Module 1
Understanding dementia
Module 1: Understanding dementia

Introduction

As life expectancy rises in the developed world, more people are being diagnosed with dementia. In 2015 there were approximately 90,000 people living with dementia in Scotland. Over the next 20 years it is predicted that the number of people in the population who are over 65 years will increase significantly. As a result there will be a disproportionately greater increase of people in the oldest age groups, so it is likely that numbers of people with a diagnosis of dementia in Scotland will increase considerably. These numbers may change over the years, as will many of the statistics given in this module, and it is important that you should keep up to date by checking the Scottish Government website, or Alzheimer Scotland website.

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.

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.

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.
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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 that people with dementia can have the best possible quality of life as their dementia progresses, and these are issues we will explore throughout the other modules in this learning resource.

Types of Dementia

<table>
<thead>
<tr>
<th>Alzheimer’s disease</th>
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<tbody>
<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>
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</table>

Atypical forms of Alzheimer’s disease

Atypical Alzheimer’s disease is found in around 5% of people diagnosed when over 65. However, it accounts for around one third of people who are diagnosed under 65.

**Posterior cortical atrophy (PCA)**

The early symptoms of PCA often include difficulties identifying objects or reading, even though the person’s eyes are healthy. People may also have problems judging distances when going down stairs, or appear uncoordinated when carrying out tasks.

**Logopenic aphasia** causes difficulties with language. The person’s speech can become slowed and lack fluency due to word retrieval difficulties.

For further information see the Alzheimer’s Society factsheet ‘What is Alzheimer’s disease?’ available on their website.
### Understanding dementia

**Vascular dementia**

<table>
<thead>
<tr>
<th>Prevalence</th>
<th>Vascular dementia is the second most common type of dementia affecting around 150,000 people in the UK in 2015.</th>
</tr>
</thead>
<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 younger people with dementia in the UK.</td>
</tr>
<tr>
<td>Typical symptoms</td>
<td>Symptoms of vascular dementia will vary depending on the underlying causes. These can include problems with concentration and verbal communication, visuospatial difficulties and memory problems (though this may not be the first symptom), periods of acute confusion and epileptic seizures. Planning and making decisions or problem solving can be difficult. 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>
</tr>
</tbody>
</table>

For further information see the Alzheimer’s Society factsheet ‘What is vascular dementia?’ available on their website.

**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.
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### Dementia with Lewy bodies

<table>
<thead>
<tr>
<th>Prevalence</th>
<th>Dementia with Lewy bodies (DLB) may account for about 10% of those with a diagnosis of dementia in the UK.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age groups affected</td>
<td>As with all forms of dementia, it is more prevalent in people over the age of 65, but in rare cases people under 65 may develop DLB.</td>
</tr>
<tr>
<td>Typical symptoms</td>
<td>These include, in common with most other types of dementia, memory loss, shortened attention span, disorientation and verbal communication difficulties. Additionally, people with DLB will often experience symptoms associated with Parkinson’s disease, for example, tremor and muscle stiffness, visual hallucinations, and fluctuations in symptoms from day to day, or within the same day. People may also be prone to fainting or unexplained falls and sleep disorders can be common.</td>
</tr>
<tr>
<td>Progression</td>
<td>DLB is a progressive disease. This means that over time the symptoms will become worse. In general, DLB progresses at about the same rate as Alzheimer’s disease, typically over several years. As the condition progresses many people have problems with speech and with swallowing with additional risk of choking.</td>
</tr>
</tbody>
</table>

For further information see the Alzheimer’s Society factsheet ‘What is dementia with Lewy bodies?’ available on their website.

### Fronto-temporal dementia

<table>
<thead>
<tr>
<th>Prevalence</th>
<th>Fronto-temporal dementia (previously known as Pick’s disease) is a relatively rare type of dementia.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age groups affected</td>
<td>Fronto-temporal dementia is more likely to affect people under the age of 65 than other types of dementia.</td>
</tr>
<tr>
<td>Typical symptoms</td>
<td>Earlier on in the condition, it is typical for memory to remain intact, but personality and behaviour tends to change. People may lack insight into what is happening to them, lose the capacity to empathise with others, behave in socially inappropriate, disinhibited or occasional aggressive ways, or become withdrawn and lacking in motivation. Additionally, people will often experience verbal communication difficulties, spatial disorientation, a shortened attention span, and may develop compulsive behaviour, such as over-eating.</td>
</tr>
<tr>
<td>Progression</td>
<td>The rate of progression of fronto-temporal dementia varies enormously, ranging from less than two years to more than ten years. As the condition progresses, the damage to the brain becomes more generalised and symptoms become similar to those of Alzheimer’s disease.</td>
</tr>
</tbody>
</table>

For further information see the Alzheimer’s Society factsheet ‘What is frontotemporal dementia?’ available on their website.
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.

