

The Progression of Dementia in People with Down's Syndrome

Alzheimer's disease in people with Down's syndrome can be thought about in three stages; early stage, middle stage and late stage. The person's cognitive and functional ability will deteriorate across these three stages and their level of dependence will increase.

It is important to remember the person may appear to move into the next stage, often because of an illness such as pneumonia or a chest infection or urinary tract infection (UTI), and may return to the previous stage once the illness has been treated.

These are the commonly found features of each stage of dementia:

Early Stage

- Subtle changes in behaviour and mood
- Performance at day placements deteriorate
- Problems with memory, particularly for recent events
- Ability to learn new information is affected
- Language and word finding problems
- Decline in social, community and daily living skills
- Disorientation
- Difficulties with steps, stairs and kerbs due to depth perception problems

Middle Stage

- Memory losses become more pronounced and the individual may forget personal information or the names of familiar people
- Language problems become more evident
- Confusion and disorientation around time and place and they may have problems finding their way around familiar environments
- Difficulties with and then loss of self-care skills
- More severe changes in personality and social behaviour, e.g. mood changes, inactivity or apathy, behavioural issues such as wandering, sleep problems, agitation, hallucinations and delusions
- Problems with eating and drinking
- Disturbed sleep patterns

Late Stage

- Loss of eating/drinking skills and problems of choking
- Problems with walking and balance, individuals become chair or bed bound
- Problems with recognising very familiar people
- Will require 24hr care
- Will become less active and less interested in favoured activities
- Greater risk of infections, particularly pneumonia.

Remember that the dementia is constantly progressing. People will deteriorate at different rates and will experience the disease in different ways. Some people will deteriorate steadily, others may be faster or slower and this can change at any time. People will often not be clearly in one stage and show signs of more than one stage.

Often people offering care and support on a daily basis to a person with dementia adapt to the changes in the person and are perhaps not as aware of how they have changed over time. It is often when the person with dementia is assisted to have a holiday and is out of their familiar environment that staff and carers realise the extent of the issues.