<td><strong>Age groups affected</strong></td>
</tr>
<tr>
<td><strong>Typical symptoms</strong></td>
</tr>
<tr>
<td><strong>Progression</strong></td>
</tr>
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For further information see the Alzheimer’s Society factsheet available at: www.alzheimers.org.uk/factsheets
Other types of dementia

Approximately 23,000 people in the UK have a rarer form of dementia. Two of these are conditions caused by alcohol: Korsakoff’s syndrome and alcohol-related dementia. These are serious brain disorders but will only be progressive if the person continues to drink alcohol. There are some other rarer types of dementia that can be stopped from progressing, including those caused by deficiencies of thyroid hormone, vitamin B12 and folic acid. Most types of dementia are, however, progressive. Some of the more widely known of the rarer dementias include Creutzfeldt-Jakob Disease (CJD) and Huntington’s disease. Between 15-30% of people with Parkinson’s disease will develop a type of dementia closely resembling Dementia with Lewy bodies.

The effects of dementia on the brain

Every type of dementia involves progressive physical damage to the brain. The main areas affected in most types of dementia are the temporal, parietal and frontal lobes. Damage to each lobe will lead directly to problems related to the function of the particular lobe.

The Brain

**Frontal Lobe:**
Helps to regulate behaviour

**Parietal Lobe:**
Organises your body in space

**Temporal Lobe:**
Stores new information

**Occipital Lobe:**
Makes sense of visual information
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Some examples of the potential impact of damage to specific lobes of the brain are outlined below:

Parietal Lobe
As the Parietal lobe helps people to organise their body in space, damage in this area:
- Can often lead to people having problems in processing visual information, for example, difficulty in recognising faces and objects.
- Can lead to people having problems in carrying out a sequence of actions, for example getting dressed.
- Can affect people’s body sense - that is knowing which part of your body is where,
- Can affect people’s spatial awareness – this means knowing where objects are relative to their own body.

Frontal Lobe
As the Frontal Lobe helps people to organise and control their behaviour, damage in this area:
- Means a lack of inhibition might develop
- Means people might experience initiating actions difficult
- Means people can experience problems with planning, decision-making and abstract thinking, making it very difficult for a person to make a choices in certain situations
- Means people often experience problems with reasoning.

Temporal Lobe
As the Temporal Lobe helps people to store new information, damage in this area:
- Can cause problems for people in understanding and producing speech
- Can cause problems in remembering recent events
- Can cause problems with more recent memories, but memories from the past can remain intact
- Means people experience a short attention span.

For further information - the Open Dementia Programme from Social Care Institute for Excellence (Module 3) may help you understand the effects of damage in different areas of the brain in dementia. This can be accessed at the following web address http://www.scie.org.uk/assets/elearning/dementia/dementia03/resource/flash/index.html

When dementia causes damage to the brain, a person will most likely experience problems with carrying out day-to-day activities. If we understand a little about how the brain works, this can help to explain some of the problems that the person with dementia is facing. Having an accurate diagnosis of the disease or disorder causing the dementia can help us to understand the symptoms and difficulties people might be experiencing. This can be helpful for making plans for the future.

Later in this module we will look at the impact of a diagnosis on people with dementia and their families and carers.

Although the brain damage in dementia is progressive and therefore people’s abilities may deteriorate over time, there are many additional factors related to other aspects of people’s lives that can influence their journey through dementia both positively and negatively. The role you can play as a worker in improving a person’s quality of life will be considered throughout this learning resource.

Remember
Some behaviour changes in dementia are due to damage to the brain. Staff can help and support people with dementia to take steps to help them cope with and compensate for these changes. Staff can also adapt the environment or their own behaviour to help people cope and develop new strategies.

Remember
There are many additional factors related to other aspects of people’s lives that can influence their journey through dementia both positively and negatively. There is always the potential for improvement in a person’s quality of life.
The dementia journey

Dementia is a journey that has a recognised pathway of progression. The Promoting Excellence framework is designed around this pathway, as the priorities and needs of a person with dementia and their family and carers will differ at different stages of the pathway. Staff need to be able to recognise and respond appropriately to support people with dementia and their families and carers across the whole dementia journey.

Promoting Excellence identifies 4 stages of the dementia journey and these are:

Keeping well, prevention and finding out it’s dementia

While acknowledging the life changing impact, challenges and difficulties that often surround receiving a diagnosis of dementia, the framework recognises that receiving a diagnosis is not the starting point for that person in the dementia journey. Striving to prevent the onset of dementia, maintaining good health and maximising well-being are general ambitions for all of us in an ageing and health conscious society.