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.
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 choice 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.

**Occipital Lobe**
The occipital lobe receives visual information from the eyes. It transfers this information to the parietal lobe to support the construction of 3-D visual images. Damage in this area:

- Can lead to difficulties in the perception of shape, movement and colour.
- Can contribute to the inability to recognise or identify objects that a person sees.

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.

For further information - the Open Dementia Programme from Social Care Institute for Excellence, module: ‘What happens in the brain’ may help you understand the effects of damage in different areas of the brain in dementia. This can be accessed on their website.
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.

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.

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.
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 exact 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 or religious and beliefs they have.

End of life and dying well

Dementia is a progressive condition. The 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.

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.
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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 GPs 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.

Reflection

- How did reading about George’s difficulties make you feel?
- How would you feel if you were experiencing these difficulties?
- How do you think George and his son feel about these difficulties?
- What problems could be caused by these kinds of memory difficulties?
- What practical support might people need with correspondence, appointments and household organisation?

Record your answers here
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 and 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.

**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 Caroline lives nearby and visits every evening. While raising her own children, Ellen worked 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 several occasions you have come to the flat and found that Ellen had made herself a cup of tea with cold water.

Caroline 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. She is thinking about getting the cooker disconnected because she is worried about her mum.

**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.

**Remember**

It is important to try to make sure that our contacts and communications with people with dementia are likely to create positive feelings.
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 circumstances, 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 tele-healthcare solutions that can support people to remain independent for longer. We will explore tele-healthcare in more detail later in this learning 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 when they become disorientated to the time of day, the place they are 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.
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Joan’s Story

Joan is 85 and has lived in the same small Scottish town all her life, as have her children John and Elaine. Joan is part of a close and sociable family. She hardly spent any time on her own until the death of her husband 7 years earlier. Joan 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 Joan.

Joan was diagnosed with dementia a year ago. She lives alone but receives a lot of support from her children who take it in turns to have her over to their houses on different days during the week, bringing her home in the evenings. Joan’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 Joan went to stay with her daughter Elaine for a while and felt frightened to go back home again.

Reflection

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

Record your answers here
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 if 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.

**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. 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.
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 do not 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.

In later modules we will look at person-centred ways to support communication with people with dementia.

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.
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. There is a risk of confusing the 3 conditions, especially delirium and dementia, because they all have symptoms in common. Older people and people with dementia are more at risk of developing delirium.

Remember

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

Although it can sometimes come on fairly quickly as a result of a stroke or other brain injury, dementia symptoms usually progress 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 is a common and serious medical condition that results in a person becoming more confused than usual with disruptions in thinking, consciousness and behaviour. The person may have difficulty paying attention to what is going on around them. They may not seem like their usual self and may be more agitated, have hallucinations and become suspicious, or they may become drowsy, withdrawn and difficult to wake. Delirium develops rapidly over hours or days and tends to vary during the day with the person confused at some times, and appearing like their usual self at other times.

Delirium is commonly triggered by infection, changes in medicines or trauma such as surgery. Anyone can develop delirium, but older people and people with dementia are at much greater risk. When a person has delirium it is often the only sign of physical illness and can range from confusion and sleepiness to being extremely anxious, agitated and unable to sit still. It can last for several months and will continue to get worse if not treated.

Delirium can be prevented and treated if dealt with urgently. It is therefore essential that if you work with people with dementia in hospital and the community you are aware of how to prevent it and how to ensure that someone with suspected delirium receives rapid assessment and appropriate management.

NES have produced learning resources to support you to develop your knowledge and skills about delirium that you can access from their website.
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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 the ability to orientate themselves in time and space are unusual.

- People with depression will occasionally experience an inability to remember things, but are 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, and 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.

