Module 1: What dementia is and what it isn’t

Learning aims

On completion of this module you will be able to:

• challenge some common myths and negative attitudes about dementia
• describe what dementia is
• list common signs and symptoms of dementia
• describe some of the complex difficulties people with dementia face and some causes of these difficulties.

Estimated time required: 20 minutes

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Section 1: Introduction

Hello and welcome to module one, entitled ‘What dementia is and what it isn’t’.

Dementia is receiving an increased amount of coverage in the media and in this module we will explore some common misconceptions to help you establish a more accurate understanding of the word ‘dementia’.

We will also look at the recent history of views about dementia and dementia care to better understand present day approaches to work with people with dementia.

Finally we will explore some key facts about dementia and look at why and how certain difficulties may arise.
Section 2: Views of dementia

In this section you will learn about:
- how dementia is often covered in the media
- positive views of dementia
- a recent history of views about dementia and dementia care, leading to present-day approaches to working with people with dementia.

Dementia is a condition resulting from a disease such as Alzheimer's disease or vascular dementia. The disease causes permanent and progressive damage to the brain.

Mental functioning becomes impaired in many different ways, and people experience a range of difficulties in everyday life. However, there is much that can still be positive in the lives of people living with dementia.

Much of what we hear and read about dementia does not suggest that there is any possibility of living well with dementia. In order to learn how to provide constructive support to people with dementia, it is important to discard some of these unhelpful views.

Dementia in the media

Below you can see several headlines typical of the portrayal of dementia in the news today.

Take a look at each headline and the commentary underneath it.

**DEMENTIA IS A LIVING DEATH FOR 700,000 BRITONS**

Our commentary

People with dementia are not zombies. This headline implies that life is over and there is nothing that can be done for people with dementia. But much can be done to support people to live well with dementia and to continue to have an impact on the world around them.
Our commentary
People with dementia are not terrorists. Mentions of bombs and ‘explosions’ of dementia serve only to associate dementia with death and destruction, and portray people with dementia as frightening.

Our commentary
People with dementia do not lose their identity. It is usually the attitude of those around a person with dementia that can deny somebody their identity.

Our commentary
It is important to talk in terms of ‘living with’ dementia rather than ‘suffering from’ it. Headlines like this only serve to reinforce a pitiful, worthless impression of people with dementia in the public eye.

(OVER TO YOU!) Spend a few moments to think about:
1. How well do you think these headlines present dementia?
2. What might be unhelpful or misleading about them?
3. What words or phrases have you heard used to describe dementia?

Please note: any word in blue can be found in the accompanying glossary.
Our commentary

Here is a more positive headline. This article turns on its head the assumption that a good quality life ends once dementia takes hold. It is a move forward from the negative labels that suggest a kind of living death.

Let’s now take a look at how work with people with dementia has changed over the years.

How attitudes to dementia care have evolved over time

Take a look at the timeline below to read about approaches and key events. As you do reflect on how the approach to dementia care has evolved and is still evolving.

For more comprehensive accounts, please go to the references section in this module.

1600s and 1700s

Institutions (later called asylums) were set up to house the outcasts of society, including ‘the mad’. In many, inmates were treated much like animals in a zoo (Kitwood, 1995).

‘Treatments’ included bloodletting, purges and cold baths (Porter, 1997).

1800s

Many types of ‘non-conformity’ were re-classified as disease (Kitwood, 1995). The numbers of older people with mental illnesses, including dementia, were steadily increasing in asylums (Keady and Adams, 2001). They were to become ‘forgotten people’ (Adams, 2008). Many new asylums were built.

1906

Alois Alzheimer presented a key paper in which he described the ‘diseased brain’ of Auguste D, a patient who had recently died. He concluded that her symptoms – including memory impairment and disorientation – were caused by the changes in her brain.

The condition later became known as Alzheimer’s disease.
1948
The NHS was established. Mental nursing care revolved around vigilance, perseverance and ‘scrupulous punctuality’ (Altschul and Simpson, 1982). People with dementia were generally described in de-humanising terms. Medical diagnosis was seen as the basis for understanding behaviour (Houliston, 1961).

1960s
Demeaning and depersonalising care was still commonplace. Still, many people with dementia were housed indefinitely on long-stay wards. A hopeless view of dementia predominated. Task-focused care, with little communication, was the norm (Adams, 2008).

1979
The Alzheimer’s Disease Society was founded, principally as a carers’ organisation. Its focus was on the stress and burden of carers.

1980s–1990s
The closure of the asylums. The rapid growth of private care settings, group homes and care in the community. Services developed to support people with dementia to stay at home, including day hospitals and community mental health nursing.

