



Wellbeing for Life Signs and Symptoms of Dementia



Learning Outcomes

- To be aware of the signs and symptoms of dementia.
- To understand how dementia may manifest itself in a person with a learning disability or a person with profound or multiple learning disabilities.
- To be aware of other health conditions with similar symptoms to dementia.
- To understand what best practice is for spotting signs and symptoms, including baseline assessments for people with Down's Syndrome.



How Dementia ‘Begins’

Dementia causes damage to the brain, which over time means that the person’s brain starts to work less efficiently and cannot function in the way it has in the past.

Early symptoms of dementia are often mild, meaning that the person may not notice changes and family and friends might not recognise these changes either. As symptoms progress they will get worse, although this is often a slow process (but can be quicker for a person with a Learning Disability). As symptoms become more severe, they will have a greater impact on the person’s day to day life and everyday activities.

Sometimes the changes in a person with a learning disability are attributed to their “learning disability” and not seen as a potential health condition. This is known as diagnostic overshadowing. For more information, please see our Module on ‘Timely Diagnosis’ in Theme 5 The Dementia Pathway.

It is important to remember that each person will experience dementia in a way that is unique and personal to them. This module will give you a sense of general signs and symptoms, but you should always be aware of any changes in the person that aren’t listed and speak to the person’s GP if you have concerns.



Is Dementia all about Memory Loss?

Memory loss is when a person loses the ability to remember information and events that they would normally be able to recall. It is normal to become a bit forgetful as you get older – dementia-related memory loss is when the person's deteriorating memory is regularly affecting their daily life. This type of memory loss usually manifests itself with the person being unable to remember recent events but still recalling past events with ease.

Many people believe that dementia is all about memory loss, but that is a common misconception.

While memory loss may be a significant symptom in one person's dementia, it could be much less prominent in another person's dementia. For example, memory loss is widely associated with Alzheimer's disease (which is the type of dementia closely linked to Down's Syndrome), but is far less common in Frontotemporal dementia, where other symptoms like changes in personality and difficulties with language are much more common.

It is therefore important to be mindful of the many different symptoms that could indicate a person is developing dementia.



Common Dementia Symptoms

Dementia symptoms will vary from person to person. As well as memory loss, other common examples include:

- **Difficulty performing familiar tasks** - the person may struggle to make themselves a drink or a sandwich, do their washing or make their bed.
- **Recognition** – the person may not recognise a familiar face or be able to name someone they know well.
- **Problems with communication** – the person may find it difficult to follow conversations, or communicate in their usual way(s).
- **Repetition** – the person may ask the same questions repeatedly. For more information, please see our Module on 'Changed Behaviours' in Theme 5 The Dementia Pathway as well as the Changed Behaviour booklet 'Repetition'.
- **Disorientation to time and place** – the person may arrive at work at the wrong time, not be able to find their way around their home, or get lost when out and about.

Common Dementia Symptoms



- **Compulsion** – the person may feel a need to constantly walk around, even when this is unsafe. For more information, please see our Module on ‘Changed Behaviours’ in Theme 5 The Dementia Pathway
- **Concentration** – the person may no longer be able to focus on an activity or a TV programme.
- **Poor judgement** – the person may walk out into a busy road or touch something on the cooker that they would have previously known was too hot to handle.
- **Problems keeping track of things** – the person may miss appointments.
- **Misplacing things** – the person may begin regularly losing their glasses or other personal items.



Common Dementia Symptoms

- **Changes in mood/behaviour** – the person may be unusually anxious or upset, irritable or aggressive. For more information, please see our Module on ‘Changed Behaviours’ in Theme 5 The Dementia Pathway
- **Changes in personality** – the person may become less sociable.
- **Changes in perception** – the person may become paranoid, delusional or have hallucinations. For more information, please see our Module on ‘Changed Behaviours’ in Theme 5 The Dementia Pathway
- **Loss of initiative** – the person may not want to follow hobbies or interests they’ve previously enjoyed.
- **Learning something new** – the person may be reluctant to operate a new phone or appliance.
- **Visual perception** – the person may hesitate at doorways, pavement curbs or when floor coverings change.



Common Dementia Symptoms

- **Onset of epilepsy** (particularly in people with Down's Syndrome) or changes in the person's existing epilepsy - 80% of people with Down's Syndrome and dementia have epilepsy For more information, please see our Module on 'Epilepsy in Later Life' in Theme 3 Health and Wellbeing
- **Physical changes** – the person may be losing weight, having difficulty swallowing food, have changes in their continence, mobility problems or increased falls/accidents. For more information, please see our Modules on: 'Eating and Drinking' in Theme 1 Fit for the Future, 'Safer Swallowing' in Theme 3 Health and Wellbeing, and 'Reducing the Risk of Falls' in Theme 3 Health and Wellbeing

Remember: It may be that a person you support commonly experiences one of these symptoms, and if that is normal for them then that would not be considered a sign of potential dementia development.



