

Dementia Awareness – Handout

This handout is designed to be used as a brief aid to remind you of the contents of your dementia awareness session.

Definition of dementia

The term dementia is used to describe a collection of symptoms when the brain is affected by specific diseases and conditions. These symptoms include:

- A decline in memory, reasoning and communication skills
- A gradual loss of skills needed to carry out daily activities

Dementia is a progressive condition and currently there is no cure.

Common types and causes of dementia

Alzheimer's disease

This is the most common cause of dementia. It occurs when amyloid proteins called plaques and tangles develop in the brain and cause the brain cells to die.

People often experience a gradual progression with Alzheimer's disease and there are three main stages:

Early stage – Alzheimer's disease usually begins gradually with very minor changes in the person's ability or behaviour. This is often just attributed to just part of getting older. It is only usually on reflection that we identify that this could have been the beginning of the disease.

Middle Stage – As the disease progresses the changes in the person become more obvious. The person will need more support to manage their day to day needs. Relatives of informal carers of the person may require more support too.

Late Stage – At this stage the individual will need more help and support. They will eventually become more and more dependent on others and require nursing care.

Vascular dementia

Our brain cells need a good supply of blood. Blood is delivered through a network of blood vessels called the vascular system. If the vascular system within the brain becomes damaged and blood cannot reach the brain cells, the cells will eventually die. This can lead to the onset of vascular dementia.

A number of conditions can cause or increase damage to the vascular system. These include high blood pressure, heart problems, high cholesterol and diabetes. This means it is important that these conditions are identified and treated at the earliest opportunity. Effective treatment of these conditions may significantly delay or stop the development of vascular dementia.

The onset of vascular dementia can often be more sudden than the onset of Alzheimer's disease (which progresses gradually).

Fronto-temporal dementia

Fronto-temporal dementia is caused when the nerve cells in the frontal and/or temporal lobes of the brain die. This causes loss of some important chemical messengers within the brain. Fronto-temporal dementia is one of the less common forms of dementia, however it is a significant cause of dementia in younger people (under 65). Fronto-temporal dementia is estimated to be the third most common cause for this age group.

Symptoms of Fronto-temporal dementia include:

- lose their inhibitions – behave in socially inappropriate ways and act in an impulsive or rash manner; this could include making tactless or inappropriate comments about someone's appearance
- lose interest in people and things – lose motivation but (unlike someone with depression) they are not sad
- lose sympathy or empathy – become less responsive to the needs of others and show less social interest or personal warmth; this can make the person appear selfish and unfeeling
- show repetitive, compulsive or ritualised behaviours – this can include repeated use of phrases or gestures, hoarding and obsessions with timekeeping
- crave sweet or fatty foods, lose table etiquette, or binge on 'junk' foods.

It is common for a person with fronto-temporal dementia to struggle with planning and organising or making decisions. These difficulties may first appear at work or with managing finances.

Dementia with Lewy bodies

Caused by tiny spherical protein deposits that develop inside the nerve cells in the brain. Their presence in the brain disrupts the brain's normal functioning, interrupting the action of important chemical messengers, including acetylcholine and dopamine.

Lewy bodies are also found in the brains of people with Parkinson's disease, a progressive neurological disease that affects movement. Many people who are initially diagnosed with Parkinson's disease later go on to develop a dementia that closely resembles dementia with Lewy Bodies.

There are also symptoms that are particular to dementia with Lewy bodies. In addition to the symptoms above, a person with DLB may:

- experience detailed and convincing visual hallucinations (seeing things that are not there), often of people or animals
- find that their abilities fluctuate daily, or even hourly
- fall asleep very easily by day, and have restless, disturbed nights with confusion, nightmares and hallucinations
- faint, fall, or have 'funny turns'.