Diagnosing dementia can be difficult and should be timely to reflect the wishes of the person. It may take some time before it is formally recognised that the difficulties the person is experiencing are in fact due to the development of dementia. However long the process has taken, receiving a diagnosis of dementia is life changing for the person and their family. It can be a frightening and emotional time for everyone involved. It is crucial, that the appropriate services and supports are in place and easily accessible during this stage of the journey.

Living well with dementia

There are many ways to live well with dementia and no two people will experience the journey in the same way, or have the same care or support needs. During this stage of the journey, people with dementia should be fully involved in any decisions about their care and actively encouraged to stay as physically healthy as possible. It is important that people remain as active, independent and in control as their abilities allow and are fully enabled to exercise their rights.

Living well with increasing help and support

As the dementia journey progresses, people will need additional support in carrying out their day to day activities. This support might be from health and social services but these should be flexible enough to complement personal and community supports which surround the person and their family. The necessary support and care provided must be tailored to the needs of the person, including recognising their rights and being respectful of any cultural, spiritual, religious and belief needs they may have.

End of life and dying well

Dementia is a progressive condition. Palliative and end of life care needs for someone who has dementia are often complex. Their families and carers may need a different approach to support them after what may be many years of caring for their loved one.

Remember

“I have the right to a diagnosis”

Standards of Care for Dementia in Scotland (2011)
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Remember

No two people will experience dementia in exactly the same way, and people’s experience through the various stages of the dementia journey will be unique to them.

Common difficulties people with dementia will experience

Every person is unique and dementia affects people differently - no two people will have symptoms and difficulties that develop in exactly the same way. A person’s personality, general health and environmental and social situation are all important factors in determining how this will affect them.

Nevertheless, while no two people will experience dementia in exactly the same way, there are some relatively common symptoms that many people will develop at some point in their dementia journey. In Module 3 we will look at some of the other health and well-being issues experienced by people with dementia.

The following section outlines some of these common symptoms and the experiences of people affected by them.

Memory loss or forgetfulness

One of the most common symptoms of dementia is memory loss, often more noticeable in relation to short term memory. Many people’s memory can become a little worse as they grow older and they may notice more frequent memory lapses. However, when someone has dementia, they may experience difficulty in retaining new information or even forget the names of familiar people such as family members, as well as strangers. They may forget appointments, the content of recent conversations or forget whether they have eaten lunch.

George’s Story

We met George in the Informed about Dementia DVD and here you can learn more about him.

You might like to revisit Chapter 2 of the DVD to remind you about some of the difficulties George has been experiencing.

George is 55 and lives at home. He was married and worked in the housing department of the local council for 30 years until he was retired 12 months ago on the grounds of ill health. Around the same time his wife left him and George has since found it difficult to engage with the community groups he once loved - the community council, the heritage group and the bowling club. He has one son, Barry, who lives with his partner in the north of England. George is very proud of his son and sees him two or three times a year.

George has recently been experiencing difficulties remembering things like GP appointments. In the DVD, we saw that this had been quite frustrating for George but that, with a bit of support from the GP receptionist, he was supported to overcome his memory difficulties in that situation.

Unfortunately George’s memory problems were affecting quite a few of his everyday activities. On Barry’s recent visit, George’s neighbour had mentioned that on a few occasions he had noticed that George had left the front door open when he had gone out and he had sometimes needed to remind George quite late in the evenings that his door was open. Barry had also noticed that there were piles of unpaid bills and unopened letters on the table and out of date food in the fridge. Barry, feeling quite concerned for his father, spoke to George about this situation. George became quite upset but acknowledged that he was forgetting quite a lot of things these days but he did not know what to do about it.
As the dementia journey progresses, people’s problems with their memory will cause them more difficulty. They will often find it difficult to remember what happened only a few hours or minutes earlier but can recall, often very accurately, events from decades ago. Sometimes they may repeat the same question because of their memory difficulties but will be unaware they are doing this. Often the memories that people with dementia hold have strong emotional connections for them they will remain intact although a person may need support in recalling them.

Because people with dementia often have difficulty in remembering recent events, they are more likely to retain memories with strong emotional connections. If they become upset in a particular situation they are likely to retain this feeling even after they have forgotten what happened. If someone has had an enjoyable experience, they may forget what they have done but are likely to remember the pleasant emotions.

**Remember**

It is important to try to make sure that our contacts and communications with people with dementia are likely to create positive feelings.
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Difficulties with everyday tasks

It is common for people with dementia to experience some difficulty in undertaking everyday tasks such as cooking, cleaning, organising or even making a cup of tea. Memory difficulties and other types of cognitive difficulties can impact on people’s ability to undertake many routine activities that we would take for granted on a day to day basis.

