



**Down's Syndrome
Association**

A Registered Charity No. 1061474

Health Series



Getting older



The
Down Syndrome
Medical Interest
Group

A Down's Syndrome Association publication

Our resources and Information Team are here to help

Please see our website for up-to-date information: www.downs-syndrome.org.uk

If you would like to talk about any of the issues raised in this resource, then please get in touch with our helpline by calling 0333 1212 300 or by emailing us on

info@downs-syndrome.org.uk.

Helpline Monday - Friday 10am-4pm | Telephone: 0333 1212 300

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.

Life changes that accompany getting older

Sometimes the most obvious cause of a change in someone's behaviour can be overlooked, particularly if that person has difficulties with communication. Those undertaking assessments may have to rely on evidence from someone who has known the person 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 person 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 If the person you support has lost someone they love; their behaviour is very likely to be affected; they may become withdrawn and depressed or even aggressive.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 them from the truth may seem like the kind way to do it but may make them confused as well as upset. For more information, refer to our resource on bereavement at the 'families and carers' section of our website under 'health and wellbeing'.

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 them in the event of your death. Many families make the decision to explore the possibility of supported living or residential care. People with Down's syndrome often take a long time to adjust to change, and may be somewhat disoriented and confused for a while after moving, particularly if they are facing greater demands as a consequence of more independence. They may show symptoms of anxiety or 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. You can find further information about 'where to live' in the 'parents and carers' section of our website.

If your son/daughter moves home, make sure their new support workers have a copy of our information resource for support staff. This resource can be downloaded from the 'supported living' section of our website.

Retirement

More and more adults with Down's syndrome are leading active and fulfilling lives in their communities. As with the rest of the population, retirement involves an element of choice. Some people want to carry on working, perhaps with reduced hours, when they reach retirement age. Older people with Down's syndrome have the choice to retire, to continue with some or all of their daily activities (perhaps at a reduced rate), or to pursue alternative interests and activities.

People with Down's syndrome should be made aware that retirement is a natural progression in anyone's life but that it is not a 'one size fits all' occurrence. Discussion

and planning around retirement for a person with Down syndrome should be an important part of ageing.

Slowing down

We tend to slow down and move a bit more slowly as we get older; this is just part of the process of ageing and it is no different for people with Down's syndrome. However, they may begin showing classic signs of ageing at an earlier age than might be seen in the general population. However, dramatic loss of function / ability is not a normal part of ageing. Adults who have a sudden dramatic decline should have a thorough health check from their GP and, if appropriate, be referred to other relevant health professionals for further investigation.

You should always expect health professionals to take your concerns seriously.

We sometimes hear of cases, via our Helpline, of diagnostic overshadowing. This is where symptoms of poor health and/or behaviour changes are put down to the fact the person has Down's syndrome rather than because they are unwell.

Don't accept symptoms being explained away by the phrase 'it's because they have Down's syndrome'.

Getting support now and planning for the future

The first step to getting additional day to day help for the person you support is to ask your local authority to carry out a needs assessment. In addition, if you are an unpaid carer, you can ask your local authority for a carers assessment of your needs. Your GP can organise these assessments on your behalf if you wish.

The following information is available from the 'family and carers' section of our website:

Click on the 'day-to-day support for adults' button for factsheets about needs assessments and care planning

Click on the 'adulthood' then the 'getting older' buttons for information about planning for the future. Here you will find an article by Dalia Magrill about supporting older families to prepare for the future and a link to a guide from the Foundation for People with Learning Disabilities 'Thinking Ahead'.

We have further information about why it is important for people with Down's syndrome to be heard and included in any planning and decision making processes about their future at the 'families and carers' section of our website under 'adulthood' 'making choices'.

Making decisions - Mental Capacity Act (MCA) (2005) and Code of Practice

This law, which applies in England and Wales, sets out what should happen if someone is unable to make a decision for themselves. Its purpose is:

- To support individuals to make their own decisions wherever possible
- To protect those who cannot.

The Act is supported by a Code of Practice with specific guidance for professionals (e.g. social care, health, paid carers) who work with people who lack capacity. It is important for family carers to be aware of what the Code says.