Activity

Design a poster for your work area which can help 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.
- Every type of dementia involves a process of progressive damage to the brain which affects people differently at different stages of their dementia journey.
- 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.

Remember

People with delirium need immediate medical attention.
What are the protective and risk factors relating to dementia?

Dementia can affect anyone and 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 and behaviours that could increase our chances of developing dementia. These are known as risk factors.

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.

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.

<table>
<thead>
<tr>
<th>Age Prevalence</th>
<th>Estimated prevalence</th>
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<tbody>
<tr>
<td>20–64 years</td>
<td>0.1%</td>
</tr>
<tr>
<td>65–69 years</td>
<td>0.7%</td>
</tr>
<tr>
<td>70–74 years</td>
<td>1.4%</td>
</tr>
<tr>
<td>75–79 years</td>
<td>3.1%</td>
</tr>
<tr>
<td>80–84 years</td>
<td>6.4%</td>
</tr>
<tr>
<td>85–89 years</td>
<td>10.5%</td>
</tr>
<tr>
<td>90+ years</td>
<td>15.9%</td>
</tr>
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</table>

Estimated prevalence rates of dementia by age group in 2015

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
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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.

**Gender**

Women are slightly more likely to develop Alzheimer’s disease than men, even if we take account of the fact that women are more likely to live longer. The reasons for this are unclear.

<table>
<thead>
<tr>
<th>Age</th>
<th>Estimated prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
</tr>
<tr>
<td>20–64 years</td>
<td>0.1%</td>
</tr>
<tr>
<td>65–69 years</td>
<td>0.6%</td>
</tr>
<tr>
<td>70–74 years</td>
<td>1.3%</td>
</tr>
<tr>
<td>75–79 years</td>
<td>2.8%</td>
</tr>
<tr>
<td>80–84 years</td>
<td>5.2%</td>
</tr>
<tr>
<td>85–89 years</td>
<td>7.6%</td>
</tr>
<tr>
<td>90+ years</td>
<td>10.2%</td>
</tr>
</tbody>
</table>

Estimated prevalence rates of dementia by age group and gender in 2015

**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.
- Atrial fibrillation (the heart beat is irregular and usually faster).

**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 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.
Enabling better use of specialist services such as dementia services, geriatric medicine, and neurology.

Preventing or delaying transition into institutional care.

In later modules we will discuss early interventions which can promote the best possible health, 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 influence this. These appear to relate to people’s 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 if possible and/or appropriate.
Module 1: Understanding dementia

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.

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;

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.

If you wish to increase your knowledge and skills about dementia and diagnosis to the Enhanced Practice Level of Promoting Excellence - you can find the learning resource ‘Promoting Excellence in supporting people through a diagnosis of dementia’ on the Mental Health and Learning Disabilities page of the NES website.
Module 1: Understanding dementia

- 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;
- poorly fitting dentures;
- sight or hearing difficulties.

Communication skills are increasingly affected as dementia progresses. 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. The loss of language skills for the person with dementia tends to start with those words used least and those 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. The person 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.

Augmentative and Alternative Communication (AAC) is a term used to describe a huge range of methods and means that can help people to get their message across when they find speaking difficult. You can find information about this on the ‘Now Hear Me’ website.

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 that 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?

Record your answers here:

The physical environment

Living well with dementia can pose significant challenges. Something that might seem simple to a 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”

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 strengths 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.
Module 1: Understanding dementia

- Noise levels and the use of noise absorbing materials.
- Stimulation, exercise and activity.
- Private and communal space uses.
- Use of assistive technology.

SCIE have a useful section of their website to help you explore this area. Visit the ‘Dementia friendly environments’ section on the Dementia Gateway to find out more.

Where there is a desire to create environments which are safe and secure, it is also important to adopt positive approaches to risk for people with dementia. 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 affect on well-being, morale and self confidence and, when well considered, can support people to flourish.

What do you need to consider when creating 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.

Dementia Friendly Communities

A key way to enable people to live well with dementia is to support them to remain in their own homes and communities for as long as possible. In order to do this it is important that communities are inclusive, i.e. the members do everything that they can to respect all citizens, ensure full access to resources, and promote equal treatment and opportunity. As well as this the community values diversity, works to eliminate all forms of discrimination and engages all its citizens in decision-making processes that affect their lives.