Ellen’s story

We met Ellen in the Informed about Dementia DVD

Ellen is 80 and lives at home. Her husband died 6 years ago and she has 3 children and 4 grandchildren. Her sons both live at a distance and her daughter Carolyn lives nearby and visits every evening. While raising her own children, Ellen worked by keeping accounts for her husband John’s car repair business and was a treasurer of the local WRVS. She has always been busy and enjoyed using her skills to support the family business and organise their home life and she particularly enjoys cooking.

You are working with Ellen to support her to remain at home. Two days a week when she does not attend the lunch club, you call in to support her with preparing lunch. Ellen has always been a keen cook and usually you just support her to get everything ready for lunch. However, on the last few occasions you have noticed that Ellen has been turning on the gas on the cooker but forgetting to ignite it. On one occasion you came to the flat and found that Ellen had made herself a cup of tea with cold water.

Carolyn has been round for lunch recently and has told you she has found tins of soup in the oven and burnt toast under the grill at different times, and she is thinking about getting the cooker disconnected because she is worried about her mum.

Reflection

1. How did reading about Ellen and Carolyn’s difficulties make you feel?
2. How would you feel if you were experiencing these difficulties?
3. How do you think Ellen would feel about having the gas cut off from the cooker?
4. What do you conclude about the experience for people with dementia who are struggling with everyday tasks?
5. When a person with dementia has difficulty carrying out an everyday task, how do you think you could help?

Record your answers here:
The story we have told about Ellen demonstrates the experiences of a person with dementia who has problems sequencing actions and remembering what they have just done. This can often leave people feeling like a failure and really frustrated.

You may remember from the DVD that Leanne had put up signs for Ellen to try to help her to remember things. This can be useful in some circumstance though it is important not to add to the confusion people might experience with too many signs. Other services and agencies such as occupational therapy can become involved and there are also telehealth-care solutions that can support people to remain independent for longer. We will explore telehealth-care in more detail later in this resource.

Difficulties with disorientation and confusion

Gradually, over a period of years, as people progress through the stages of the dementia journey they will experience problems meaning that they become disorientated to the time of day, the place they are in, and the people who are around them. People who have dementia may find they can become lost in environments which were previously very familiar, such as the street where they live. They may forget how they got to a certain place and therefore, how to get back home.

Millie’s story

Millie is 85 and has lived in the same small Scottish town all her life, as have her daughters. Millie is part of a close and sociable family. Millie hardly spent any time on her own until the death of her husband 8 years earlier. Millie was very active in the local church and at various stages she led the Sunday school, Guides and Brownies and latterly, the Women’s Guild. Participating in the life and work of the Church is very important to Millie.

Millie was diagnosed with Dementia a year ago. She lives alone but receives a lot of support from her two daughters who take it in turns to have her over to their houses on different days during the week, bringing her home in the evenings. Millie’s short term memory has been gradually deteriorating and she has become more confused and disoriented. One night last winter she went out late in the pouring rain and was knocking on neighbours doors in a distressed state. Worried neighbours called the police who took her home. After this incident Millie went to stay with one of her daughters for a while but felt frightened to go back home again.

Adapted from a case study provided by Durham local authority


Remember

“People with dementia should feel safe and secure and are able to be as independent as possible”

Quality of Life Indicators. Promoting Excellence (2011)
As the dementia journey progresses people with dementia may become confused about the time of day. For example this could cause people to get up in the middle of the night wanting to go out. They may fail to recognise people they know well and become distressed or suspicious when apparent strangers try to assist them with tasks. Their ability to think, to reason and to calculate can all become impaired. This can lead to them making decisions which do not appear to make sense, or to experience difficulty in solving problems. Handling money may become problematic if the person finds it difficult to recognise currency, work out their change or they become uncertain about the value of money. Eventually, people with dementia will probably need help with even simple daily activities such as washing, dressing, eating or going to the toilet.

**Language and communication difficulties**

Communication is a very complex process for us all and many communication skills can pose difficulties for people with dementia. They can experience difficulty in expressing their feelings and opinions. Similarly, people can find it more difficult to understand the communication of others. Some skills people have in expressing themselves can be well preserved, while other aspects of expression can cause them a lot of difficulty. People who have dementia will differ in how their language and communication skills are affected, but there are often similarities in the types of day-to-day communication problems people can experience.

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**Reflection**

1. How did reading about Millie’s difficulties make you feel?
2. How would you feel if you were experiencing these difficulties?
3. How do you think Millie’s family were feeling?
4. What other problems could be caused by experiencing confusion or disorientation?
5. What practical help or support could be given to support someone experiencing these difficulties?

