

Aging and its Consequences for People with Down Syndrome

Adapted from the booklet written by Prof. Tony Holland & Marie Benton

For each one of us, getting older is associated with many changes, both biological and social. For someone with Down syndrome these changes can be particularly daunting and difficult. There is evidence to suggest that some biological problems related to aging can occur earlier in people with Down syndrome than in the general population.

These pages aim to highlight some of the issues that may prove particularly relevant to people with Down syndrome and to their parents and caregivers as they get older. Although reference has often been made to the link between Down syndrome and Alzheimer's disease, it is not by any means inevitable that the person you care for will develop any form of dementia. Very often an apparent decline in a person's abilities will be diagnosed as something else that can be easily treated.

Dementia is the name given to a collection of illnesses, one of which is Alzheimer's disease that have a characteristic pattern of symptoms and signs and generally occur later in life. The main symptoms of dementia are deterioration in the person's memory (usually of recent events) and loss of other abilities such as finding one's way around, communicating through language and performing particular tasks, such as getting dressed. The incidence of Alzheimer's disease in the Down syndrome population is estimated to be 3 to 5 times higher than in the general population, and it is thought to occur 30-40 years earlier. Far too often in the past the symptoms of dementia would be ascribed to the person's disability rather than their dementia (particularly when being assessed by strangers). These days far more is known about the subject; however, there is still a danger that the person with Down syndrome will be given a diagnosis of dementia when it could be something else that would show similar symptoms but is easily treatable. ***A diagnosis of dementia cannot therefore be made without first eliminating the other possibilities.***

■ SOCIAL CHANGE

Sometimes the most obvious cause of a change in someone's behavior can be overlooked, particularly if that person has difficulties with communication. Often a doctor will rely on evidence from someone who has known them for a long time. The following are some of the social changes that can affect people as they get older. It is by no means a comprehensive list and the possibilities for each individual will of course vary enormously.

- Moving- to new environment or returning home after living on their own
- Job change- new people, new environment can cause anxiety
- Bereavement- loss of friend or family member
- Retirement- work is a wonderful way to stay connected to the community- retirement may not be seen as a good thing

■ BIOLOGICAL CHANGE

The following are all health problems that can show similar symptoms to dementia: -

Depression

It is not generally appreciated that the risk of depression increases as people get older. There is also evidence that people with Down syndrome may be more prone to depression than those in the general population. Depression in later life, if it is severe, can mimic the features of dementia and it is sometimes referred to as 'pseudo-dementia'.

The main features of depression are:

- Change in mood: the person may become more withdrawn, perhaps irritable, easily tearful or tearful for no obvious reason. This may be worse at particular times of day, specifically in the early morning. Sometimes this can be associated with increased anxiety or obsessive behavior.
- Loss of interest in a previously enjoyed activity, such as a hobby, sport, or a particular TV program.
- Deterioration in the ability to concentrate; the person can no longer easily focus on something that previously they could do well, and is easily distracted.
- Change in sleep pattern – usually waking earlier in the morning, but can include sleeping excessively.

- Change in appetite – usually a loss of appetite, which can lead to significant weight loss, but it can occasionally be an increase in appetite.

Depression is diagnosed primarily on the history of the person changing in the ways listed above. While many people with Down syndrome will be able to describe how they feel and if very depressed, may report some suicidal tendencies, for some it may be difficult for them to describe their inner thoughts and feelings. Under these circumstances others, who know the person well, may have observed changes such as an increase in tearfulness or loss of interest or deterioration in concentration. Changes in appetite and sleep may be very important markers of depression. Treatment has become increasingly effective. Severe depression is initially best treated usually through the use of the newer anti-depressant medications, but in addition it is important to deal with any other major issues in a person's life, such as the quality of the environment, or bereavement, if it has occurred. If you suspect that the person you care for is suffering from depression, your first port of call should be his/her General Practitioner. If the GP cannot treat the symptoms personally, he/she will refer you on to someone who can.

Thyroid Disorders

The thyroid gland is situated in the neck and produces the hormone thyroxin, which is one of the factors that control the body's metabolic rate. The gland can either become over-active (hyperthyroidism) or under-active (hypothyroidism). It is the latter that is more common in later life and the percentage of people with Down syndrome affected increases with age. The development of under-activity of the thyroid gland can occur slowly and go unnoticed. The key changes that should lead to a suspicion that someone may have hypothyroidism are:

- Dry skin/ brittle hair
- General mental and physical slowing
- Mood changes
- Increased intolerance of cold
- Unexplained weight increase

Some or all of the above symptoms may cause your doctor to suspect under-activity of the thyroid gland. The diagnosis is confirmed through a blood test. This blood test measures the levels of two substances; thyroxin (the hormone produced by the thyroid gland) and another hormone (Thyroid Stimulating Hormone - TSH), which is produced by the pituitary gland (situated at the base of the brain) and drives the thyroid gland to make thyroxin. If the former is low and the latter is high this confirms the diagnosis. Giving the patient replacement thyroxin daily, in tablet form, can treat hypothyroidism. We know of many people who have deteriorated quite considerably because of undiagnosed hypothyroidism, but once it was recognized and treated, many of the symptoms disappeared. As under-activity of the thyroid gland is relatively common in people with Down syndrome and its presence can be difficult to detect, yearly blood tests to test for this are recommended.