Dementia Symptoms when a Person has a Learning Disability

A person with a learning disability will already have some differences in thinking, language and behaviours, and may already require support in their day to day life.

Indeed, if the person is currently receiving good support that is responsive to their changing needs, some of the early signs that are associated with dementia could unwittingly be masked by that good support.

When thinking about the early signs of dementia, you firstly need to be aware of the person's existing personality, current communication skills and the amount of support they already need. Think about how these elements have changed – does the person need increasing levels of support? Have their communication skills continually decreased? Do personality changes appear to be permanent and/or deteriorating further?

Early signs of dementia are often seen as a change of behaviour in people with a learning disability. Remember: You are looking for a deterioration in their skills and abilities **AND** a change in their personality.



Dementia Symptoms when a Person has a Profound or Multiple Learning Disability

For people with a profound or multiple learning disability it can be a lot harder to notice changes in their skills and abilities. This is due to the profound level of their learning disability which means they rely on support from others for all everyday activities.

Potential signs of dementia in a person with a profound or multiple learning disability include:

- Changes in communication – not using signs or their normal method to communicate
- Lack of eye contact
- No longer smiling at a familiar person
- Loss of interest in food
- Not appearing to recognise familiar objects
- Signs of distress - shouting out or crying
- Loss of interest in previously enjoyable activities
- Being fearful of known situations e.g. having a bath or going outside
- No longer responding to their name

These are just examples of behaviours that you may see. You are observing for any change in how the person has been previously.



Symptoms Don't Always mean the Person has Dementia

Other Health Conditions

There are numerous conditions with similar symptoms and behaviours to the early signs of dementia, and could therefore be mistaken for dementia. These include:

- **Physical Health:** Lack of Vitamin B, Urinary Tract Infection (UTI) or other infections, Under Active Thyroid, Constipation, Diabetes, Dehydration, Poor diet, Stroke, Parkinson's Disease, unrecognised and untreated pain For more information, please see our Module on 'Pain and Distress' in Theme 3 Health and Wellbeing
- **Mental health:** Depression, Delirium, Anxiety, Deterioration in an existing mental health conditions
- **Sensory:** Visual problems (for example cataracts), Hearing problems (for example a build-up of wax or age-related hearing loss)



Symptoms Don't Always mean the Person has Dementia

Life Events

Traumatic life events could also produce symptoms that mimic some of the signs of dementia, these include:

- Life events: loss of a family member, a change in staff, a house move, a new learning centre.
- Abuse: any form of physical, emotional, sexual or other abuse that is current or recent.
- A poor environment may also lead to some of the behaviours associated with the early signs of dementia.
- Limited social interaction, reduced social activities, isolation, lack of opportunities to do a variety of things or try new activities.

Symptoms Don't Always mean the Person has Dementia

Symptoms could include:

- Disorientation
- Forgetfulness
- Slow responses
- Tiredness
- Trouble with balance



Remember: It is important to get the right diagnosis for the person. Treatments are available for many of the conditions listed above that can greatly improve or cure symptoms, and therapies may be available to help the person cope with the aftermath of traumatic life events.



Best Practice for Spotting Signs and Symptoms

Because spotting the signs and symptoms of dementia can be difficult, it's important to follow best practice which includes:

- **Side-by-side:** Make sure you involve the person with every step – remember it's all about them.
- **Reflect:** Reflection within the workplace and home is something that you should do on a daily basis as this gives you a chance to think about the person and pick up changes in what they are doing. For example: if the person is regularly requiring more support when making a drink or a sandwich.
- **Speak up:** If you have any concerns share them with your line manager, colleagues and/or at a team meeting. You may have vital information that no one else has picked up on yet.
- Speak to the person's GP if you have concerns.

Best Practice for Spotting Signs and Symptoms

- Keep accurate and written Health Records: Keeping records will help get a timely diagnosis as there will be evidence of any changes.

Mobility/Falls										
Date		1	2	3	4	5	6	7	8	9
Refusal or unable to mobilise	AM									
	PM									
	N									
Changes in mobility	AM									
	PM									
	N									
Reoccurring falls	AM									
	PM									
	N									
Falls	AM									
	PM									
	N									
Normal activity	AM									
	PM									
	N									

Records can also help with joined-up thinking - if you are spending a lot of time with the person you may not notice small and subtle changes, but accurate, non-bias recording can help to build up a consistent picture of what is happening day-by-day. For more information, please see our Module on 'Timely Diagnosis' in Theme 5 The Dementia Pathway.





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