Record your answers here:
Donald’s story

Donald is a 68 year old retired joiner who is married to Sheila. They have 3 children and 4 grandchildren. He has been very active and involved in his local golf club and 20 years ago he was captain of the golf team and was secretary to the club committee for 10 years. Acting as secretary to the committee was a significant part of his life. Donald is very physically fit and has continued to attend the club regularly to play a round of golf. Donald is also a keen reader and is extremely interested in Scottish history. Donald was recently diagnosed with dementia.

Donald has stopped going to the golf club and he and Sheila discuss why this has happened. Donald explains that he does not enjoy it there any more because sometimes when he has been talking to people he has forgotten their names and then halfway through a sentence he has forgotten what he was talking about. He is also having difficulty in marking his score card and when his friends remind him what the score is he sometimes does not seem to be able to follow what they are saying. Donald says he feels stupid and he thinks people are getting annoyed with him.

Reflection

1. How did reading about Donald’s difficulties make you feel?
2. How would you feel if you were experiencing these kinds of difficulties?
3. What other problems could be caused by experiencing difficulties in communication?
4. What practical help or support could you give to people experiencing communication difficulties?

Record your answers here:
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As the dementia journey progresses, people’s ability to process information becomes slower and more difficult for them and their responses to communication from others can become delayed.

Communication can become frustrating, as the person with dementia struggles to find the right word or uses the wrong word with increasing frequency. They may begin to experience difficulty in holding conversations as they struggle to find the right words to express their thoughts and feelings. We need to make sure we don’t respond unhelpfully to such difficulties, for example:

- Assuming that we know what the person is trying to communicate
- Wrongly completing sentences on their behalf rather than allowing them sufficient time to express themselves.

Negative experiences in communication may result in people with dementia withdrawing from conversations and social interaction, becoming isolated and feeling depressed.

Later in this module we will look at the impact of the environment on people with dementia.

Dementia, depression and delirium – you need to know the difference

It is sometimes difficult to distinguish between dementia, delirium and depression. Most people tend to confuse the three conditions, especially delirium and dementia, because they all have symptoms in common. However, older people and people with dementia are more at risk of delirium.

Remember

Older people and people with dementia are more at risk of delirium.

Although it can sometimes come on fairly quickly as a result of a stroke or other brain injury, dementia symptoms are usually progresses slowly. Most common types of dementia begin with subtle symptoms and difficulties which grow more obvious with the passage of time.

Delirium and Dementia

- Delirium develops quickly. There is usually a sudden and significant change in a delirious person, often in a matter of hours. There is a sudden onset of agitation, hallucinations, and rapid changes in a person’s level of consciousness. Because delirium is usually a sign that something important and potentially very damaging is occurring, people with delirium need immediate medical attention.
- Delirium can result from an infection, or other physical problems. Unlike dementia, once the physical problem is treated the delirium usually passes.
- People with dementia are more at risk of delirium.

It is always helpful to consider whether particular difficulties people may be experiencing can, be made worse by unhelpful care or support approaches or a confusing environment.

Remember

We can do a lot to support people to overcome the difficulties they are experiencing by understanding their experiences making simple adaptations to the way we communicate with them and offer support.
Depression and Dementia

Because the symptoms of depression and dementia can be similar and can co-exist, an older person with dementia may sometimes be wrongly thought to have depression, and vice versa. But it is important to note that depression is common among people at all stages of their dementia journey.

- In depression, other impairments typical of dementia such as in language, visual perception and ability to orientate themselves in time and space are unusual.
- A depressed person will occasionally complain of an inability to remember things but is more likely to recall information when prompted. In contrast, depending on their diagnosis and severity of symptoms, a person with dementia is less likely to benefit from such cues to aid recall, will tend to experience more significant memory problems and/or lack of insight into these.
- In severe depression, the powers of reasoning and memory may be very badly impacted, and it is this state that is most easily confused with dementia. However, in a person with depression, this impairment is mainly due to poor concentration and the condition is reversible with appropriate treatment or if depression improves spontaneously. This is not the case with dementia.

Self assessment quick quiz

Check whether you have understood the main points so far
Answer true or false to the following questions

1. Alzheimer’s disease affects only affects older people.
2. Dementia can cause problems with visual perception.
3. All types of dementia have the same symptoms.
4. Dementia is a progressive condition which has different stages.
5. It is only brain damage that is responsible for the problems experienced by people with dementia.
6. There is nothing that can be done to improve the quality of life of people with dementia.
7. Everyone with dementia will experience it in the same way.
8. Delirium can take years to develop.
9. People cannot have dementia and depression at the same time.

