

## KARE's Dementia Guidelines

These guidelines were developed to support staff to have a better understanding of dementia, to understand some of the indicators for dementia and how to best support an individual and their families following a diagnosis

### What is Dementia?

Dementia is a syndrome which results in progressive cognitive decline. It is associated with loss of some functional abilities and in many cases, behavioural and psychological symptoms. There may be memory loss, usually related to short term memory, communication difficulties, changes in personality or mood and problems with spatial awareness.

Despite the strong association between dementia and old age, it is not solely a disease of old age. There are significant numbers within the overall dementia population with early onset dementia.

People with Down's syndrome face an increased risk in this regard. It is an Alzheimer's type dementia that particularly affects people with Down's syndrome but they can develop other dementias separately or alongside the Alzheimer's disease.

A person's long term memory contains all of the memories that have been acquired by the person throughout their life, starting with their most recent memories and working back toward their childhood memories. A person who develops Alzheimer's Dementia in their 50's will be unable to form any new memories after this time. At first their long term memories will remain intact. However, as their dementia progresses their long term memories will also begin to deteriorate and eventually disappear altogether. This deterioration of memory will begin with the person's most recent memories and will progress until only memories of early childhood remain. Hence, their memory can be said to be "rolling back". One way of thinking about this is that the person's memories are books on a shelf that are removed one by one and never put back.

*Dementia is a terminal condition.*

## Early Signs of Dementia

The following signs may be indicative of early signs of dementia but it is important to remember that the concerns you have may be due to a number of other causes, or, may resolve on their own.

The early signs can be very subtle, may not happen every day and can be easily missed.

### Early signs include changes in:

- Personality
- Mood
- Behaviour
- Short term memory
- Ability to complete activities of daily living
- Ability to communicate
- Mobility
- Depth perception e.g. bumping into things, not being able to judge distance.
- Interest in things
- Ability to learn new things

Many people with Down's syndrome may already have some of these behaviours and difficulties. It is when there are **changes** in the person's normal behaviour that you should be concerned about the possibility of dementia.

## Differential Diagnosis

### **What is differential diagnosis and why is it important?**

Obtaining a correct diagnosis is extremely important in terms of ensuring that the person receives the correct treatment or intervention. If you are concerned you need to out rule some of the following factors. For example

- Stress
- Thyroid
- Depression
- Sensory changes – changes in hearing, vision
- Pain

### **If you have concerns regarding a person and a possible diagnosis of dementia what should you do?**

- Share your concerns with other staff and family members – do others have similar concerns.
- Record specific concerns on contact sheets/in a diary for the person with dates and details of examples of concern e.g. couldn't remember familiar family member's name. It is important to have a written record of concerns.
- Talk to the Nurse available in the house or local service to outrule other possible causes.
- Refer to GP for medical review – bloods, full health check etc.
- Ensure hearing, vision and dental checks up to date.

**If you continue to have concerns complete the “clinical supports referral form” with the information above included:**

- Referral will be typically assigned initially to the Psychology Department who will meet with the staff and family to discuss their concerns and agree an appropriate course of action.
- The Psychologist will complete a baseline assessment, if warranted.
- The Psychologist will link with other members of the Clinical Team and Psychiatry, as necessary.
- A diagnosis of dementia can take considerable time requiring ongoing recording of information by staff and family.

## The Three Stages of Dementia

Alzheimer’s Dementia in people with Down’s syndrome can be thought about in three stages.

The person’s cognitive ability will deteriorate across these three stages and their level of dependence will increase.

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

### Early Stage:

- Subtle changes in behaviour and mood
- Performance on usual tasks deteriorate e.g. difficulties with everyday activities previously independent at.
- 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 and 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, place and many have problems finding their way around familiar environments.
- Difficulties with/loss of self-care skills.
- More severe changes in personal and social behaviour e.g. mood changes, inactivity or apathy, behaviour disturbances such as wandering, sleep problems, agitation, hallucinations and delusions.
- Problems with eating and drinking.
- Disturbed sleep patterns.

## Late Stage:

- Loss of eating/drinking skills.
- Problems with walking and balance, individuals become chair or bed bound.
- Problems with recognising people.
- Often require 24-hour care.
- Will become bedridden and inactive.
- 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, whilst deterioration in others may be faster or slower. This can change at any time. People will often not fall clearly into one stage and may show signs of more than one stage at any given time.

