Ageing and its Consequences for People with Down's Syndrome

A Guide for Parents and Carers

A DOWN'S SYNDROME ASSOCIATION PUBLICATION

Ageing and its consequences for people with Down's syndrome

For each one of us, getting older is associated with many changes, both biological and social. For someone with Down's syndrome these changes can be particularly daunting and difficult. There is evidence to suggest that some biological problems related to ageing can occur earlier in people with Down's syndrome than in the general population. The marked improvement in life expectancy for people with Down's syndrome (an average of 50-60 years, compared to an average of 9 years around 1900) also means that the problems relating to the condition and old age are only now being researched and addressed.

This booklet aims to highlight some of the issues that may prove particularly relevant to people with Down's syndrome and to their parents and carers as they get older. Although reference has often been made to the link between Down's 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. Although there is no greater incidence of dementia than in the general population, in people with Down's syndrome 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 learning 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's 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.

Doctors at the Adult Down Syndrome Center of Lutheran General Hospital, Chicago, studied the causes of a decline in function in 148 adults with Down's syndrome. Out of those 148, only 4% were given an eventual diagnosis of Alzheimer's disease. The rest of those people all had different problems associated with ageing.

This booklet will explore the most obvious of these other problems, so that as the carer of an older person with Down's syndrome you are aware of what to look out for. Much more detailed information about dementia can be found in our accompanying booklet, "Down's syndrome and Alzheimer's disease".

SOCIAL CHANGE

Sometimes the most obvious cause of a change in someone's behaviour 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.

Bereavement

Losing people that are close to us is one of the hardest things we have to face as human beings; that is certainly no different for someone with Down's syndrome. If the person you care for has lost someone they love, their behaviour is very likely to be affected; they may become withdrawn and depressed or even aggressive. Sometimes it helps to explain the situation to the person in a clear and unambiguous way; trying to protect him/her from the truth may seem like the kind way to do it but may make him/her confused as well as upset. It may also be useful for him/her to speak to a bereavement counsellor. For more information, refer to our information sheet on bereavement.

Moving Home

If your son or daughter with Down's syndrome has always lived at home, it is natural as you get older to begin to worry about what will happen to him/her in the event of your death. Many people make the decision to explore the possibility of residential care. People with Down's syndrome often take a long time to adjust to change, and may be disoriented and confused for a while after moving. They may show symptoms of depression (see below). For people who are already living away from home, there will still be the possibility that they will have to move to a facility better able to cope with their needs as they get older. For more information, contact your local Social Services, or the voluntary organisation Housing Options, who can be reached at www.housingoptions.org.uk or on 0845 4561497.

Retirement

More and more adults with Down's syndrome are now completing further education and going on to find work. Other people have a regular day care facility that they have visited for a long time. They may reach an age where, for various reasons, it is no longer possible for them to go out quite so often. For many people retirement can bring with it feelings of loneliness and a lack of self-esteem. People with Down's syndrome should be made aware that retirement is a natural progression in anyone's life, and helped to find alternative interests.

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's syndrome may be more prone to depression than those in the general population. The reasons why some people are more at risk than others are varied; they could include a general predisposition to depression as well as the impact of events in their lives, such as past abuse or recent bereavement. 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 listed below: -

Features of depression

- 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 behaviour.
- Loss of interest in a previously enjoyed activity, such as a hobby, sport, or a particular TV programme.
- 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. Whilst many people with Down's 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 GP. 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 thyroxine, which is one of the factors that controls the body's metabolic rate. The gland can either become over-active (hyperthyroidism or thyrotoxicosis) or under-active (hypothyrodism). It is the latter that is more common in later life and the percentage of people with Down's 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: -

Features of hypothyroidism

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

Diagnosis and treatment of hypothyroidism

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; thyroxine (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 thyroxine. If the former is low and the latter is high this confirms the diagnosis. Giving the patient replacement thyroxine 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 recognised and treated, many of the symptoms disappeared. As under-activity of the thyroid gland is relatively common in people with Down's 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's syndrome will recognise 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 two years) is recommended.

Hearing Loss

With all hearing problems the 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's syndrome. Over-the-counter wax softening drops can be used to help remove the wax, but should never be used if there is a possibility that the eardrum has been perforated.