Activity

Design a poster for your work area which can help the staff quickly identify the main distinguishing features of dementia, delirium and depression.
Below is a summary of the main points so far:

- There are many diseases and disorders which can cause dementia.
- Alzheimer’s disease and vascular dementia are by far the most common.
- Alzheimer’s disease affects approximately 5,000 people under the age of 65 in the UK.
- Every type of dementia involves a process of progressive damage to the brain which affects people differently at different stages.
- Each lobe of the brain has many different functions and specific difficulties will result from damage to each lobe.
- There are many similarities in the symptoms that occur in different types of dementia, but also some key differences.
- Although there are many common symptoms, each person’s experience of these will vary.
- Unhelpful care approaches or a confusing environment can cause problems for people with dementia as well as the damage to the brain.
- Depression and delirium can sometimes be confused with dementia.

What are the protective and risk factors relating to dementia?

Dementia can affect anyone, from bakers to bankers, from politicians to pop stars. There is nothing we can do that will provide total protection against dementia, but there are some things that might decrease the risk of developing it. These are known as protective factors. There are also certain things that could increase our chances of developing dementia. These are known as risk factors.

- Growing old.
- Occasionally drinking moderate amounts of wine.
- Taking regular exercise.
- Having a close relative with dementia.
- Having high blood pressure.
- Having Down’s syndrome.
- High blood cholesterol levels.
- Suffering severe or repeated head injuries.
- Drinking large amounts of alcohol regularly.
- Smoking.
- Eating large amounts of saturated fat.
- Eating polyunsaturated fatty acids (for example, oily fish).
- Being obese.
- Eating fresh fruit and vegetables.

Risk factors are characteristics that appear to have some relationship to the development of a disease. If these risk factors are present, there is an increased likelihood that the disease will develop, though this is by no means a certainty. There are some risk factors that can be modified, for example lowering blood pressure which reduces the risk of a stroke. Other risk factors cannot be modified - for example a person’s age or family history.
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Age
Age is the most significant known risk factor for dementia. It is possible to develop dementia early in life, but the chances of developing it increase dramatically as we get older. One in 50 people between the ages of 65 and 70 years have some form of dementia, compared to one in five people over the age of 80 years.

Genetics
There is evidence that the genes we inherit from our parents may contribute to the likelihood of us developing certain diseases. The relationship between our genes and the development of dementia is still not fully understood, but there are some families in which it appears that an increased risk of developing dementia is inherited from one generation to the next. This most often occurs in families where dementia appears relatively early in life. There are specific genes that can affect a person’s risk of developing Alzheimer’s disease. Nonetheless, having a parent or other close relative with later onset Alzheimer’s disease only slightly increases the risk of developing the disease, compared with if there were no cases of dementia in the family at all.

Learning disabilities
Improvements in medical and social care have led to a significant increase in the life expectancy of people with learning disabilities. As with the general population, the effect of ageing on people with learning disabilities (which includes the increased risk of developing dementia) is becoming an increasingly important issue.

People with learning disabilities can be affected by dementia in very similar ways as other people. However, for people with learning disabilities, the early stages of dementia are more likely to be missed or misinterpreted. This can be because the person may find it hard to express their experiences, and communication issues may make it more difficult for others to assess change.

People with Down’s syndrome are at particular risk of developing dementia and the prevalence of dementia in people with other forms of learning disability is about four times higher than in the general population.

Physical health conditions
Conditions that affect the heart, arteries or blood circulation can specifically increase a person’s chances of developing Vascular Dementia. These conditions include:
- mid-life high blood pressure
- high blood cholesterol levels
- stroke
- diabetes
- heart problems such as a heart attack or irregular heart rhythms
- Mid-life obesity can also increase a person’s risk of developing dementia in later life.
- severe or repeated head injuries

Diet
The risk of developing many types of illness, including dementia can be affected by our diet. A healthy and balanced diet that enables a person to maintain a normal body weight is likely to reduce the likelihood of developing high blood pressure or heart disease which, as we saw above, can put a person at greater risk of developing dementia. Too much saturated fat has a negative impact on our vascular system whereas the polyunsaturated fatty acids found in oily fish might also help to protect the heart and blood vessels and lower the risk of developing dementia. Fresh fruit and vegetables contain many vitamins and antioxidants, which may prevent heart disease and protect the brain.

Smoking
Smoking has an extremely harmful effect on the heart, lungs and vascular system, including the blood vessels in the brain. Smoking increases the risk of developing Vascular Dementia.

Alcohol
Prolonged periods of excessive alcohol intake or regular consumption beyond recommended safe limits, can increase our risk of developing some types of dementia.