In relation to people with dementia such communities are often called dementia-friendly communities. This can be described as being a place in which it is possible for the greatest number of people with dementia to live a good life and where people with dementia are enabled to live as independently as possible and to continue to be part of their community. For example people are supported to find their way around, and feel and be safe. They can access the local facilities that they are used to and where they are known (such as banks, shops, cafes, cinemas and post offices). Most importantly people with dementia are able to maintain their social networks so they feel they continue to belong.

There are a number of Dementia Friendly Communities in Scotland and you might like to find out what is happening in your local area.

Carers, families and people with dementia

Carers and families can be an essential source of support in enabling people to live well with dementia. If a person with dementia is supported by an unpaid carer, such as a family member or close friend, it is important that we also take that
person’s views into account when planning care and support. However, despite the important role they hold, carers may experience distress, and even depression, as a result of the pressures associated with the caring role. Carers may describe a feeling of frustration at not being involved as an equal partner in discussions about care and support, even though they are often directly affected.

You will need to be skilled at recognising the needs and wishes of carers, whilst ensuring the rights of the person with dementia remain paramount.

It can be difficult to get the balance right, however, if you work with the carer in a person-centred way, and appreciate how hard their role can be, you will find it easier to build a positive relationship based on empathy and understanding.

To support you to work better with carers, the Scottish Social Services Council and NHS Education for Scotland developed core principles for working with carers and young carers.

**Core Principles for Working with Carers and Young Carers**

- Carers are supported and empowered to manage their caring role
- Carers are free from disadvantage or discrimination related to their caring role
- Carers are enabled to have a life outside of caring
- Carers are recognised and valued as equal partners in care
- Carers are fully engaged in the planning and shaping of services
- Carers are identified for working with carers and young carers
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 sections, at a range of ages. Dementia can also affect people alongside other conditions including physical and mental health conditions and learning or physical disabilities. It is important to recognise that social inequalities and experiences of discrimination or prejudice may have a significant impact on people with dementia, their families and carers. Equality and diversity is about the whole person, it is an integral part of a person’s 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 person’s 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.
A person’s experience of dementia is informed by their cultural background, core values, beliefs and identity. This calls for sensitive approaches to dementia support and care. It is critical that staff consider the experience of the person with dementia within their own context and provide culturally appropriate care and support.

However, if we always use a person-centred approach we will identify individual needs and preferences. For example, we will not assume that all people who speak the same language practice the same religion, or that everyone who follows the same religion will 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. Around 3200 younger people under 65 are currently living with dementia in Scotland in 2015.

Younger people often experience difficulties and delays in the process of diagnosis. They 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 respond to their unique needs for support and care. A further issue facing younger people living with dementia is stigma and discrimination. This can be particularly heightened because dementia is especially associated with older people.

Remember younger people with dementia that you work with are likely to:
- Have a job at the time of diagnosis.
- Have a young family.
- 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 further information about the physical and social impact of dementia on younger people with dementia see the Alzheimer’s Society factsheet ‘Younger people with dementia’ on their website. You can also find a booklet called ‘Young onset dementia’, designed for younger people, on the Health Scotland website.

For children and young people in families where someone is living with dementia it can be particularly difficult and it is important that the whole family is supported.
Module 1: Understanding dementia

For more information see the Alzheimer’s Society factsheet ‘Explaining dementia to children and young people’ on their website. Health Scotland have also produced a booklet ‘Understanding dementia: A guide for young people’ available on their website.

People with dementia and sensory impairment

Living with both hearing loss and dementia can often make communication more difficult and this can either result in, or exacerbate, social isolation. If a person’s hearing loss is managed well, this can help them to cope better with their dementia.

It is important to remember that there are significant cultural and language differences between people who are born deaf and use sign language – and those who lose their hearing, or who prefer to use spoken language.

The early signs of dementia are often missed in Deaf people, because of difficulties with communication. Awareness of dementia in the Deaf community is low and poor access to information in accessible languages and appropriate media can make this problem worse.