Sensory Impairment

Another possible cause of a decline in abilities in later life is that the person in question simply cannot see or hear as well as he/she used to. Some people with Down syndrome will recognize this. However, others may not be able to communicate or understand the fact that their hearing or vision is getting worse. This fact, and the deterioration itself, may leave him/her feeling isolated and vulnerable. Regular testing of hearing and vision once every 1-2 years is recommended.

Hearing Loss

With all hearing problems a person may seem confused, display a loss of interest in the world around them or a decline in his/her abilities. The hearing loss may be caused by a variety of things, including:

- Build-up of earwax-This is a common occurrence in people with Down syndrome. If you suspect that the person with Down's syndrome that you care for has a hearing problem, always first consult his/her GP. It may be necessary for the excess wax to be removed by a simple irrigation or suction process.
- Fluid behind the eardrum-This may require draining the fluid through a tube that is placed through the eardrum. It is a simple process usually performed at the ENT (Ear, Nose and Throat) department of your local hospital. A referral would be made by your GP, so again the GP should be your first port of call.
- Inner Ear problems- As these cannot be detected by examination of the outer ear or eardrum, your GP will refer the patient for a comprehensive hearing evaluation. Some adults with Down syndrome will develop

a decline in their ability to hear high-pitched sounds, including some speech consonants. A hearing aid can often correct this.

Visual Impairment

Just as in the general population, a person with Down syndrome's eyesight is likely to deteriorate as he/she gets older. As with hearing loss, deterioration in someone's vision is likely to make him or her feel confused and vulnerable. The sight loss can be a gradual decline or can be fairly rapid (often for women, it is triggered by menopause). As well as checking regularly (doctors recommend once every 2 years) whether glasses are required for reading or long distance, your optometrist should also be checking for the following:

- Cataracts- The occurrence of cataracts (opaque formations in the lens of the eye) in people with Down syndrome in later life is well established. These can be removed and artificial lenses put in place instead, under local anesthetic.
- Glaucoma-This is a condition where pressure builds up in the chamber of the eye and causes damage to its main nerve. If the pressure is higher than usual treatment is available in the form of surgery and/or medication. While glaucoma can come on suddenly with severe pain in the eye and loss of vision it more commonly in later life develops slowly and therefore goes unnoticed, certainly in the early stages. Symptoms to watch out for can include enlarged or differently sized pupils.

Orthopedic Problems

All of us can be affected by increasing stiffness and degeneration of our joints as we get older. However, people with Down syndrome do seem to suffer an increased sensitivity to instability in the neck joint. This is known as atlantoaxial instability as it occurs where the atlas (first vertebra) meets the axis (second vertebra). The vertebrae can slip, causing compression of the spinal cord. Doctors recommend yearly physical examinations to check for changes that would be consistent with spinal cord compression.

As a caregiver you should watch out for the following symptoms:

- Difficulty holding up the head
- Neck pain
- Weakness of arms or legs
- New onset of urinary or stool incontinence
- Difficulty walking
- Loss of fine motor control

Menopause

It is now thought that women with Down syndrome reach menopause 5-6 years earlier than other women. The average age is thought to be 46 (as opposed to 51 in the general population). They will go through the same stages and experience the same symptoms as any other woman.

Often the emotional symptoms of the menopause will be dismissed as challenging behavior caused by the woman's disability, rather than being correctly diagnosed. This difficulty can be compounded by the fact that women with Down syndrome often have problems describing their symptoms. They are often not aware of a "hot flash"; being unable to tell the difference between a flash and feeling hot due to the weather, for example. The better informed the woman is the better she will be able to recognize her own symptoms, and the easier a diagnosis will be. It is therefore essential that women with Down syndrome be educated about what will happen to their bodies as they get older, before it begins to affect them. Often people with a disability don't "pick up" this sort of information socially as other people would, so the information given must be clear and unambiguous.

The early onset of the menopause is often associated with osteoporosis, and it is true that women with Down syndrome are more susceptible to this disease. It affects the bones; over the years bones become thinner, more porous and therefore weaker. The bones are therefore more susceptible to fracture, which can create serious complications for the older, less able woman.