Physical exercise
Regular physical exercise helps to keep the heart and vascular system healthy, which can help to reduce our risk of developing Vascular Dementia.

Activity
Design a leaflet for your work area which can help to promote healthy lifestyle behaviour that can reduce the likelihood of developing some types of dementia.
Remember

The same health behaviour that can protect against peoples’ likelihood of developing dementia can also positively influence people to be able to live well with dementia.

In later modules we will explore approaches to promoting health and well-being for people with dementia.

The impact of a diagnosis of dementia

There is considerable evidence to show that receiving a diagnosis of dementia can be very helpful for a number of reasons. These include:

• More time for the person with the dementia diagnosis and their families to come to terms with and adjust to the diagnosis.
• More time to consider and provide care and treatment options to improve functioning and quality of life.
• More time for the person with the diagnosis and their carers to make future plans and arrangements (especially regarding financial and legal matters) before the condition becomes more severe.
• Enabling better use of specialist services such as dementia services, geriatric medicine, and neurology
• Preventing or delaying transition into institutional care.

*Out of the shadows
Alzheimer’s Society (2008)*

In later modules we will discuss early interventions which can promote the best possible health and well-being and quality of life following a diagnosis of dementia.

It is important that we remember that the impact of a diagnosis of dementia on the person and their families and carers may be difficult to predict and there are a range of factors that can have an effect. These appear to relate to the individual’s own personality, background and circumstances, as well as the way in which the diagnosis is provided. For some people, a diagnosis of dementia comes as a shock, whereas for others it can confirm their suspicions and provide relief in receiving confirmation regarding what is happening. People can experience a range of emotions including feeling numb, frightened, angry, worried, sad, guilty or frustrated. However, some people may also feel relieved to find there is a medical reason for their memory problems.

People with dementia may sometimes find it difficult to recognise or explain their emotions, particularly if they are already experiencing difficulty finding words. If you are working with someone who has recently been diagnosed with dementia it is important to:

• Be sensitive to what the person may be feeling.
• Pay attention to verbal and non-verbal signs of emotion.
• Support the person, acknowledging that this is a difficult time for them.
• Reassure the person where possible and/or appropriate.

Sometimes it is natural for us to want to make the person feel better but unfortunately, at times, well-intentioned comments or actions may not be helpful. For example, telling a person with a diagnosis of dementia that they should try not to feel sad or that they have nothing to worry about is unlikely to be helpful and has the potential to make their distress worse. Imagine how you would feel in a similar situation. It is quite possible that the person will simply think that you do not understand how they feel or what they might be experiencing.

Always be aware that a diagnosis of dementia is also likely to affect the person’s family and carers. They may quite often have been the first to notice that something is wrong. For some people, it is a long-awaited explanation after weeks, months or years of...
worry, consultations and tests. For others, this news may come as a complete shock.

**Remember**

When people receive a diagnosis of dementia it can affect them in different ways. It is important to respond sensitively – and this applies to families and carers as well.

**The impact of dementia on communication**

Communicating positively with people with dementia is important in supporting the best quality of life for them and their families and carers. It is important to identify a person’s communication strengths and weaknesses, and how to minimise any potential barriers to effective communication. We need to consider which factors are due to dementia, including language difficulties, and consider how these might affect quality of life for individuals.

The effects of dementia on language can include:
- choosing incorrect words to name items or express thoughts or feelings.
- the use of single words rather than more detailed phrases or complete sentences.
- difficulties in pronunciation.
- replacing words with others that are similar in meaning or sound, but which do not effectively convey the meaning the person had intended.
- difficulty in following a conversation, particularly where there are a number of individuals involved.
- difficulty understanding the meaning of words and phrases spoken by other people.
- reduced concentration leading to the person with dementia being more easily distracted.
- where English is a person’s second language, this can increase the likelihood that they may forget the meaning of words in this second language.

Additionally, we should distinguish which other factors can be barriers to communication.

The other factors can include:
- inappropriate environment – physical, social or care.
- boredom.
- effects of medication.
- inappropriate communication from others.
- abuse.
- apathy.
- fear.
- pain.
- aggression from others.
- mental health issues.
- other medical issues e.g. results of strokes, Parkinson’s disease.
- inappropriate dentures.
- sight or hearing difficulties.

Communication skills are progressively affected as dementia develops in the person. In the early stages, there may be difficulty in finding words and the person may try to talk around the word they are looking for, to convey meaning. They may be less fluent and communicating may require more thought and effort from them. The loss of language skills for the person with dementia starts with those words we use least and those we learned last.