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. Doctors advise against using cotton buds or anything similar to clean the ears, as they can interfere with the body's natural ability to expel the wax, or even push it further back inside the ear.

- 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's surgery 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's 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's 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, triggered by the menopause). As well as checking regularly (doctors recommend once every two 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's syndrome in later life is well established. These can be removed and artificial lenses put in place instead under local anaesthetic.

- 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. Whilst 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.

Orthopaedic problems

All of us can be affected by increasing stiffness and degeneration of our joints as we get older. However, people with Down's syndrome do seem to suffer an increased sensitivity to instability in the neck joint. This is known as atlanto-axial 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 carer 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's syndrome reach the 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 as the body stops producing eggs and the hormones needed to reproduce.

There are three stages (known as peri-menopause, the menopause and post-menopause). The menopause is said to have taken place if a woman has not had a period for 12 months or more. At any time in these stages she may experience any of the following symptoms: -

- Hot flushes
- Tiredness
- Aches and pains
- Weight gain and food cravings
- Depression and mood swings
- Changes in skin and hair condition

Often the emotional symptoms of the menopause will be dismissed as challenging behaviour caused by the woman's learning disability, rather than being correctly diagnosed. This difficulty can be compounded by the fact that women with Down's syndrome often have problems describing their symptoms. They are often not aware of a "hot flush"; being unable to tell the difference between a flush and feeling hot due to the weather, for example. The better informed the woman is the better she will be able to recognise her own symptoms, and the easier a diagnosis will be. It is therefore essential that women with Down's syndrome be educated about what will happen to their bodies as they get older, before it begins to affect them. Often people with a learning disability don't "pick up" this sort of information socially as other people would, so the information given must be clear and unambiguous. Further advice and materials on sex education can be obtained from National Office on 0845 230 0372.

The early onset of the menopause is often associated with osteoporosis, and it is true that women with Down's 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.

Possible menopause treatments

- Hormone Replacement Therapy

  This (commonly known as HRT) is usually a course of tablets prescribed by your GP, which replaces oestrogen that the body now lacks. For some women it helps enormously with symptoms such as mood swings and hot flushes. If taken for a long time soon enough after the menopause it is also thought to help prevent osteoporosis. However, these advantages must be weighed against the disadvantages. Some women experience unpleasant side effects such as nausea or migraine. HRT is also said to increase a woman's chances of getting breast cancer and uterine cancer. Women with Down's syndrome should again be educated about these possible benefits and side effects so that they can make an informed decision about their treatment.

- Nutrition

  As a natural alternative to HRT, a healthy and balanced diet can work wonders when women are experiencing menopausal symptoms. As well as minimising weight gain and reducing food cravings, eating the right things can reduce tiredness and hot flushes and help the menopausal woman to maintain an emotional equilibrium.
  As a general rule she should try to steer clear of highly processed (junk) and salty foods and eat a diet rich in fresh fruit and vegetables. Particularly beneficial are those foods that contain high levels of natural plant oestrogens. The most important of these is soya, which can be found in soya beans and soya products like tofu, miso, soya milk and soya yoghurt. Also beneficial are nuts and seeds, pulses like chickpeas, lentils, aduki and mung beans, as well as apples, cherries, plums, rhubarb, cranberries, broccoli, carrots, french beans, peas, potatoes, and mushrooms. Soya can also be taken in supplement form. Visit your local health food shop for more information. For those suffering from hot flushes, cutting down on spicy foods, hot drinks and alcohol may help.

POSITIVE STEPS YOU CAN TAKE

Community Care Assessment

As the needs of the person you care for change and the level of care he or she requires increases, it may be useful to have a Community Care Assessment carried out by Social Services. You can either call your local Social Services directly to request one, or you can be referred by your GP or another professional. Social Services will then work closely with health services and other organisations where necessary to ensure that the appropriate level of care is given.

The person carrying out the assessment will usually come to visit the person in question in his or her own home. It may be a one-off visit or it could take several. Don't worry that this sort of assessment would automatically mean the person with Down's syndrome being taken out of their home environment and put into residential care. Very often (particularly with dementia patients) it is understood that a familiar environment is the best place for that person and everything will be done to provide adequate support at home.

