

Making a difference together: Understanding dementia



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About this PowerPoint

- This PowerPoint contains information about dementia, learning disabilities and dementia, and some of the changes which occur when dementia is present, and how to respond to these appropriately.
- The slides are purposely detailed to include as much information as possible. You can include as much or as little as required, depending on the purpose of the PowerPoint.
- The slides are generic to allow them to be altered to fit your requirements.

Aims

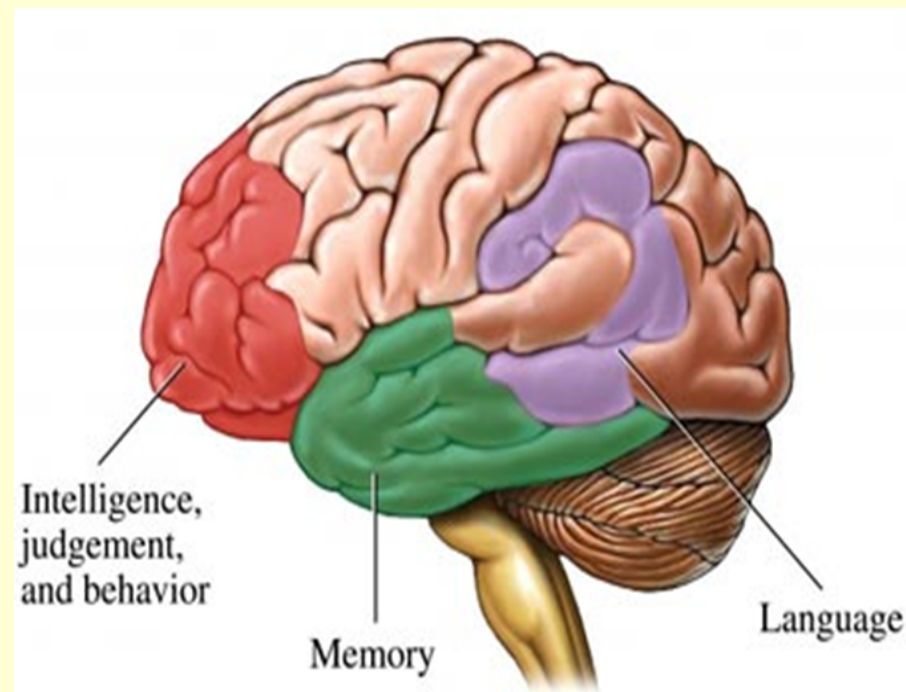
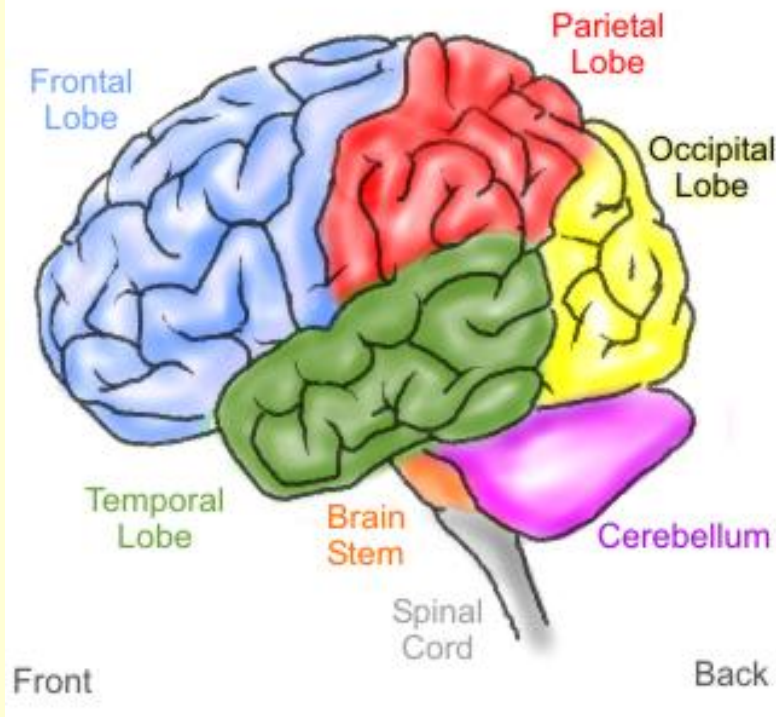
- To encourage the importance of thinking from the perspective of the person with dementia
- To provide knowledge of how dementia may be experienced by a person with a learning disability.
- To highlight issues relating to the support of people with a learning disability and dementia

What is dementia?