The Act has five key principles to guide carers who have concerns over someone's capacity to make a decision:

- Every adult has the right to make their own decisions if they have the capacity to do so. Family carers and healthcare and social care staff must always assume that a person has capacity to make a decision unless it can be established they do not.
- People must have support to help them make their own decisions. This principle is to stop people being automatically labelled as lacking capacity just because they have a learning disability. Types of support could include using a different form of communication, providing information in different formats (photographs, drawings, tapes) or having a structured programme to improve a person's capacity to make particular decisions (e.g. a healthy eating programme)
- People have the right to make decisions others might think are unwise - it does not mean they lack capacity. They may need further support to help them understand the consequences of their decision.
- It is important that any decision made on behalf of someone is made in their 'best interests' and that the person themselves and those who know them best are involved in the decision-making.
- A person making a decision on behalf of someone must always ask themselves if there is another option that would interfere less with the person's rights and freedoms.

There is information about making every day financial, health and welfare decisions post 16 years old at the 'families and carers' section of our website.

Circles of support

To support overall wellbeing, a circle of support, centred on the adult with Down's syndrome, can be set up, keeping the needs, wants, hopes and dreams of the person who has Down syndrome at the centre and the focal point. A circle of support can occur naturally or by being thought about and intentionally set up.

Circles of support can be another way of adding an extra layer of support for an adult with Down's syndrome. A circle of support is a group of people who know a person well, such as family, friends and supporters, who meet regularly to help the person they support achieve what they want. This can include sharing ideas to tackle problems, providing a strong network of relationships, helping the person feel more independent and taking action to get things done. A circle of support usually includes between 3 – 10 people. There is no formal process to setting up a circle of support and you can organise it yourself.

There is further information about circles of support in the 'families and carers' section of our website under 'adulthood' 'making choices'.

Benefits and financial help

Benefits change all the time and the benefits system can sometimes seem complicated and somewhat daunting. We give information and advice about which benefits are often useful to people with Down's syndrome and their families. There is information about benefits, including information about commonly claimed benefits and detailed benefit guides, at our website in the 'parents and carers' section under 'benefits and financial' help. The advice on our website is general in nature. If you have specific questions about your own circumstances or the circumstances of the person you support, please call us (Tel: 0333 1212 300) and ask to speak to one of our benefits advisers.

Wills and trusts

In order to leave money or assets to a person with a learning disability so it can be managed on their behalf without it having an effect on their ability to draw benefits, you would need to either set up a Discretionary Trust or leave instruction in your Will for a Discretionary Trust to be set up to protect the assets and/or monetary assets left to that person. This would need to be set up by a solicitor who specialises in Wills and Trusts and we would recommend using a solicitor who is STEP qualified. You can find a list of STEP qualified solicitors here: <https://www.step.org/member-directory>

To set up a Discretionary Trust, you would need two nominated trustees to manage the trust on the person's behalf. As it is a Discretionary Trust, it must leave some room for the trustees to make decisions, so you would also need to nominate more than one beneficiary. You can then set out a letter of wishes to inform the trustees how you would like the trust administered, i.e. you name the person as the first beneficiary and ask that he/she benefits before any other party listed in the trust deeds. You should select trustees whom you feel would follow your wishes in this regard as legally speaking they do not have to follow the letter of wishes, provided they are enabling a party listed as a beneficiary in the trust deed to benefit. You can find more information about wills and trusts at 'families and carers' section of our website.

Our information about wills and trusts provides a short introduction to the relevant issues; it is in no way intended to replace professional legal advice.

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 in addition to normal regular health appointments. 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 delay 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 support to

be as fit and healthy as possible for as long as possible can work wonders in sustaining his or her quality of life.

Annual health checks

Every adult with Down's syndrome should have a comprehensive and thorough annual health check with their GP. Free annual health checks with their GP for adults with learning disabilities were introduced as a way to improve people's quality of life.