Mid-1990s
Important changes began to take hold in the way people with dementia were viewed, led by the work of Tom Kitwood and the Bradford Dementia group. This was known as a person-centred approach, where the focus was on the person, not just the disease. Many therapeutic methods for dementia care were developed.

2000 to present
There is growing equality and inclusion of people with dementia in the Alzheimer’s Society, which is no longer purely a carers’ organisation. The Commission for Social Care Inspection is established with a focus on the quality of dementia care. In 2009 the National Dementia Strategy, that sets out to transform the quality of dementia care, is launched.

As you have seen from the timeline, approaches to the care of people with dementia have progressed considerably over time.

However, it would be a mistake to assume that the production of a national strategy and mention of the words ‘quality’ and ‘inclusion’ mean we are now living in a dementia-friendly world.

Some negative attitudes left over from the age of the asylums can still be seen today both in practice and in the media.

Please note: any word in blue can be found in the accompanying glossary.
Over to you!

1. What historical views of dementia do you think still have an influence today?

When you are ready, please move on to the next section, which will help you begin to challenge some common misconceptions about dementia.
Section 3: Fact or fiction?

In this section you will:
- learn some facts and some common misconceptions about dementia
- establish an understanding of what dementia really is.

Fact or fiction quiz

Read each statement below and decide if it is fact or fiction.

1. Confusion in older people is usually an indication of dementia.
   **Fact or fiction?**

2. Dementia is a normal part of the ageing process.
   **Fact or fiction?**

3. Dementia only affects old people.
   **Fact or fiction?**

4. Difficulty retaining memories of recent events is often one of the first symptoms of dementia.
   **Fact or fiction?**

5. Physical damage to the brain occurs in dementia.
   **Fact or fiction?**

6. Difficulties experienced by people with dementia are sometimes preventable.
   **Fact or fiction?**

Now turn to the next page for our commentary on each one.
Our commentary

1. Confusion in older people is usually an indication of dementia.

This is fiction

There are many causes of confusion, most of which are treatable. Sudden or acute confusion is called delirium. It can be caused by a physical health problem, such as an infection or constipation. Depression is another common cause of confusion in older people. Confusion can also result as a side effect of medication, or a change of environment or circumstance, such as moving home or the death of a partner.

2. Dementia is a normal part of the ageing process.

This is fiction

Most older people do not develop dementia. Over the age of 80, less than 20 per cent of people have dementia. Many older people do find that their memory is not as good as it used to be, but dementia involves much more than a slight memory impairment. Therefore dementia is not a normal result of aging, but rather is the result of a disease such as Alzheimer’s. There are over 100 diseases that can cause dementia.

3. Dementia only affects old people.

This is fiction

While the prevalence of dementia does increase with age, many younger people also develop dementia. The more common types of dementia, including Alzheimer’s disease and vascular dementia, are more likely to affect older people, but some less common dementias are just as likely to affect people at a younger age. Younger people developing dementia may face some particularly difficult issues, for example in relation to having to give up work or coping with a young family.

4. Difficulty retaining memories of recent events is often one of the first symptoms of dementia.

This is fact

In many types of dementia, a worsening in the ability to retain information is one of the first symptoms noticed. The person may, for instance, frequently forget where they have put things, or have no memory of a conversation they engaged in earlier. Some dementias, though, follow a different course and other symptoms appear first.

Please note: any word in blue can be found in the accompanying glossary.
5. Physical damage to the brain occurs in dementia.

This is fact

Dementia is an ‘organic’ disorder – this means a condition in which physical impairment is present. Areas of the brain progressively affected usually include the temporal, parietal and frontal lobes. These lobes of the brain control functions such as memory, recognition, sequencing of actions, verbal communication, and regulating behaviour. Difficulties with these functions are therefore likely to arise from the physical damage occurring in dementia.

6. Difficulties experienced by people with dementia are sometimes preventable.

This is fact

While the symptoms caused by physical damage to the brain are not preventable, many people with dementia also experience difficulties that are caused by preventable factors. For example, if a person is deprived of communication, they may become withdrawn. The withdrawal is not a symptom of their brain damage, and could have been prevented. Pain and ill-health can also cause many difficulties, including those which could be mistaken for symptoms of dementia.

Before you move on, spend a few moments thinking about what the last activity taught you.

(Over to you!)

1. Did you correctly separate fact from fiction?
2. Did anything surprise you?

To summarise, it is vital to recognise that confusion has many causes and a thorough medical assessment is needed so that treatable conditions can be addressed.

Dementia is neither an inevitable consequence of old age, nor is it a condition that only affects older people. In supporting a person with dementia it is important to remember that they are coping with the effects of physical damage to the brain, and will need our help and understanding.

