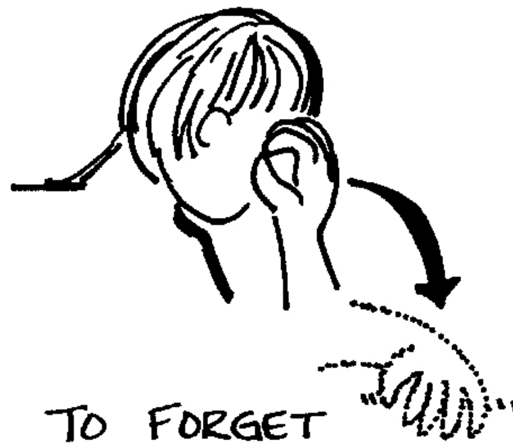
Dementia: What You Need To Know, What You Need To Do.



Guidance and Resources On Dementia For Carers of People With Down's syndrome.

Max Neill 2005

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Introduction.

People with Down's syndrome are more likely than the general population to develop Dementia.

They are also more likely to develop dementia at an earlier age.

This table shows the percentage of people with Down's syndrome who develop dementia at different ages:

Age	Percentage with signs of dementia.
30's	2%
40's	10-15%
50's	33%
60's	50-70%

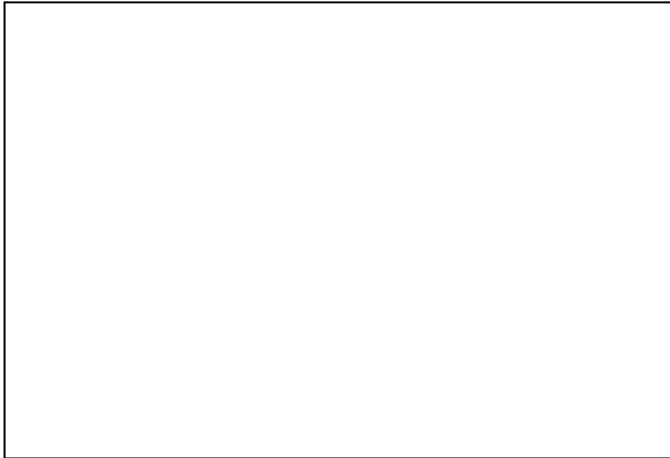
Although there is no cure for dementia, an early diagnosis can mean getting the help a person needs earlier, and have a significant effect on maintaining their quality of life.

It is therefore well worth knowing:

- What dementia is.
- Signs and symptoms of dementia.
- Other possible causes of these signs and symptoms.
- How to assess a person's skills.
- What you can do to help someone live with dementia.
- Where to get more information and help.

Be 'Dementia Ready'!

What is Dementia?



Alois Alzheimer: first described Alzheimer’s disease in 1906.

Dementia is characterised by a progressive and usually gradual decline in a person’s ability to learn, to remember, to use practical and social skills, and to process information from their senses.

Dementia also affects a person’s language abilities, emotions and behaviour.

Alzheimer’s disease is caused by changes in the nerve cells of the brain, which interfere with the way these cells communicate with each other, and with the signals they send to the rest of the body.

It is often not diagnosed, especially in people with learning disabilities, partly because the symptoms can be quite subtle and develop slowly, because symptoms can often be wrongly attributed to the learning disability, and because carers can often ‘compensate’ for the person’s cognitive deficits by guiding and prompting them, or by filling gaps in their speech.

Dementia is irreversible, but early detection can mean that it is possible to make plans for the future, adaptations can be made in a person’s environment, and additional care services involved, in order to preserve the person’s quality of life for as long as possible.

Signs And Symptoms Of Dementia.

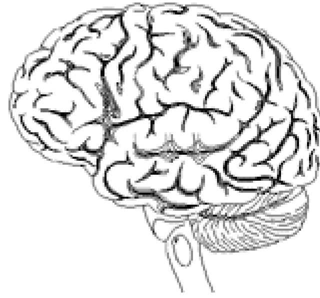
People with Down's syndrome tend to have similar symptoms of dementia to other people with the disease, though the progression of the disease can be more rapid.