Deterioration in sight is very common among older people, and yet it can frequently be missed as the symptoms may be misinterpreted as resulting from dementia. It is important to understand and recognise the signs of sight loss and to ensure that people have regular eye examinations. There are many ways in which communication can be improved with people with sight loss and dementia. We should make the most of what sight a person has and always ensure that the correct glasses are worn for the activities undertaken and that they are kept clean. Environmental improvements, and specialist equipment and technology can also support people with sight loss and dementia to be more independent.

For people with any type of sensory loss it is important that they have access to interpretation or other types of communication support where required.

There is more information about supporting people to live well with dementia and sensory impairment in later modules.

People with a learning disability and dementia

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 with up to 75% over the age of 60 years of age likely to develop dementia. The prevalence of dementia in older people with other forms of learning disability is higher than in the general population. However as is the case with any suspected cognitive decline it is important that other causes for any changes are eliminated.

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 environment should be appropriate for people offering a stable, predictable and calming atmosphere. It is also important that any other physical, mental, social, and emotional health needs are met. In particular, older people with learning disabilities are more likely to be affected by arthritis and other conditions that can affect
Module 1: Understanding dementia

mobility. People with Down’s Syndrome are also particularly susceptible to thyroid conditions and hearing problems. It is essential that people with a learning disability who are living with dementia are not disadvantaged by lack of access to general healthcare.

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.

As a result of the improvements in health care and the resulting ageing population an increasing number of people with learning disabilities are still living at home with family carers who are now 70 or older. Those carers may be parents, siblings, grandparents, other close relatives or friends. As family carers start needing more support themselves, the families have often developed routines and ways of coping that mean that both the older person and the person with a learning disability are looking after each other. This is known as mutual caring. Taken alongside the increasing prevalence of dementia with age it is quite possible that any or all those involved in a mutually caring relationship may be living with dementia.

A critical factor for families in this situation is that they do not fit neatly into services and support. Often, nobody is sure which service should take responsibility for provision of support and they may be passed around and fail to get adequate support from anyone. This can result in inequitable access to appropriate health and social support and difficult situations can deteriorate and a crisis may arise.

The only way to deal with this is by ensuring that a ‘joined up’ approach is taken. The key thing is that you are able to recognise mutual caring, appreciate the complexity and sensitive nature of the situation and have some ideas about how you can offer different levels of support.

You can find a useful resource on the University of the West of Scotland website called Jenny’s Diary that can support you to have conversations about dementia with people who have a learning disability.

Lesbian, gay, bisexual and transgender (LGBT) communities

Before considering the experience of people from LGBT communities who are living with dementia it is important to clarify some terminology commonly used.

■ **Sex** refers to a person’s biological status and is typically categorised as male, female, or intersex (i.e. atypical combinations of features that usually distinguish male from female).

■ **Gender** refers to the attitudes, feelings, and behaviours that a given culture associates with a person’s biological sex.

■ **Gender identity** refers to a person’s sense of oneself as male, female, or transgender and the way in which they act to communicate gender within a given culture; for example, in terms of clothing, communication patterns and interests is referred to as their **gender expression**.

■ **Sexual orientation** refers to the sex of those to whom a person may be sexually and romantically attracted. Categories of sexual orientation usually include people who are attracted to members of their own sex (gay men or lesbians), attraction to members of the other sex (heterosexuals), and attraction to members of both sexes (bisexuals). Although these categories continue to be widely used, there is a school of thought that suggests that sexual orientation occurs on a continuum.

Previous experiences of discrimination can make people from LGBT communities who are living with dementia reluctant to disclose their sexual orientation and/or gender identity. This can sometimes mean that people avoid using formal care and support services.
The fear of discrimination may act as a barrier to early diagnosis of dementia and may also cause distress for people in the later stages of their dementia journey. We should ensure that when talking about LGBT people or issues, or discussing relationships, gender or sexuality in everyday conversation, that this is done in a non-judgemental and affirmative way, even if you don’t know if there is someone who is LGBT present.

**Lesbian, gay, bisexual and transgender people living with dementia**

It is important that we avoid making assumptions that the people living with dementia that we are working with are heterosexual. This includes assumptions about people based on our own expectations, regarding the nominated next of kin. It is also important that do not force people to talk about their sexual orientation if they do not wish to. Older people may not be comfortable with the phrases lesbian, gay or bisexual so we should employ the terminology favoured by the person we are working with. It is also important to include same-sex partners in planning care where it is the wish of the person with dementia.