The person carrying out the assessment will ask questions about all aspects of life. He/she will be able to help with services like: -

- special equipment to make things easier around the house
- meals on wheels
- day care centres
- respite care
- home care
- residential care

As the carer of someone with Down's syndrome you are also entitled to ask for a Carer's Assessment, to look into your needs as a full-time carer. The person from Social Services can do these assessments together, or you can request them independently of each other.

Once the assessment has been carried out, Social Services will write a care plan based on the information they have been given. Once this plan has been written they are legally obliged to provide the help that they have promised. For more information on the Community Care/ Carer's Assessments, contact your local Social Services or call National Office.

Keeping Healthy

Many of the health issues facing an older person with Down's syndrome are the same as for everyone else. It is important as we get older to maintain a healthy diet and take regular exercise, as well as having regular health checks. A healthy diet and regular exercise can prevent many illnesses from developing. Studies have shown that regular walks can protect elderly people from cognitive decline and prevent the onset dementia. As people get older it is often easier to live a more sedentary lifestyle; it becomes more difficult to get around and factors such as retirement enforce more time spent at home. Encouraging the person you care for to be as fit and healthy as possible for as long as possible can work wonders in sustaining his or her quality of life. For more information on balanced diet and exercise ideas, call National Office.

Summary

In many places, comprehensive services for older people with learning disabilities are sadly lacking. GPs may be aware of the fact that people with Down's syndrome can suffer from Alzheimer's disease, but may ignore other conditions that can be treated, such as depression. It may also be difficult to find appropriate care or accommodation for the person with Down's syndrome you care for. As his/her parent or carer, your knowledge of that person's particular characteristics (particularly if you have known him or her for a number of years) is an invaluable tool for social and health care professionals when decisions are being made about that person's care.

Further Information

The Foundation for People with Learning Disabilities
83 Victoria Street
London SW1H 0HW
Tel. - **020 7802 0300**
www.learningdisabilities.org.uk

British Institute of Learning Disabilities
Campion House
Green Street
Kidderminster
Worcestershire DY10 1JL
Tel. - **01562 723010**
www.bild.org.uk

Mencap
123 Golden Lane
London EC1Y 0RT
Tel. - **0808 808 1111**
www.mencap.org.uk

Alzheimer's Disease Society
Gordon House
10 Greencoat Place
London SW1P 1PH
Tel. – **020 7306 0606**
www.alzheimers.org.uk

Housing Options
78a High Street
Witney
Oxfordshire
OX28 6HL
Tel. – **0845 456 1497**
www.housingoptions.org.uk

Disabled Living Foundation
380 – 384 Harrow Road
London W9 2HU
Tel. – **020 7289 6111**
www.dlf.org.uk

Mind
Granta House
15 – 19 Broadway
Stratford
London E15 4BQ
Tel. – **0845 766 0163**
www.mind.org.uk

Nutritional Advisory Group for Elderly People (part of the British Dietetic Association)
5th Floor, Charles House
148/9 Great Charles Street Queensway
Birmingham
B3 3HT
Tel. – **0121 200 8080**
www.bda.uk.com/groups/1nage/

British Menopause Society
4-6 Eton Place
Marlow
Bucks
SL7 2QA
Tel. – **01628 890199**
www.the-bms.org

Cruse Bereavement Care
126 Sheen Road
Richmond
Surrey RW9 1UR
Tel. – **020 8940 4818**
www.crusebereavmentcare.org.uk

Authors
Professor Tony Holland, PPP Foundation Chair in Learning Disabilities, Section of Developmental Psychiatry, University of Cambridge
Marie Benton, Information Officer, Down's Syndrome Association

HELP FOR PEOPLE WITH DOWN'S SYNDROME

DOWN'S SYNDROME ASSOCIATION
A Registered Charity

If you would like further information on the Down's Syndrome Association, or are interested in joining as a member, please give us a call on the number below.

National Office:
Langdon Down Centre,
2A Langdon Park, Teddington, Middlesex TW11 9PS
Tel: 0845 230 0372
Fax: 0845 230 0373
Email: info@downs-syndrome.org.uk
Website: www.downs-syndrome.org.uk

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Registered Office: Langdon Down Centre, 2A Langdon Park, Teddington, Middlesex TW11 9PS

Most of our literature is available free of charge on www.downs-syndrome.org.uk. However, each piece costs us **£2.90 t**o write, produce and post in printed form.

If you can, **please make a donation** of any amount so we can continue to supply information free to those who need it. Thank you.

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