Common early symptoms of Alzheimer's disease
• Loss of interest in activities • Short term memory loss • Withdrawal of spontaneous communication • Loss of amenability and sociability • Loss of domestic skills • Increase in wandering • Loss of Road Sense • Problems in unfamiliar places • Epileptic fits • Loss of comprehension • Confusion or disorientation (Marler and Cunningham 1994)

Common symptoms in later stages of Alzheimer's disease
• Loss of personal care skills • Loss of mobility • Episodes of depression • Hallucinations • Delusions • Irrational fears • Screaming • Incontinence • Verbal aggression • Physical Aggression (Marler and Cunningham 1994)

The progression of the disease can be different for different people, and can seem to progress more or less rapidly, or even pause at different times.

Alzheimer’s Disease and the Brain.



Signs and symptoms of dementia may vary according to which part of the brain is affected by the disease.

The following table charts the various functions of different parts of the brain.

Temporal Lobes (left)	Verbal memory, smell, taste, short-term memory.
Temporal Lobes (right)	Visual memory, smell, taste, short-term memory.
Parietal Lobes (left)	Organisation skills, language, making sentences, sequencing (such as getting dressed, making a cup of tea), distinguishing right from left.
Parietal Lobes (right)	Thinking in three dimensions, location in space, length and depth, seeing steps and obstacles.
Frontal Lobes	New Learning, planning and organising, the ‘initiator’: – the part of the brain that gets us going. People with damage to this region may need prompting to start or stop an activity.
Limbic System	Sleep, appetite, emotion.
Cerebellum	Balance and coordination of voluntary movements, like walking, sitting or climbing stairs.
Hypothalamus	Important in memory and learning.

Other possible causes of dementia-like symptoms.

There are a number of other disorders that might cause some of the symptoms of dementia listed earlier in this pack, many of which require early treatment.

It would be wrong to automatically assume that someone has dementia, just because they have Down's Syndrome.

Other possible causes can include:

- Normal age-related cognitive decline.

"While aging brings changes in the quickness and ease of thinking and remembering, the changes do not dramatically differ from prior levels, do not occur rapidly, and should not significantly interfere with daily activities" (Insel and Badger 2001)

- Acute confusion.

Acute confusion/delirium can be caused by infections, central nervous system disorders, using many different medications at once, malnutrition, dehydration, gastrointestinal and genitourinary disorders, heart and lung problems, difficulties with vision, hearing and other senses, bereavement and loss and even impacted earwax.

- Depression

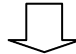
Symptoms of depression include; sleep disturbance, lack of interest, guilt, reduced energy, difficulty concentrating, appetite changes, psychomotor disturbances and suicide, it can lead to lack of concentration, memory deficits and slowed speech. (Insel and Badger 2001)

Is It Dementia? – A Procedure For Investigating possible dementia in people with learning disabilities.

If you notice the following changes:

Decline in abilities and/or loss of skills
Deterioration in personality or behaviour
Poor memory and/or confusion

Then you should consider all the following:



Stress	**Thyroid**	**Depression**	**Sensory Impairments**	**Physical Causes**	**Dementia**
Concentration problems Irritability Decline In Abilities	Lethargy Weight Gain Cold Intolerance Changes in skin and hair	Disturbed Sleep Loss of Appetite Low Mood Withdrawal from usual activities Tearful	Ignores Instructions Mobility Problems Loss of Confidence Shouting or raised voice	Withdrawal Aggression Self Injury Pacing Screaming Crying	Loss of Recent Memory Loss of Skills Changes in Mood Orientation Difficulties Sleep Disturbance Language Difficulties
NO *Or*	NO *Or*	NO *Or*	NO *Or*	NO *Or*	NO *Or*
Yes Identify Stressor: Recent Life event? (E.g. Death, a Move, Illness etc) Offer Support and Reassurance Relaxation and Anxiety Management	Yes See GP Annual Blood Tests Under or Over Active Thyroid Medication	Yes See GP Medication and/or counselling	Yes Complete full health surveillance: Check Eyes Ears Feet Access appropriate services	Yes See GP; Medical History and Physical Investigations Medication changes Diabetes Pain Urinary Tract Infections Nutritional Deficiency/ Dehydration	Yes Refer to CTLD Follow on referral to appropriate clinicians Eg GP Psychology Neurology O.T. S.A.L.T. Physio Memory Clinic

(Adapted from: Earnshaw, K. & Donnelly, V. 2000)

How to assess a person’s skills.