We also need to be aware that the physical damage to the brain is progressive, and while memory problems may be the first noticeable symptom, other symptoms will appear over time and the person is likely to need an increasing level of support.
Section 4: Symptoms of dementia

In this section you will learn about:
- common symptoms of dementia
- clinical terminology for symptoms
- the fact that many difficulties have multiple causes and cannot simply be attributed to dementia.

Although dementia is progressive, it is certainly not a hopeless condition. Some difficulties can be prevented, and there are many ways of supporting people through their experience of dementia.

Now we’d like you to consider some of the problems most commonly reported by carers of people with dementia, and explore their possible causes.

Take a look below at some of the problems commonly voiced by carers of people with dementia.

You will learn more about dementia, including finding out how likely it is to occur, and what the causes might be. We have also included the clinical term for the problem, where there is one.
1. Vivian: ‘My wife can’t remember what she did five minutes ago.’

Explanation: Short-term memory loss is a common symptom of dementia.
Clinical term: Anterograde amnesia

2. Derek: ‘She knows what she wants to say but often can’t find the words. Sometimes she doesn’t seem to understand me.’

Explanation: Difficulty with verbal communication is a common symptom of dementia. Other factors can contribute, including a noisy or stressful environment or our own communication being unnecessarily complex.
Clinical term: Dysphasia/Aphasia

3. Margaret: ‘He speaks quite openly about what he thinks of people. He was such a shy man before.’

Explanation: People with dementia may have a lowered ability to regulate their speech and behaviour. This can be a fairly common symptom of dementia.
Clinical term: Disinhibition

4. Malcolm: ‘She does things in the wrong order or doesn’t finish them. But I know she can do them, like getting dressed, or making a cup of tea.’

Explanation: Dementia can cause an inability of the brain to send the right signals for the sequencing of required task, despite a person being physically capable of doing each action. This is a common symptom of dementia.
Clinical term: Dyspraxia/Apraxia

5. June: ‘He hit me in the face when I was trying to help him get undressed.’

Explanation: Aggression is not normally a direct symptom of dementia. Episodes of aggression are usually attempts to communicate important feelings. It may be, for example, that the person is feeling threatened or is in pain.

6. Helen: ‘He often talks about seeing things or hearing things that are not there.’

Explanation: Dementia can cause people to see or hear things that are not there, but more often if a person talks about things that aren’t there it is because he has misinterpreted sights or sounds in the environment, such as shadows, mirrors, patterns on the carpet, or noise from the television.
Clinical term: Visual and auditory hallucinations/Agnosia

Please note: any word in blue can be found in the accompanying glossary.
7. Nischal: ‘Sometimes she thinks she’s back 30 years, or even when she was a little girl.’

Explanation: People with dementia frequently experience a different reality, such as believing they are in a different time and place. This is, in part, due to memory problems, but it may also indicate the person’s needs – for example, 30 years ago this woman may have been leading an active, fulfilling life, and her belief that she is back in that time tells us that she needs more activity and fulfilment in her present-day life.
Clinical term: **Disorientation in time**

8. Keith: ‘She just sits there all day. She doesn’t want to do anything and will barely talk to me.’

Explanation: It is quite common for people with dementia to become depressed or withdrawn, but this is not usually a direct symptom of the condition. More often it results from the person finding it difficult to cope with their symptoms, feeling isolated, feeling out of control of their lives, or having no opportunity to use their remaining strengths.
Clinical term: **Depression/withdrawal**

9. Yoko: ‘He is always asking where he is. He ends up following me all around the house.’

Explanation: It can be quite common for a person with dementia to feel lost even in very familiar surroundings. Following his wife around also indicates that he is probably feeling insecure, both because he is not sure where he is, and also because his poor short-term memory does not enable him to remember where his wife is unless he has her in his sight.
Clinical term: **Disorientation in space**

10. Stanley: ‘She keeps having accidents, not getting to the toilet on time.’

Explanation: Usually, ‘having accidents’ is an indirect result of other symptoms of dementia or disabilities – for example, forgetting where the toilet is, or not being able to unfasten clothing. The environment often contributes to these ‘accidents’ too. For example, if the door to the toilet looks like every other door, the person will receive no clues to compensate for their memory problems. As dementia progresses, the brain can fail to recognise a full bladder. The person may not realise that they need to go to the toilet, and will possibly have no awareness that urination or defecation is occurring.
Clinical term: **Incontinence**

Please note: any word in blue can be found in the accompanying glossary.
11. Betty: ‘He accused me of stealing his wallet.’

Explanation: It can be quite common for a person with dementia to make accusations. Usually this is the result of the struggle to come to terms with loss of memory and the fear of being taken advantage of. People often rationalise losing things by blaming family members or thieves if they cannot remember where they have left things.
Clinical term: Paranoia

12. Jack: ‘She seems to forget how to chew. The food can stay there for ages. Sometimes she coughs and splutters.’

Explanation: As dementia progresses, people may have increasing difficulties with chewing and swallowing.
Clinical term: Dysphagia

13. Cathy: ‘Sometimes he doesn’t recognise me, and once he told me to get out of my house.’

Explanation: Difficulty in recognising faces can be quite a common symptom of dementia. This can be very stressful for the individual, as he may, for instance, mistake a family member for an unknown intruder. Sometimes a person may be more able to recognise someone by their voice or another aspect of their appearance, such as familiar clothing.
Clinical term: Prosopagnosia

14. Donald: ‘She won’t sit still but spends the day wandering.’

Explanation: The term ‘wandering’ implies aimlessness, but in fact people with dementia walk for many different reasons. Walking is not a symptom, but an action that communicates a need. It might be, for example, that the person is going somewhere or looking for something, is experiencing pain or discomfort, is in need of exercise, is seeking stimulation, or is trying to find the toilet.
Clinical term: Walking

15. Clive: ‘She keeps on and on repeating the same thing.’

Explanation: People with dementia often repeat themselves because they have forgotten having already said something. It may also be that what the woman is saying or asking has particular significance for her, and perhaps she feels that she has not been listened to or given the response that she needed. Repetition can also occur as a direct symptom of dementia, when the person will become ‘stuck’ on a particular word or phrase and find themselves unable to move on to the next word.
Clinical term: Repetition/perseveration

Please note: any word in blue can be found in the accompanying glossary.
The previous real-life examples explored and explained some difficulties that people might experience with dementia. It also highlighted the fact that many of these difficulties cannot be understood simply as symptoms of a disease and have multiple causes, some of which can be addressed. This will be further explored in Module 7.

It is important to understand the emotional impact of the symptoms of dementia in order to support the individual through their experience of dementia and avoid unnecessary problems. These topics are considered in more depth in Modules 5, 6 and 7.

**Over to you!**

Spend a few moments to think about:
1. Did this make you think any differently about difficulties associated with dementia?
2. Did you discover any reasons for problems you have encountered?

This brings us to the end of the first module, which has explored ways in which views on dementia have changed, and equipped you with a basic understanding of dementia and some associated difficulties.

Although dementia is a **progressive condition** there are many ways in which people with dementia can be helped to live with the condition rather than suffer from it.

Below is a summary of the main points from this module:
- Dementia is a term used to describe the symptoms that occur when the brain is affected by specific diseases and conditions.
- Dementia is often misrepresented – literally given a bad press.
- New approaches to dementia care have developed in recent years.
- Dementia is progressive but not hopeless.
- Some difficulties associated with dementia are caused directly by changes in the brain, but many have multiple causes.
### Section 5: Self-assessment

This self-assessment will allow you to test your understanding of some key messages and facts covered in this module. Choose between true and false for each question. You will then see the right answers and some feedback on page 18, and where to look in this module to review.

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<th>Question 1</th>
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<tr>
<td>Dementia results from diseases that cause permanent and progressive damage in the brain.</td>
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<td>The use of words such as 'sufferers' or 'victims' in the press when referring to people with dementia helps portray a realistic image of dementia to the public.</td>
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<td>People with dementia lose their identity.</td>
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<td>A good quality life ends once dementia takes hold.</td>
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<td>We are still not living in a dementia friendly world.</td>
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<th>Question 6</th>
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<td>Most older people do not develop dementia.</td>
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Please note: any word in blue can be found in the accompanying glossary.
### Question 7

Aggression is a common symptom of dementia.
- True
- False

### Question 8

Difficulty recognising people and faces can be common in dementia.
- True
- False

### Question 9

Wandering is a common symptom of dementia.
- True
- False
Answers

1. The correct answer is ‘true’.

2. The correct answer is ‘false’. Much can be done to support people to live well with dementia.

3. The correct answer is ‘false’. It is usually the attitude of those around a person with dementia that can deny a person their identity.

4. The correct answer is ‘false’. There is much that can still be positive in the lives of people living with dementia.

5. The correct answer is ‘true’. Looking at how dementia care has evolved over hundreds of years, some attitudes and practices akin to those of the old asylums still remain.

6. The correct answer is ‘true’. Over the age of 80 less than 20 per cent of people have dementia.

7. The correct answer is ‘false’. Episodes of aggression are usually attempts at communication and not normally a direct symptom of dementia.

8. The correct answer is ‘true’.

9. The correct answer is ‘false’. The term ‘wandering’ implies aimlessness, but many people with dementia walk for many different reasons.

Please note: any word in blue can be found in the accompanying glossary.
Section 6: References


Hill, A. (2008) ‘Dementia is a living death for 700,000 Britons. That figure is rising sharply. Can we cope?’ *The Observer (Focus)*, 17 February.