- Umbrella term
- Used to describe a group of symptoms, and consists of a wide range of diseases and disorders of the brain.
- With differing fundamental causes, they result in progressively deteriorating intellectual functioning, including a decline in cognitive performance and memory (Kerr, 2007; Prasher, 2005; Janicki & Dalton, 1999)
- Different types such as Alzheimer's disease, Lewy body, frontal lobe
- Each type of dementia affects a person in a different way
- **understanding the person's sense of reality is essential**

The Brain Structure

Regions of the Human Brain



Images used with permission from
Watchman, Kerr & Wilkinson (2010)

The brain is a complex structure; different regions of the brain control different functions. It is important to understand which part of the brain is affected by dementia, as this will indicate which clinical symptoms develop. For instance, Alzheimer's disease initially affects the temporal lobe, which is where our memory is located (Watchman, Kerr & Wilkinson, 2010)

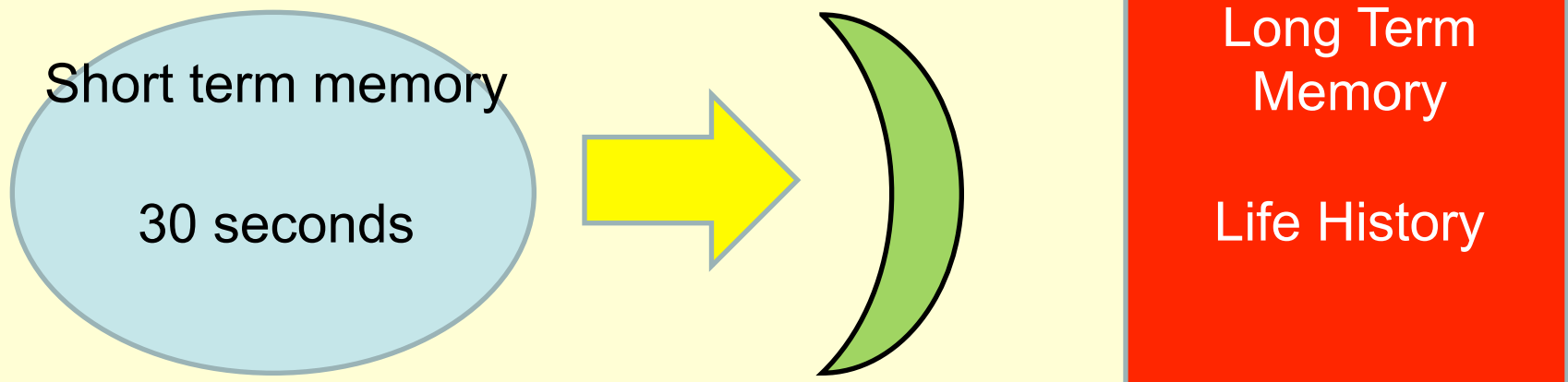
Understanding Dementia

The Two Laws of Dementia (Buijssen, 2005)

1) The law of disturbed encoding

No longer able to successfully transfer information from short term memory and store it long term memory.

Main consequence: unable to form new memories for the things they experience or for things they are told.



Understanding Dementia (Continued...) (Buijssen, 2005)

2) Law of role back

- Long term memory contains all memories that have been acquired from most recent working back towards childhood memories.
- At first long term memories will remain intact, however as dementia progresses, long term memories will also begin to deteriorate and eventually disappear altogether.
- Deterioration begins with the most recent memories and progresses until only memories of early childhood remain, hence memory can be said to be rolling back

Learning Disabilities and Dementia: Risk Factor

Risk in people with Down's syndrome:

- 1 in 50 aged 30 – 39
- 1 in 10 aged 40 – 49
- 1 in 3 aged 50 – 59
- More than half of those who live to 60 or over

(Alzheimer's Society, 2013)

Risk in people with other types of LD:

- 1 in 10 aged 50 – 65
- 1 in 7 aged 65 – 75
- 1 in 4 aged 75 – 85
- Nearly three-quarters of those aged 85 or over