It is beneficial to diagnose dementia as early as possible, but it is often difficult to spot a slow decline in the abilities of someone you see every day.

Because of the higher risk of dementia in Down’s syndrome, and the earlier onset, it is advisable to regularly assess a person’s various skills, establishing a ‘baseline assessment’ so that it is possible to spot changes in ability sooner rather than later.

It is advised that in people with Down’s Syndrome, a baseline assessment should first be done at the age of 30, and then at 35, 40, 43, 46, and then annually.

There are many different formats for a baseline assessment of skills; these include the Adaptive Behaviour Scale (ABS), Dementia Questionnaire for People With Learning disability (DMR) and the Star Profile. A new specific measure for people with Downs’ Syndrome is the Adaptive Behaviour Dementia Questionnaire (ABDQ) (Prasher, Holder and Asim 2004).
What is really important is that the same measure is used consistently for each assessment so that they can be compared.

Carers often feel that they already have more than enough form filling to do, but these assessments are recognised by learning disability professionals and can be used as evidence toward reaching a diagnosis that can help unlock the extra resources the person might need as their illness progresses.

With or without these assessments, it is often the attention of the people who live or work most closely with the person to changes in their behaviour and skills that first alerts services to the possibility of dementia.

What you can do to help someone live with Dementia.

> "What are we trying to achieve when helping the person with Down's syndrome who is also affected by Alzheimers disease? We cannot remedy it or put it right. So we are looking for ways to combat (or compensate for) the effects of it. In this way we hope to maintain the person's lifestyle as best we can." (Marler and Cunningham 1994)

Support:

In the early stages of dementia, people are quite likely to be aware that something is not right. Unless there are very good reasons not to, a person should be told about their illness, and reassured that they will be cared for and supported.

A 'Dementia-friendly' environment:

In order to maintain as much independence as possible, a person with dementia needs to live in as familiar an environment as possible, with people who are as familiar to them as possible. This is not a time to introduce drastic changes into a person's life; it is a time to start thinking about ways to enable them to keep their independence as long as possible.

An environment should be as stress-free and calm as possible, and designed with a person's sensory and other problems in mind.

- Daily routines should be maintained.
- Flooring should be one colour throughout, as changes in colour and texture can be seen as steps or obstacles. Flooring should not be shiny, as this can look like water.
- Pictures and signs can be used to help a person find their way around the house, the toilet door could be painted a bright colour to make it easy to find.
- Mirrors can be removed or covered, as a person may not recognise their own reflection, lighting should not glare,
- People who the person spends time with, including other people with learning disabilities, should be helped to understand the condition and how they can be involved in the person's support.

Maintaining Skills:

- The emphasis with a person with dementia should be on maintaining abilities, NOT on teaching new skills.
- Skills relating to dignity, toileting and eating, and activities enjoyed by the person themselves are particularly important.
- People should be enabled to continue using familiar community resources and leisure activities for as long as possible.
- Activities should be stimulating, predictable and failure free.
- Tasks should not be time-limited, and should take place in a calm environment free of bustle and distraction.
- Tasks can be broken down into component parts and taught in a way that maintains skills.
- The environment itself should be organised in a way that makes it easy to know where things are, important items like keys, money, TV remote control should be kept in the same place.

> The maintenance of skills is only possible in a milieu which aids concentration and reduces stress, and which values relationships and people's emotional well being. A concentration on achievement will lead to confrontation, stress and damage to self-esteem. (Kerr 1997)

Communication

People with Dementia continue to communicate – but it becomes harder for us to work out what they are trying to say. Carer’s need to be alert as much to the emotional content of what is being said as to the words being used.