The annual health check for people with learning disabilities is a Directed Enhanced Service (DES). This is a special service or activity provided by GP practices that has been negotiated nationally. Practices can choose whether or not to provide this service. The Learning Disability DES was introduced in 2008 to improve healthcare and provide annual health checks for adults on the local authority learning disability register. To participate in this DES, staff from the GP practice need to attend a multi-professional education session run by their local Trust. The GP practice is then paid a sum of money for every annual health check undertaken.

The benefits of annual health checks

- additional support to get the right healthcare
- increased chance of detecting unmet, unrecognised and potentially treatable health conditions
- action can be taken to address these health needs.

How to get an annual health check

- The GP may get in touch with the person with Down's syndrome to offer an annual health check but this doesn't always happen.
- A person with Down's syndrome and/or a supporter can ask their GP for an annual health check. You do not need to be known to social services to ask for an annual health check.

Not all GPs do annual health checks for people with learning disabilities but they should be able to provide details of other GPs in your area who offer this service.

What happens next?

- The GP practice may send out a pre-check questionnaire to be filled out before the annual health check takes place.
- The GP may arrange for the person with Down's syndrome to have a routine blood test a week or so before the annual health check.

Who attends the annual health check?

If the person with Down's syndrome (age 16 years or over) has capacity and gives their consent, a parent or supporter can attend the health check as well.

How long should an annual health check be?

Guidance from the Royal College of GPs suggests half an hour with your GP and half an hour with the Practice nurse.

What areas of health should be looked at as part of the annual health check?

We have produced a check list for GPs which contains information about what should be included as part of a comprehensive and thorough annual health check. This includes a list of checks that everyone with a learning disability should undergo as part of an annual health check and a list of checks specific to people with Down's syndrome. You can find the health check list at the 'annual health checks' section of our website under 'families and carers and 'health and wellbeing'.

Information about health issues for GPs

There is information at our website for GPs about some of the more common health conditions seen in people with Down's syndrome. You will find this information at the 'annual health checks' section of our website under 'families and carers and 'health and wellbeing'.

GPs learning disability register

People with learning disabilities experience poorer health compared to the rest of the population, but some ill health is preventable. Over one million people in the UK have a learning disability but only 200,000 are on their GPs learning disability register.

We know that people with a learning disability often have difficulties accessing health services and face inequalities in the service they receive. The Government is asking parents and supporters to speak to their GP and ensure their sons/daughters or the people whom they support are registered. It is hoped that this drive will ensure better and more person centered health care for people with learning disabilities.

The Learning Disability Register is a record of people with a learning disability who are registered with each GP practice. The Register is sometimes referred to as the Quality Outcomes Framework (QOF) Register.

It's never too early (or late) to join your GP's Learning Disability Register; you can join at any age.

If you are not sure you are on the Register, you can ask the receptionist at your GP Practice to check for you.

The doctor may have made a note on the record that a person has Down's syndrome but this does not automatically mean they have been put on the Register. When you speak to the GP about being registered, the needs and support of the person in health settings can be discussed. This information can be entered on the person's Summary Care Record

(SCR) so that all health professionals at the practice know about their needs and how best to support them.

If the person is over 16 years of age or older, they must give their consent (see section in this resource about the Mental Capacity Act 2005):

- for information about their support needs to be added to their SCR
- to which information can be shared and with whom

Reasonable adjustments in health care

You may have heard the term 'reasonable adjustments' and wondered what it meant. Since the Disability Discrimination Act (1995) and the Equality Act (2010) (this does not apply to Northern Ireland) public services are required by law to make reasonable adjustments to help remove barriers faced by people with disabilities when trying to use a service. The duty under the Equality Act to make reasonable adjustments applies if you are placed at a substantial disadvantage because of your disability compared to people without a disability or who don't have the same disability as you.

So for people with physical disabilities reasonable adjustments may include changes to the environment like ramps for the ease of wheelchair users. For people with learning disabilities 'reasonable adjustments' may include easy read information, longer appointments, clearer signs at the practice, help to make decisions, changes to policies, procedures and staff training to ensure that services work equally well for everyone.

If a patient with Down's syndrome is not on their GP's learning disability register, then reasonable adjustments to care for that person cannot be anticipated and made.