As dementia progresses, the person may develop a range of more specific language problems. Some people experience expressive dysphasia, this means they may understand what is said to them but experience difficulty in expressing this understanding or conveying their response. They may also develop receptive dysphasia, where they find it difficult to understand what is being said to them.

It may be the case that as the dementia journey progresses and the person’s ability to communicate diminishes, their ability to process information deteriorates and their responses can be delayed. People may become less likely to initiate conversation under these circumstances.

Sometimes we may wrongly think that if the person with dementia does not understand it will not matter if we talk about them while they are there. We may believe that even if the person does comprehend something of what is being said, that they will forget about it in five minutes. However, our body language and gestures are likely to be understood and the person with dementia could be aware that they are being talked about, even if they do not fully grasp the meaning of what is said. This can be upsetting and it is possible that they will continue to feel upset long after they have forgotten why.
Each person will experience the dementia journey in their own way. These unique experiences will therefore impact on their ability to communicate and this will change over the different stages of their journey.

For people to live well with dementia and experience the best quality of life possible, person centred approaches which support positive communication and involve the person, their families and carers should be used.

In Module 2 we will explore person centred approaches to communication and in Module 4 we look at communicating with people with dementia when they are distressed.

The impact of the environment on people with dementia

The environments where we support and care for people with dementia are complex and can have a profound effect on the quality of life people experience. They involve many inter-related aspects which initially might not appear relevant until explored and fully understood. It is important however to understand that it is not only the physical environment that merits our attention, but that other aspects also impact on our lives and particularly for people with dementia.

Activity

In what ways do you think the environment where you work could impact on the person with dementia? Think of both positive and negative impacts.

Now ask someone with dementia (and their carer if appropriate) who uses your service, what they think about the environment and assess your thoughts in light of their responses.

Is there anything you should change as a result?
The physical environment

Living well with dementia can pose significant challenges. Something that might seem simple to the person without cognitive impairment can feel difficult, frustrating, confusing and even frightening for someone with dementia. This is why the environment should be assessed and modified, sometimes in very simple ways, to promote independence and quality of life for people with dementia. A well designed environment can make a big difference to how a person with dementia can manage their daily activities and therefore their quality of life.

Remember

“I have the right to be as independent as possible and be included in my community”.

The Standards of Care for Dementia in Scotland (2011)

It is crucial that the environment is enabling and is not a barrier for the person with dementia. Neither should it isolate them, in fact, the physical environment can play an important part in improving the lives of people with dementia by complementing treatments, supporting people to maintain the use of their abilities and helping them to cope with difficulties such as impaired memory and loss of reasoning and learning skills. A few simple changes can have a significant, positive impact.

In creating a safe, relaxing and calm area designed to reduce stress levels and maximise independence for as long as possible, some of the areas you will want to consider are:

• Décor – use of colours, furnishings.
• Signage.
• Lighting.
• Noise levels and the use of noise absorbing materials.
• Stimulation, exercise and activity.
• Private and communal space uses.
• Use of assistive technology.

A useful website to visit to help you explore this area is: www.scie.org.uk/publications/dementia/environment/index.asp

Where it is important to create environments which are safe and secure, it is also important to adopt positive approaches to risk for people with dementia and environmental changes can minimise risks while, at the same time, maximising independence.

The social and cultural environment

Social and cultural environmental factors can also have a profound effect on well-being, morale and self confidence and, when well considered, can support people to flourish.

What do you need to consider when trying to create a social and cultural environment which is physically, psychologically and emotionally beneficial for people with dementia?

Such an environment would have opportunities for:

• Independence and participation in carrying out activities and self care.
• Personalised care and attention and providing for unique needs.
• Stimulation, exercise and activities meaningful to the individual.
• Social interaction and continuing links with the community.

Some of the wider aspects which also impact on the social and cultural environment are the attitudes of staff.

There is more information about the social and physical environment, and about risk enablement in later modules.

Promoting equality and respecting diversity when working with people with dementia

Dementia can affect anyone from any background, socioeconomic group, culture, religion and as we saw in the previous section, at a range of ages. Dementia can also affect people alongside other conditions including physical and mental health conditions and learning or physical disabilities.
Equality and diversity is about the whole person, it is an integral part of a persons well-being and is key to ensuring that we provide person centred care and support.

Equality is about ensuring that people are treated fairly according to their needs and making this normal practice and behaviour. Diversity is about respecting differences.

Respecting diversity includes respecting a persons spiritual, cultural and religious beliefs. Spirituality could be described as the need for meaning and value. Recognising specific needs of people from different religions/beliefs as well as from the same religion/belief helps in developing a person centred service.