Do’s and Don’ts of Communication With A Person With Dementia
Do • Find a quiet calming place. • Approach the person from the front, and establish eye contact. • Try not to stare, as this can be intimidating. • Smile once you have been seen. • Identify yourself, and use their name. • Make sure you are seen before touching a person, many people with Down’s also have hearing loss and visual impairment. • Try to talk to the person on your own. • Talk at the time of day when that person is usually most lucid. • Speak slowly and clearly. • Keep questions simple, and only ask one question at a time. • Be direct, and say what you mean – Don’t say ‘I can’t be everywhere at once’, try ‘I will be with you soon’. • Use pictures and photographs and objects to help your communication. • Encourage the person to talk about the past. • Talk about real concrete things, rather than abstract ideas. • *Give the person plenty of time*.
Don’t • Try to communicate when there are distractions, such as other people talking, or the TV is on (Even with the sound turned down). • Use long complicated sentences. • Talk about something a long time before it will happen, as this can cause anxiety. • Assume that the person will know what you are talking about when you use words like ‘he’ ‘she’ or ‘it’. • Keep repeating something if you are misunderstood. • Use gestures that might seem threatening. • Shout. • Try to rush the person. (Adapted from Kerr 1997 p35-36)

Reminiscing

It is our memories that help us know who we are. Reminiscing reminds us of our place in the world, and our identity. It is usually a pleasurable activity, and becomes increasingly important as we get older, as we look back on our lives and integrate our experiences. This is likely to be just as true of people with Down's syndrome and dementia.

It is also important for those caring for someone with dementia to know who they were and what they were like before the effects of the disease. That person remains, though it becomes more difficult for us to reach them.

Reminiscing can be encouraged and facilitated by activities such as:

- Group reminiscences; using videos, music, photographs and stories about the past.

- One-to-one reminiscence; uses similar techniques, but can be less overwhelming than group work, and can use more personal memorabilia.

- Visits to familiar places and old friends.

- Making a 'life book' or a 'life box'; a collection of personal photographs, videos and significant objects that can be used by the person to talk about the past.

Everyone who knows the person can be involved in these activities, including carers, friends and relatives, who can find collecting items for a life box a positive way of helping with the person's care, and expressing the meaning and value of the person's life.

Sources Of Further Information

Organisations:

Downs Syndrome Association Langdon Down Centre 2a Langdon Park Teddington TW11 9PS	Tel: 0845 230 0373 URL: www.downs-syndrome.org.uk Email: info@downs-syndrome.org.uk
Down's Syndrome Scotland 158/160 Balgreen Road Edinburgh EH11 3AU	Tel: 0131 313 4225 URL: www.dsscotland.org.uk Email: info@dsscotland.org.uk
Alzheimer's Society Gordon House 10 Greencoat Place London SW1P 1PH	Tel: 020 7306 0606 URL: www.alzheimers.org.uk Email enquiries@alzheimers.org.uk
British Institute of Learning Disabilities (BILD) Campion House Green Street Kidderminster Worcestershire DY10 1JL	Tel: 01562 723010 URL: www.bild.org.uk Email: enquiries@bild.org.uk

Books/Articles/Resource Packs

Dodd, K. Turk, V. Christmas, M. (2002) *Down's Syndrome and Dementia; Resource Pack*. Kidderminster; BILD.

Earnshaw, K. Donnelly, V. (2000) *Down's Syndrome & Alzheimer's Disease; A Training Pack for Carer's and Staff Working With Individuals Who Have Dementia.* Bradford; Bradford Community Health NHS Trust.

Insel, K.C. Badger, T.A. (2002) Deciphering the 4 D's: cognitive decline, delirium, depression and dementia – a review. *Journal of Advanced Nursing* 38(4) Pp360-368.

Kerr, D. (1997) *Down's Syndrome and Dementia; Practitioner's Guide.* Birmingham; Venture Press.

Kerr, D. Innes, M. (no date) *What is Dementia? A Booklet About Dementia For Adults Who Have A Learning Disability.* Edinburgh; Scottish Downs Syndrome Association.

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Wilkinson, H. Kerr, D. Cunningham, C. Rae, C. (2004) Home For Good; Preparing to Support People With Learning Difficulties In Residential Settings When They Develop Dementia. York; Joseph Rowntree.