Health issues for older people with Down's syndrome

Following are some of the health issues that older people with Down's syndrome may develop. Sometimes these health issues, singly or in combination, may 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 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 here:

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. Some people with Down's syndrome will be able to describe how they feel and if very depressed, may report some suicidal tendencies. Some, however, may find it difficult 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 their GP. If the GP cannot treat the symptoms personally, they will refer you on to someone who can.

For more information, refer to our resource on depression which you will find in the 'families and carers' section our website under 'health and wellbeing'.

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 (hypothyroidism). 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:

- **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 whose symptoms disappeared once it was diagnosed and treated. As under-activity of the thyroid gland is relatively common in people with Down's syndrome and its presence can be difficult to detect, annual blood tests are recommended to test for hypothyroidism.

Some adults may find blood tests difficult. It is possible to carry out limited thyroid testing using a few drops of finger prick blood instead of a larger amount from a vein. If this screening method is used it should be repeated every year. *Emla* cream that numbs the skin when applied about 40 mins before the test is done can prove a useful strategy. There is information at our website about supporting people to have a blood test in the 'families and carers' section our website under 'health and wellbeing'.

Your local Community Learning Disability Team (CLDT) can be a good source of advice. CLDTs usually have clinical psychologists and Learning Disability Nurses who can work with adults with learning disabilities around needle phobia. There is further information about CLDTs at the end of the health section of this resource.

For more information, refer to our resource on thyroid disorders which you will find at the 'families and carers' section our website under 'health and wellbeing'.

As a person ages, there can sometimes be a change in their thyroxine levels even if they have been taking thyroxine medication for some time. If you notice any changes in a person you support, make an appointment with their GP for a blood test and further investigation.

Don't wait for their next scheduled blood test.

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 they 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 the person feeling isolated and vulnerable. Regular testing of hearing and vision is recommended. Hearing should be checked annually and vision should be tested at least every two years.

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 whom you support 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 may 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.

For more information, refer to our resource on hearing which you will find at the 'families and carers' section our website under 'health and wellbeing'.

Visual impairment

Just as in the general population, the eyesight of a person with Down's syndrome is likely to deteriorate as they get 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 it can be fairly rapid (often, for women, triggered by the menopause). As well as checking regularly (doctors recommend at least once every two years)

whether glasses are required for reading or long distance, the 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, in later life it more commonly develops slowly and therefore goes unnoticed, certainly in the early stages. Symptoms to watch out for can include enlarged or differently sized pupils.
- **Age-related Macular Degeneration (AMD)**
This is a deterioration of the light sensitive surface lining a particular part of the inside of the eye. It leads to loss of central vision. This deterioration can be detected by eye examination. Progression tends to be slow although in some cases it can happen rapidly. There are two types of AMD; wet AMD and dry AMD. At present there is no cure for macular degeneration. Treatment for dry AMD aims to help a person make the most of their remaining vision. Wet AMD can be treated with medication. This aims to stop a person's vision from getting worse.

For more information, refer to our resource on eye conditions in adults which you will find at the 'families and carers' section of our website under 'health and wellbeing', 'annual health checks'.

Visual acuity

Up to 50% of people with Downs Syndrome will need to wear glasses, but even when glasses are worn, 100% of people with Down's syndrome have poorer visual acuity than other people. Visual Acuity is still poor even when a person with Down's syndrome is wearing correctly fitted glasses for either long or short sight.

People with Down's syndrome see the world differently – their world lacks fine details and sharp contrasts. In order to compensate for the poorer visual acuity, we can make the world around them **BIG** and **bold**.

BIG and **bold** printed materials and images will help – people with Down's syndrome are visual learners so to help them succeed make sure they can see things. It is very important to take their poorer visual acuity into account in all learning environments.

Neck instability (Craniovertebral instability)

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. In people with Down's syndrome ligaments tend to be lax and muscle tone is often low. In a small number of people with Down's syndrome certain vertebra in the neck are able to move more than is seen in other people. This may lead to slippage of the vertebra. If the vertebra slips far enough, it can cause bruising of, and pressure on, the spinal cord. Bruising can occur gradually or as the result of a sudden trauma. Mild symptoms occur in most people before dislocation of the vertebra occurs, so it is important to be on the lookout for these so that preventative action can be taken if necessary.