Common signs and symptoms of Dementia

- Forgetfulness
- Difficulty with familiar activities
- Language difficulties
- Loss of motivation and initiative
- Problems with spatial orientation
- Mood swings and changes in behaviour
- Changes in personality
- Inability to reason
- Becoming withdrawn
- Mislaying objects in odd places (such as wallet in the fridge)

Importance of early diagnosis

Only 44% of people in the UK that have dementia have a diagnosis. There are approximately 820,000 people in the UK with dementia. It is expected that by 2021 there will be over a million people in the UK with dementia. If you notice a person is having symptoms of dementia it is important to talk to their GP as soon as possible so that we can:

- Rule out other conditions that may have similar symptoms to dementia that may be treatable
- Rule out other possible causes of confusion
- Get access to advice, support and information from local agencies and support groups
- Allows the person with dementia to make plans and arrangements for the future
- Identifies the correct type of medication to help with the particular type of dementia.

Environmental challenges for people with dementia

- Lighting – People with dementia may experience visual problems so ensure that enough lighting is provided for them. Use natural daylight where possible. Use extra lighting where specific tasks are being carried out.
- Patterns – Very early on the dementia people often lose the ability to see things in 3D. This can make patterns and shadows of patterns very confusing to someone with dementia. Try to avoid net curtains (as they create patterned shadows on the walls and floors). Try not to have patterned carpets and walls too. Try to use plain, bold and contrast as this will make navigating around the home easier. Use of red coloured doors for specific rooms such as the bathroom and pictured labels can help a person with dementia identify which room they need to go to.
- Mirrors – Be aware that a person with dementia may have regressed to an earlier time in their life and no longer see themselves as the person they are now. This can be frightening for them when they see their reflection in the mirror. If someone you support seems upset when they look in the mirror try removing them or covering them up with a towel or sheet.

- Noise – People with dementia can become very distressed when their environment is very noisy. Sudden noises like plates and cutlery clattering can make them jump and increase anxiety. People with dementia also find it difficult to filter out relevant and irrelevant noise so background noise such as talking, trolleys and televisions can be very alarming for them. Try and keep noise at a minimum, especially at night when people are trying to sleep as noise levels are often a big cause of people being unable to sleep at night.
- Clutter – Try to reduce clutter as much as possible to make navigation around the home easier and safer.

Communication

We tend to think of communication as talking, but in fact it consists of much more than that. A large proportion of our communication is non-verbal, which takes place through gestures, facial expressions and touch. Non-verbal communication is particularly important when a person with dementia is losing their language skills. This may also mean that a person with dementia can behave in ways that those caring for them find difficult and this may be because they are trying to communicate something.

Tips for communicating effectively:

- When possible, if you are rushing or feeling stressed, try to take a moment to calm yourself.
- Make sure you have the person's full attention.
- Make sure that the person can see you clearly.
- Try to make eye contact. This will help the person focus on you.
- Minimise competing noises, such as the radio, TV, or other people's conversations
- Positive touch can aid communication and also help reassure the person you are supporting.
- Speak clearly and calmly.
- Speak at a slightly slower pace, allowing time between sentences for the person to process the information and to respond. This might seem like

an uncomfortable pause to you but it is important for supporting the person to communicate.

- Avoid speaking sharply or raising your voice, as this may distress the person.
- Use short, simple sentences.
- Don't talk about people with dementia as if they are not there or talk to them as you would to a young child – show respect and patience..
- Try to include the person in conversations with others. You may find this easier if you adapt the way you say things slightly. This can help relieve feelings of exclusion and isolation.

Final tips

Remember that every person with dementia is an individual with their own personality, history, family, likes and dislikes. It is important that you remember to see the **person first** and the dementia second. Good person centred care planning can help staff get to know about the person with dementia so that they can be cared for in a way that respects individuality and difference.

Try to enable people with dementia rather than assume that a person is unable to do almost anything for themselves. Focus on empowerment and positive experience as this can help maintain a person's self esteem and well being. Good risk management can help achieve this by balancing the safety and welfare of a person against living with a degree of risk and their wellbeing.