Down Syndrome and Dementia

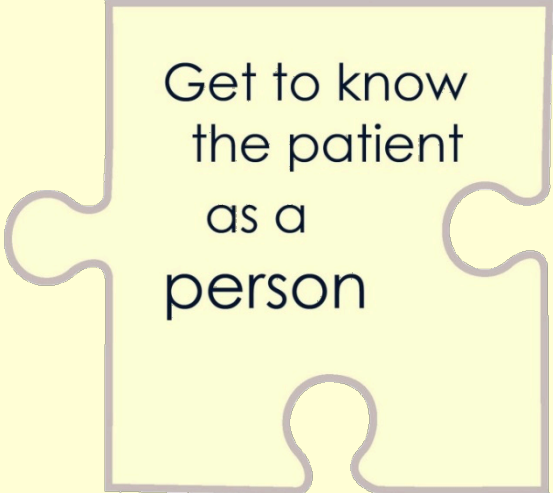
- People with Down syndrome (DS) present a special case in dementia.
- They are **significantly** more likely to present with a form of dementia, Alzheimer's disease, than the general population and people with other forms of learning disability (**Cooper & Holland, 2007**). Other forms of dementia may also present.
- The majority of people with DS develop the neuropathological features of Alzheimer's disease, neurofibrillary tangles and senile plaques, prior to the age of 40 (**Kerr, 2007**).
- Though few present with the clinical features of dementia until their 50s (**Cooper & Holland, 2007; Kerr, 2007**). A minority never present with symptoms of AD even with the presence of neuropathological features.
- Dementia presents at a **younger age** in people with DS.
- Dementia may also present **atypical**; with changes in **behaviour** preceding memory loss.

Initial changes associated with dementia

- Short-term memory loss
 - Apathy and inactivity
 - A loss of interest in activities and hobbies which were previously enjoyed
 - Deterioration/ loss of daily living skills
 - Social withdrawal
 - Reduced communication/ language difficulties
 - A sense of disorientation and confusion
 - Difficulty in depth perception, this may result in difficulties with steps
 - An increase in wandering for no reason
 - Not being aware of having forgotten something
- (Kerr, 2007; Dodd, Turk, & Christmas, 2009; Watchman, Kerr & Wilkinson, 2010)

What should I do next?

- If you believe that someone may have dementia, it is vital that a referral is made as soon as possible.
- A lack of information on this process may make this difficult and cause delays. However, it is important the referral procedure is identified and initiated.
- It is important to have the input from the individual suspected of having dementia, family members and carers in order to build up an accurate picture and supporting evidence for any diagnosis.



Get to know
the patient
as a
person

Difficulties of a Diagnosis

Diagnosis

- Diagnosis is difficult- diagnostic overshadowing
- Typical tests may not suitable and assessment tools are limited
- Baseline assessments are needed but not always given
- Not everyone is given a diagnosis- which may have implications

(Dodd et al., 2009b; Watchman et al., 2010)

Misdiagnosis

- Sensory impairments
e.g. change in eyesight or hearing
- Physical/ Social
- Undiagnosed pain
- Emotional or grief
- Effects of medication
- Mental health problems



Dementia Related Changes

- As dementia progresses, further changes begin to develop.
- Knowing how to respond to these changes is important for the care of people with dementia.
- The following slides will detail practical advice for some of the changes which occur when dementia is present; these include:
 - Behaviour
 - Communication
 - Pain

Changes in Behaviour

Behaviour changes can occur in people for various reasons and may signal a need to assess the situation .

Reasons for changed behaviour

- Environment- noise level and the people
- Confusion
- Communication
- Pain
- Isolation
- Physical or mental health problems
- Past experiences and memories
- Medication

What to do

- Communicate in a calm manner
- Find out possible triggers
- Take their perspective and try to understand what they want to communicate.
- Make adjustments to their needs

Avoid

- Making the person feel threatened.
- Act/ communicate in an aggressive manner
- Do not surprise or confront the person

Changes in Communication

As dementia progresses the communication ability of the individual will begin to change.

- Difficulty in finding words or forgetting recently learnt words
- People may repeat words
- Increase in changed behaviour: shouting, becoming flustered, upset
- People may start to lose track of a conversation
- People may become withdrawn as they struggle to communicate

(Kerr, 2007; Watchman et al., 2010)

Changes in Communication

Facilitating communication

- Focus on the individual, only speaking to them at that time, and smiling when speaking
- Make eye contact ensuring you are at their eye level
- Speak to them in a friendly tone
- Speak in the same language as the person with dementia
- Think of the environment, try to reduce background distractions and noise.
- Limit the amount of things spoken about in each sentence; keep sentences short and basic

(Watchman, et al., 2010).

Recognising Pain

- People with a learning disability and dementia experience pain. However, as dementia progresses, people may struggle to tell us of their pain and where it is.
- As intellectual functioning deteriorates, they may lack an understanding of how the body functions.
- It becomes difficult to distinguish between left and right, so identifying the wrong body part (Dodd et al., 2009a; Watchman, et al. 2010).

Changing our understanding

- Don't make assumptions due to the person's learning disability or dementia; these do not mean that they have higher pain thresholds.
- Think about the environment, for instance uncomfortable furniture.
- Try to foresee when pain relief is needed and see if the outcome brings relief (Dodd et al., 2009a; Watchman et al, 2010).

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