Neck instability - here are the signs to look out for:

- **Pain at a spot near the hard bump behind the ear**
- **A stiff neck which doesn't get better quickly**
- **Unusual head posture**
- **Changes in the way a person walks so they may appear unsteady**
- **Deterioration in a person's ability to manipulate things with their hands**

If any of the above mentioned signs occur the person should be seen by a doctor. If the onset of symptoms is sudden, an emergency appointment is needed. If there is no obvious alternative explanation for these symptoms they may be related to neck instability. An X-ray and specialist referral may need to be arranged. Guidance for doctors about assessment and management can be found at the website of the UK Down's Syndrome Medical Interest Group.

For more information, refer to our resource on neck instability which you will find at the 'families and carers' section our website under 'health and wellbeing'.

Sleep

Sleep problems are common in adults with learning disabilities with the prevalence given as anything between 9% and 34%. However, we are less clear about the prevalence of sleep disorders in adults with Down's syndrome. We believe sleep problems may be quite common in adults

There may be a higher incidence of Obstructive Sleep Apnoea (OSA) in older people with Down's syndrome. This is a condition in which the airway at the back of the throat is sucked closed when breathing in during sleep and the air flow is interrupted. OSA usually results in a person having poor quality and fractured sleep.

Amongst other things, these are some of the main signs to look out:

History of loud snoring combined with restless sleep, gasping noises when sleeping, drowsiness during the day, behaviour changes, poor concentration and irritability.

If you believe the person you support is showing signs of poor sleep, this should be investigated with their GP. As treatment for sleep problems can be effective, poor sleep should not simply be dismissed as being 'just part of the syndrome'. The GP may make a referral to a sleep clinic with a view to the person undertaking a sleep study. Sometimes

this can be carried out at home or sometimes it may have to be carried out at a sleep clinic.

For more information, refer to our resource on sleep problems in adults which you will find at the 'families and carers' section our website under 'health and wellbeing' 'annual health checks'

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) but it can happen up to ten years earlier than 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. The early onset of the menopause is often associated with osteoporosis (see information in this resource about osteoporosis).

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 may help 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.

Musculoskeletal

Osteoporosis

Osteoporosis affects the bones; as we get older our bones become thinner, more porous and therefore weaker. The bones are therefore more susceptible to fracture. Amongst other things the condition is associated with increasing age and a decrease in oestrogen after the menopause in women. Men in the general population are susceptible to osteoporosis but not as much as women are. There is some evidence to suggest that both men and women with Down's syndrome may be more at risk of osteoporosis. A healthy calcium rich diet, vitamin D and regular exercise can help to improve bone density and thus reduce the chance of developing osteoporosis. Often there are no symptoms but sometimes there may be a change in the way a person walks. If osteoporosis is suspected, a bone density test may be carried out.

Arthritis – rheumatoid and osteoarthritis

Rheumatoid arthritis is an autoimmune condition which results in inflammation in the joints. It is more commonly seen in the hands, wrist, ankles and foot bones but it can affect any joint.

Osteoarthritis affects mainly the large joints (e.g. back, shoulders, knees, hips) and it occurs because of wear and tear on the joints. It results in inflammation and degeneration of the joints.

Some adults with Down's syndrome may develop osteoporosis and arthritis at an earlier age than is seen in the general population. This may be because of lower levels of exercise and the early onset of menopause amongst other things.

Dementia – Alzheimer's disease

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. A brief summary about dementia is given below and more detailed information can be found in our accompanying booklet, "Dementia – Alzheimer's disease".

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 can occur 30-40 years earlier. Too often, in the past, the development of symptoms of dementia would be ascribed to the person's learning disability rather than recognised as being due to dementia (particularly when being assessed by strangers). These days far more is known about the subject. Assessment is essential when deterioration in later life is observed, as such change may not be due to dementia but to another condition that presents with similar symptoms but is treatable. A diagnosis of dementia should not 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.

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 their relative or supporter, your knowledge of that person's particular characteristics (particularly if you have known them a number of years) is an invaluable tool for social and health care professionals when decisions are being made about that person's care.