**Transgender people living with dementia**

It is critical that transgender people should be recognised as and treated according to their gender identity. Their body may not match assumptions made on the basis of their gender identity, and where they require personal care this should be handled sensitively and without unnecessary questions or comments. Transgender people may have specific personal care needs relating to their transition, and they may also wish to have a higher degree of privacy. They may also be cared for by non-traditional families, who should be included in planning care where it is the wish of the person with dementia.

You will find a number of useful resources to support your practice on the ‘LGBT Health and Wellbeing website’ on the ‘Resources for professionals’ page.

**Race and ethnicity**

Current evidence has its limitations, but suggests the estimated prevalence rates for dementia in Black and minority ethnic (BME) communities are similar to the general population. However, there appears to be a higher prevalence of younger people with dementia, and people with Vascular Dementia. Evidence also suggests that people from BME communities, who experience dementia, may be less likely to seek support from services, tend to make contact at a later stage of the dementia journey, and are less likely to receive an early diagnosis.

Some key points to consider include:

- Misunderstandings may indicate language barriers and may not just be due to the impact of the person’s dementia.
- There may be a need to provide access to translators. This will need to be handled sensitively -- using a family member as a translator is not always appropriate.
- The term ‘dementia’ is not always easily translated into some languages in lay people’s terms.
- Carers in minority ethnic communities may not identify with the term ‘carer’.
- Minority ethnic communities differ and it is important to be person-centred and listen to individuals and their families.
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Top ten tips to support equality and diversity issues

1. Always use a person-centred approach that recognises all the aspects of someone’s identity, such as race, religion, beliefs and sexual identity. This is essential to promote positive engagement with staff and services at all stages of the dementia journey.

2. Identify and support the cultural, language and spiritual needs of people with dementia in all care plans and reviews.

3. Remember that differences in family structures may mean that the person who is most important to the individual and who may really need to be involved may not always be the person you might have assumed it would be.

4. Make sure that communication reflects appropriate cultural, spiritual and religious values and beliefs.

5. Provide people with dementia and their families with information in their preferred language or format.

6. Make sure that cultural and spiritual diversity and gender identity is reflected in all services, including health and personal care, food services and religious practices and beliefs.

7. Ensure that people with dementia have access to culturally appropriate emotional and spiritual support.

8. Support people with dementia to engage with activities and therapies that reflect their cultural, spiritual, religious beliefs, sexual orientation or gender identity.

9. Make sure that the living environment is appropriate to support cultural, spiritual and religious values and beliefs.

10. Use professional interpreting services familiar with the care setting for dementia assessments.

Remember

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

Standards of Care for Dementia in Scotland (2011)

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.

A final thought for your reflection:

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 love ones spoken about in such disparaging terms. Sadly the media love these terms, despite my protests, and I cannot blame people for being mislead 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
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 considered the impact of a diagnosis of 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 considered the importance of equality and diversity in dementia care and support.

Reflective Account

Write a reflective account taking into consideration your learning from Module 1.

Below is a suggested structure that you may find helpful in writing your reflective account.

Please ensure that you anonymise any information

What happened?
Identify and describe a situation or incident where you were supporting a person with dementia. When recalling this situation you may wish to consider the following:

- The type of dementia that you think that the person may be living with.
- The changes and difficulties that the person may have been experiencing.
- Communication issues.
- The impact of the physical and social environment.

Describe what you did or how you responded.

Describe the outcome of your actions or response.

So what does this mean?

How did you feel about the outcome of the support that you provided at the time?

What do you feel about that now in light of your learning, having completed the module?

What did you do that went well?

Do you think your actions helped to improve quality of life for the person you were working with?

What might you now do differently?

Now what will you do in the future?

How will this affect the way you work with people with dementia in the future?

Would you act differently or would you be likely to do the same?

What further learning do you need to undertake to enhance your understanding of dementia that will help you to support people to improve their quality of life? You may want to record this using the Action into practice activity at the end of this module.
Module 1: Understanding dementia

Action into practice

From your learning in this module

- Make a note of 3 new things you have learned about dementia and about people with dementia and their families and carers.

- Make a note of 3 areas of dementia practice you would like to learn more about as you continue through this learning resource.

- Make a note of 3 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.

Make notes of your responses below: