



# Wellbeing for Life Dementia and Learning Disability



## Learning Outcomes

- To have a clear understanding of the term dementia, and current facts and statistics relating to dementia.
- To be familiar with some of the common types of dementia.
- To understand what a learning disability is, and current facts and statistics about ageing with a learning disability.
- To understand the links between learning disability and dementia, and specifically between Down's Syndrome and Alzheimer's Disease.

## What is Dementia?

The Oxford English Dictionary describes dementia as:

***“A chronic or persistent disorder of the mental processes caused by brain disease or injury and marked by memory disorders, personality changes, and impaired reasoning”***

- In practice, this means symptoms that include memory loss and difficulties with thinking, problem-solving or language. The person’s personality and ability to complete daily tasks can also be affected. For more information, please see our Module on ‘Signs and Symptoms’ in Theme 5 The Dementia Pathway.
- Dementia is caused when the brain is damaged by diseases. Alzheimer’s Disease is the most common cause of dementia, but there are others. We will look at the different types of dementia later in this module.



## What is Dementia?

- Dementia is progressive, meaning the symptoms will eventually get worse. For more information, please see our Module on 'Changed Behaviours' in Theme 5 The Dementia Pathway
- Current treatments are limited and only suitable for certain types of dementia. For more information, please see our Module on 'Treatments' in Theme 5 The Dementia Pathway
- There is no cure for dementia, although research is ongoing. Join Dementia Research <https://www.joindementiaresearch.nihr.ac.uk/>
- Living with dementia has a significant emotional, social, psychological and practical impact on a person. People experience dementia in their own way and you cannot compare one person to another. You may see similar traits but the effect will be different for each person.
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***“It is very important to focus on what the person can do, not on what they may have lost. It is also important to focus on what the person feels rather than what they remember”.***

### **Alzheimer's Society**

[https://www.alzheimers.org.uk/info/20046/help\\_with\\_dementia\\_care/31/understanding\\_and\\_supporting\\_a\\_person\\_with\\_dementia](https://www.alzheimers.org.uk/info/20046/help_with_dementia_care/31/understanding_and_supporting_a_person_with_dementia)

## Some Facts about Dementia

- There are 850,000 people with dementia in the UK, with numbers set to rise to over 1 million by 2025. This will soar to 2 million by 2050.
- One person develops dementia every 3 minutes.
- 1 in 6 people over the age of 80 have dementia.
- 70% of people in care homes have dementia or severe memory problems.
- Most people with dementia are over 65 years of age.





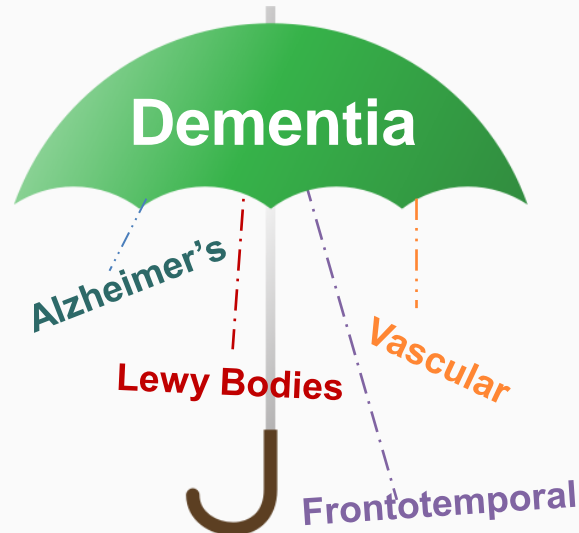
## Some Facts about Dementia

- There are over 40,000 people under 65 with dementia in the UK. This is known as young-onset dementia.
- More than 25,000 people from black, Asian and minority ethnic groups in the UK have dementia.
- Dementia disproportionately affects women – 65% of people living with dementia are women, and dementia is the leading cause of death amongst women.

Remember: dementia can affect anyone, whatever their gender, ethnic group, class, educational or professional background.

## Understanding the Term “Dementia”

- Dementia is known as an “umbrella” term because of the many different types of dementia.
- Experts do not have an exact figure for how many different types of dementia there are, but ‘over 100’ is a commonly used term.
- Imagine that you are holding an umbrella over your head and there are lots of words dangling down and each word is a type of dementia.







## Common Types of Dementia:

### Alzheimer's Disease

- Alzheimer's Disease is the most common type of dementia.
- It affects multiple brain functions and is caused by proteins building up in the brain causing structures called plaques and tangles. These lead to the loss of connections between nerve cells, and eventually to the death of nerve cells and brain tissue. This results in severe brain shrinkage in a person with advanced Alzheimer's Disease.
- A person living with Alzheimer's Disease will also have less of the chemicals in the brain that help to send signals around the brain, leading to these signals not being transmitted as effectively as they should be.
- The first sign of Alzheimer's Disease is usually problems with memory. This may include forgetting a conversation or names of places or people. This is because the early damage in Alzheimer's usually affects a part of the brain called the hippocampus, which stores our day-to-day memory.



## Common Types of Dementia:

### Alzheimer's Disease

- As the symptoms of Alzheimer's Disease often progress slowly it can be hard to spot and people may think that it is just a part of getting older.

### Vascular Dementia

- Vascular dementia is the second most common type of dementia, affecting around 150,000 people in the UK.
- It is caused by reduced blood flow to the brain due to diseased blood vessels becoming blocked through clots or leaking. When blood cannot reach brain cells, they become damaged and die.
- Vascular dementia is strongly linked to having a stroke – around 20% of people who have a stroke develop dementia, and a person who has already had a stroke has an increased risk of further strokes in the future.



## Common Types of Dementia:

### Vascular Dementia

- A person may also develop a type of vascular dementia known as single-infarct or multi-infarct dementia. These are due to much smaller strokes, when a blood vessel is blocked by a clot, and may be symptom-less for the person or the person may only have very mild symptoms that last for less than a day. These 'mini strokes' are known as a TIA (Transient Ischaemic Attack). Although the blockage may clear, if the blood supply has been affected for more than a few minutes, the area of brain tissue affected will die. This area is known as an infarct.
- Men are at a slightly higher risk of developing vascular dementia than women.
- Vascular dementia is fairly well understood thanks to the huge amount of research that has gone into understanding how to keep the vascular system (the heart and blood system) in good health. This illustrates why, in risk-reduction advice, it is often said that "what is good for the heart is good for the head".



## Common Types of Dementia:

### Dementia with Lewy Bodies

- Around 10-15% of people with dementia have Dementia with Lewy Bodies (DLB).
- Dementia with Lewy Bodies is characterised by a build-up of clumps and proteins in nerve cells in the brain known as Lewy Bodies. They damage the way the nerve cells work and communicate with each other, leading to the nerve cells dying.
- DLB is a type of dementia that shares symptoms with both Alzheimer's Disease and Parkinson's Disease, and can often be wrongly diagnosed as Alzheimer's.
- People with DLB frequently experience sleep disturbances that may begin years before they are diagnosed, and visual hallucinations are very common.
- Problems with movement, similar to those experienced by people with Parkinson's Disease, affect around two-thirds of people by the time they are diagnosed with DLB, making the person more at risk of falls. For more information, please see our Module on 'Reducing the Risk of Falls' in Theme 3 Health and Wellbeing.



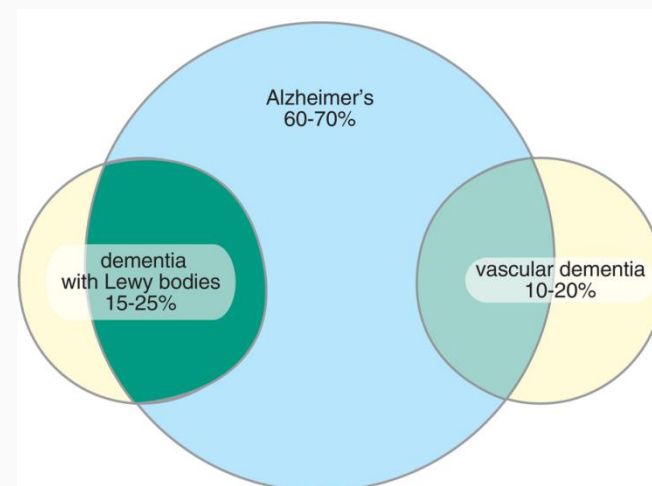
## Common Types of Dementia:

### Frontotemporal Dementia

- Frontotemporal Dementia is a less common type of dementia. It is sometimes called Picks Disease or Frontal Lobe Dementia.
- In this type of dementia, the frontal lobes (behind the forehead) and/or the temporal lobes (on either side of the brain) are affected.
- Nerve cells in these lobes die and the pathways that connect the lobes change. Some of the chemical messengers that send signals between nerve cells are also lost. As more nerve cells die, so the brain tissue in the frontal and temporal lobes shrinks.
- People with Frontotemporal Dementia experience changes in personality, behaviour and language – memory is less affected.
- It is a significant cause of dementia in people under 65 years and is often diagnosed between 45 and 65 years of age.

## Can you only have one type of dementia?

- No. It is possible to have what is known as ***‘mixed dementia’***.
- Around 10% of people are diagnosed with mixed dementia, which is when a person is experiencing more than one type of dementia at the same time, most commonly Alzheimer’s Disease and vascular dementia; although for some people mixed dementia may involve Alzheimer’s Disease and dementia with Lewy Bodies.
- When a person has mixed dementia, it is sometimes said that one half of their mixed dementia is more prominent than another – for example, this could mean that the person’s Alzheimer’s Disease is more prevalent than the person’s Vascular Dementia because more plaques and tangles have been seen than blockages from blood clots.





## If you have some dementia-like symptoms, do you definitely have dementia?

- Not necessarily. Dementia symptoms should be investigated by a doctor who specialises in diagnosing dementia. For more information, please see our Module on 'Timely Diagnosis' in Theme 5 The Dementia Pathway.
- One outcome of these investigations could be a diagnosis of '**Mild Cognitive Impairment (MCI)**', which is not dementia and may never lead to dementia.
- As the name suggests, the person may be experiencing mild deterioration in their cognition (the mental action or process of acquiring knowledge and understanding through thought, experience, and the senses), but this isn't widespread and isn't causing significant problems with the person's day-to-day life.
- Often a person with MCI will be kept under regular review in case their symptoms change.

## What about younger people?

***“Dementia is an uninvited visitor to my world, an unwelcome early 50th birthday present, one where the old me seems to be rapidly moving away to a new me.”***

*- Kate Swaffer, a lady living with dementia in Australia*

- People with dementia whose symptoms started before they were 65 are described as having ‘young-onset’ dementia.
- There are estimated to be at least 42,000 people under 65 years of age with dementia in the UK.
- The symptoms of dementia may be similar regardless of a person's age, but younger people often have different needs (for example they may still be working when they are diagnosed) and therefore require age-appropriate support.
- Dementia in a younger person can progress more rapidly, although this may be partly down to our perceptions – if the person has found it more difficult to get a timely diagnosis due to their age, their dementia may have significantly progressed by the time they are eventually diagnosed with dementia. This can be a particular challenge for people with a learning disability who develop dementia.



## What is a learning Disability?



**Valuing People Now:  
a new three-year strategy  
for people with learning  
disabilities**

'Making it happen for everyone'



The Department of Health '**Valuing People: A new strategy for Learning Disability for the 21<sup>st</sup> Century**' White Paper, published in 2001, describes a learning disability as including:

*“A significantly reduced ability to understand new or complex information, to learn new skills, with a reduced ability to cope independently which started before adulthood, with a lasting effect on development.”*

**The White Paper goes on to say:**

*“Many people with learning disabilities also have physical and/or sensory impairments”*

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/250877/5086.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf)

## Some facts about Learning Disability

- Around 1.5 million people in the UK have a learning disability.
- It is thought that 350,000 people have severe learning disabilities. This figure is still increasing  
<http://www.nhs.uk/livewell/childrenwithalearningdisability/pages/whatislearningdisability.aspx>
- When a child is born, a diagnosis of a learning disability can be detected straight away if the child has a condition like Down's Syndrome which can be more visible. Other learning disabilities, or conditions like autism, can take much longer to diagnose.



**FACT**



## Ageing with a Learning Disability

- There have been significant improvements in the life expectancy of people with a learning disability over the years. See if you can match up the ages of life expectancy to the years.
- Thanks to advances in modern medicine and improved care and support, the life expectancy of a person with Down's Syndrome has dramatically improved – on average a person with Down's Syndrome will live into their 60s or 70s.
- By 2020 it is believed that the number of people with a learning disability over the age of 65 years old will have doubled. However, as the learning disability population ages, so more people with a learning disability develop dementia.
- If a person with a learning disability develops dementia, it is often at a younger age than a person without a learning disability, and the person will face different and additional challenges to people who do not have a learning disability.

## Risk Factors for Dementia

- Dementia is not a normal part of getting older, but one of the risks of developing dementia is ageing. We know that people with a learning disability, particularly those with Down's Syndrome, are at increased risk of developing dementia, in addition to the known risk factors of getting older.
- People with a learning disability are also more likely to have additional health and social factors that are known to increase the risk of developing dementia. For example, people with a learning disability are more likely to have existing physical health conditions, be overweight and eat unhealthily, do less physical exercise, have a limited social circle and more likely to be lonely, and are less likely to participate in games and activities that keep their brain active.





## Living with a Learning Disability and Dementia

- It is difficult to have an accurate picture of the numbers of people with a learning disability and dementia. This is mostly due to the difficulties with diagnosing dementia, but also the many different causes of learning disability. For more information, please see our Module on 'Timely Diagnosis' in Theme 5 The Dementia Pathway.
- Most studies tend to group people with a learning disability without Down's Syndrome together – this is a large group of people with many different causes of learning disability. Little is known about how dementia affects people with specific forms of learning disability and more research is needed. Genetic factors may be involved, or a particular type of brain damage associated with a learning disability could be a cause.
- The other group studied is people with a learning disability with Down's Syndrome. More is known about this specific cause of learning disability and the links to dementia.



## **Dementia and Learning Disability - Facts and Figures**

### **People with a learning disability (without Down's Syndrome):**

- 50 years and older - 12% will have dementia
- 65 years and older - 20% will have dementia (in people without a learning disability the figure is 1%)
- Figures from one study (Prasher 1995) suggest that more than half of those living with a learning disability will develop dementia once they pass the age of 60.

### **People with Down's Syndrome:**

- People with Down's Syndrome are more likely to have young-onset dementia as they are more at risk of developing dementia from their mid-30's onwards
- Between 40 years and 49 years of age, about 10 – 25% will have dementia
- Over 50 years of age the number of people diagnosed with dementia increases to 50%
- Over 60 years of age, about 70% will have dementia.



## People with Down's Syndrome and Alzheimer's Disease

- Studies have also shown that by the age of about 40, almost all people with Down's Syndrome develop changes in the brain associated with Alzheimer's Disease. However, not all go on to develop clinical symptoms of dementia.
- The reason for this increased risk has not been fully identified. It is thought to be linked to the extra copy of chromosome 21 which most people with Down's Syndrome have. This chromosome carries the amyloid gene thought to play a role in Alzheimer's Disease.

Defeat dementia in Down's Syndrome <http://www.psychiatry.cam.ac.uk/ciddrg/research/dementia-in-downs-syndrome-dids/>



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