Health – sources of support

GP

Your GP will be your main source of information and support. Your GP can make referrals for you to social services, other relevant health services and local support/information services.

Community Learning Disability Teams (CLDTs)

CLDTs have been set up to serve the particular health needs of people with a learning disability and their family members, family carers and paid staff. CLDTs vary in size and make up but typically they will contain community learning disability nurses, a psychologist and a psychiatrist. You can discuss with your GP whether or not a referral to the local CLDT is appropriate. Some CLDTs take direct referrals from people with learning disabilities, their families or paid supporters thus cutting out the need to ask your GP to make a referral. You can find your local CLDT by searching online.

NHS continuing healthcare funding

It may be possible to obtain funding from the NHS for your care package (to cover health and social care needs) if your care needs are mainly related to your health. You can ask for funding if you live in your own home or in a care home. Your GP, nurse or social worker will carry out an initial checklist assessment to ascertain whether or not you meet the criteria for a full assessment from a multidisciplinary team of healthcare professionals. Your eligibility for NHS funding will depend on your assessed needs. Having a multidisciplinary assessment is not a guarantee that you will receive NHS funding. The Department of Health has produced a resource about NHS continuing healthcare and NHS-funded nursing care which can be downloaded at the link below:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/193700/NHS_CHC_Public_Information_Leaflet_Final.pdf

If the person for whom you care qualifies for NHS funding, you can ask for the funding in the form of a personal health budget. A personal health budget is an amount of money to support your health and wellbeing needs, which is planned and agreed between you (or someone who represents you), and your local NHS team.

How we can help

Helpline

You can call our Helpline team Tel 0333 1212 300 or email us info@downs-syndrome.org.uk if you have any questions about people with Down's syndrome and Ageing.

Training

We provide training for carers who are supporting people with Down's syndrome as they get older. We offers a one-day course on supporting adults with Down's syndrome, which includes an overview of health issues and how these change as an individual gets older. We also offer a one-day course for health and social care staff involved in assessing and providing for the care-needs of adults with Down's syndrome who have a diagnosis of dementia or work in services where they may attend. We work in partnership with service providers or support groups to organise a day at a venue and date of your choice. We also offer a bespoke training service whereby we can provide a training package to meet your specific needs. For further information please see our website <https://www.downs-syndrome.org.uk/about/training/> You can also call our training team Tel: 0333 1212 300 or email using training@downs-syndrome.org.uk

Benefits

You can call Tel: 0333 1212 300 or email using info@downs-syndrome.org.uk to find out if the person for whom you care is receiving the benefits they are entitled to. If you call us, please ask to speak to a benefits adviser.

Free membership of the DSA for adults with Down's syndrome

Adults with Down's syndrome are entitled to free membership of the DSA. Further information about membership can be found at our website in the 'support us' section.

DSA resources

If you would prefer a hard copy of this resource, or any of the resources referred to, please call us Tel: 0333 1212 300 or email using info@downs-syndrome.org.uk

Reviewed and updated 2018 by Stuart Mills (DSA Information Officer)

Acknowledgement to Professor Tony Holland, Health Foundation Chair in Learning Disabilities, Section of Developmental Psychiatry, University of Cambridge as the original author this resource.

The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome.

We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.

Contact us

Down's Syndrome Association

National Office

Langdon Down Centre,
2a Langdon Park, Teddington,
Middlesex, TW11 9PS

t. 0333 1212 300

f. 020 8614 5127

e. info@downs-syndrome.org.uk

w. www.downs-syndrome.org.uk

Wales

t. 0333 1212 300

e. wales@downs-syndrome.org.uk

Northern Ireland

Unit 2, Marlborough House,
348 Lisburn Road,
Belfast BT9 6GH

t. 02890 665260

f. 02890 667674

e. enquiriesni@downs-syndrome.org.uk



WorkFit® is a registered trade mark of the Down's Syndrome Association. Photographs courtesy of Members & Supporters of the DSA



www.dsactive.org



www.dsworkfit.org.uk



www.langdondownmuseum.org.uk



www.langdondowncentre.org.uk



© Down's Syndrome Association 2018