Recent research suggests that an individual’s experience of dementia is informed by their cultural background, core values and beliefs. This calls for a culturally sensitive approach to dementia support and care (Downs, 2000 (1) Hashmi 2009 (2), Laurence et al 2011(3)). It is critical therefore that staff consider the experience of the person with dementia within its cultural context and provide culturally appropriate care and support.

However it is always important to identify individual needs and preferences and not assume that all people who speak the same language practice the same religion, or that all people following the same religion practice the same rituals or share the same beliefs.

**Activity**

What do you think you might need to do to ensure that you promote equality and respect the diversity of people with dementia you work with?

Record your answers here:

Age

Age can be a barrier to appropriate support and care. Younger people with dementia can often feel that they are made to fit into a service, rather than the service being appropriate to their needs. Sometimes no specialist services exist, and younger people with dementia can find themselves lost in an inflexible system that does not accept responsibility for their support and care.

Younger people with dementia that you work with are more likely to:
- have a job at the time of diagnosis.
- have a family, including children.
- be more physically fit and active.
- have financial commitments such as a mortgage or supporting children through university.

It is important to remember that younger people with dementia are likely to have different priorities and interests to older people. Person centred support should take account of the individual priorities, interest and needs at whatever age. We will explore person centred care in Module 2.

For children and young people in families where someone is living with dementia it can be particularly difficult. This can also be a cause of concern for the person with dementia and their carer. It is important that the whole family is supported and you can find some useful guidance at Alzheimer’s Society at the following link [http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=108](http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=108).

**People with a learning disability and dementia**

People with a learning disability who are also living with dementia may not fully understand what is happening to them. Careful thought and planning by support staff should ensure that familiar language is used to explain changes. The person may be living with other residents or a partner with a learning disability when they receive their diagnosis. It is important to consider the impact of dementia on these people, as well as on the person receiving the diagnosis. It is important for staff and families and carers to gain access to specialist help, support and services.
**Top ten tips to support equality and diversity**

- Identify and support the cultural, language and spiritual needs of people with dementia in all care plans and reviews.
- Consider the different cultural understandings of dementia when discussing the subject with people with dementia and their families and carers.
- Make sure that our communication reflects appropriate cultural, spiritual and religious values and beliefs.
- Provide people with dementia and their families with information in their preferred language or format.
- Make sure that cultural diversity is reflected in all services, including health and personal care and food services.
- Identify and support the spiritual needs of your care recipients, including current and desired religious practices and beliefs.
- Make sure that people with dementia have access to culturally appropriate emotional and spiritual support.
- Support people with dementia to engage with activities and therapies to support cultural, spiritual and religious values and beliefs.
- Make sure that the living environment is appropriate to support cultural, spiritual and religious values and beliefs.
- Use professional interpreting services familiar with the care setting for dementia assessments.

To support inclusion, equality and diversity, the availability of accessible information is key to providing people with choice and control and ensuring people who use services know their rights. To ensure information is equally accessible to all people, it is important that we provide information in a range of ways and formats. This includes face to face, by telephone, online, written information in a variety of languages and formats, and services which meet the needs of people with a hearing and/or sight impairment.

We do not like the terms “dementia sufferer” or “suffering from dementia”, or “dementia victim”. These are demeaning and portray us in a negative light.

You would not want your loved ones spoken about in such disparaging terms. Sadly the media love these terms, despite my protests, and I cannot blame people for being misled into using derogatory language also.

I did likewise at one time, and could kick myself for my insensitivity. Use “person with dementia”, or “people with dementia”, or “affected by dementia” please. Thank you.

Mr. James McKillop
A person with dementia

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**Remember**

“I have the right to be regarded as a unique individual and to be treated with dignity and respect.”

The Standards of Care for Dementia in Scotland (2011)
Module 1 - Understanding Dementia

Module summary

In this module, we have built a foundation of knowledge about dementia on which the following 4 modules will be built. We have examined some of the more common types of dementia, their prevalence, how they affect the brain, and what signs, symptoms and difficulties people are likely to experience as a result.

We have also looked at the range of factors that can increase or decrease the risk of developing dementia. We have explored the impact of dementia on people’s communication skills and the impact of the environment on people with dementia. Finally, we have considered the importance of equality and diversity in dementia care and support.

Action into practice

From your learning in this module

- Make a note of three new things you have learned about dementia and about people with dementia and their families and carers
- Make a note of three areas of dementia practice you would like to learn more about as you continue through this learning resource
- Make a note of three changes you could make that you feel could enhance your practice.

When you have completed your journey through this learning resource, return to your notes and check whether you have achieved the second and third points.
Module 1 - Understanding Dementia

References