## General strategies on supporting someone with a diagnosis of dementia

When caring for someone with dementia, it is important that you take the time to think carefully about the way you care for the person. The effects of a failing memory on someone with Down's syndrome and dementia can leave the person feeling worried, scared, frustrated and irritable. Due to their failing memory, they may not be able to explain or remember why they are feeling the way they do. The person will require your support and reassurance in order to lessen the distress caused by these changes.

Taking the right approach can mean that the person will be happier, less agitated, less confused and less likely to show difficult behaviours. Adopting the right approach can make a huge difference to the person's quality of life whilst at the same time making your job easier and more rewarding. This philosophy of care should be applied to all aspects of the person's care and it is important to remember these points throughout the different stages of dementia.

### **Look at the person not the diagnosis:**

Remember that the diagnosis doesn't change who the person is, it is important to remember they will still have likes, dislikes and a unique personality. Everyone experiences dementia differently so ensure that your care is adapted to the individual and their specific needs. Help to preserve the individual's sense of self.

### **Don't stress the person:**

The person needs a stress-free environment. Stress makes the impact of the dementia worse for everyone. It will make people behave in a way that challenges. Stress makes people more agitated, confused, unhappy, angry and upset. Familiarity and predictability are essential in creating a stress free environment.

## **Adopt a flexible approach: Go with the flow!**

Take each day as it comes. Remember that the person will experience good days and bad days. If you approach each day with a flexible attitude, you will create a stress free environment both for the individual and for yourself. A good example of this would be in trying to ensure that the person remains involved in household chores for as long as possible. The person may find it difficult to stick to a rota, so it may be easier to let them stick to one chore for the whole week, or just to let them help spontaneously.

## **Promoting failure free activities:**

This will minimise stress and frustration. Keep the person involved in activities that will promote a sense of accomplishment. This will involve engaging the person in tasks they are able to do or helping them to complete the task **without doing it for them**. An example of making a task failure free, would be laying out the person's clothes in the order in which they will put them on, or if they are making a hot drink make sure they have everything they need to finish the task and prompt the person if necessary. It is important that all staff have a consistent approach to all activities.

## **Remove time pressures:**

In order to create a relaxed environment, it is important to remove time pressures from the individual and allow them to complete tasks and daily self-care skills in their own routine but at their own pace. For example, don't set time limits on the person when they are completing tasks such as washing, dressing and eating. Remember that their routine may change as the dementia progresses.

## **Using familiar staff:**

Where possible, familiar faces or voices and the knowledge regular staff have about the person helps to maintain memory and daily living skills. It also helps to ensure that the person's day remains as predictable as possible. Unfamiliar staff are unlikely to know the person's routine or what sort of prompting the person requires and the person is likely to become stressed and agitated. Although KARE endeavour to have familiar staff working with people who have dementia, this is not always possible. All efforts should be made that any staff working the individual is as fully briefed in relation to the individual as possible.

## Useful Resources related to dementia care

### Life story works

<http://www.dementiauk.org/wp-content/uploads/2015/10/Guidance-for-using-Life-Story-Work.pdf>

### General information

<http://www.hse.ie/eng/services/list/4/olderpeople/dementia/resources/>

<http://www.southwestyorkshire.nhs.uk/documents/832.pdf>

<https://www2.health.vic.gov.au/ageing-and-aged-care/dementia-friendly-environments>

### Educating service users re dementia

[http://www.learningdisabilityanddementia.org/uploads/1/1/5/8/11581920/jennys\\_diary\\_non\\_uk\\_ebook.pdf](http://www.learningdisabilityanddementia.org/uploads/1/1/5/8/11581920/jennys_diary_non_uk_ebook.pdf)

### Environment adaptation

[http://www.cpa.ca/docs/File/Publications/FactSheets/PsychologyWorksFactSheet\\_EnvironmentalAdaptationsToDementia.pdf](http://www.cpa.ca/docs/File/Publications/FactSheets/PsychologyWorksFactSheet_EnvironmentalAdaptationsToDementia.pdf)

<https://www2.health.vic.gov.au/ageing-and-aged-care/dementia-friendly-environments/interior-design>

### Nutrition and dementia

<https://www.indi.ie/news/988-new-nutrition-and-dementia-practical-guide-now-available.html>

### Interest and Activities ideas

<http://www.nhsaaa.net/media/131254/iatoolkit.pdf>