What is DOWN'S SYNDROME?

Information for parents, carers, professionals and students

SCOTTISH
Down's Syndrome
ASSOCIATION
helping people realise their potential

INSIDE this booklet

FACTS and FIGURES

WHAT IS DOWN'S SYNDROME?

Down's syndrome (DS) was first described in detail by an English doctor, John Langdon Down, in 1866. It is a congenital condition which randomly affects about 1 in every 700 babies born throughout the world, male and female alike.

A 'syndrome' means a group of recognisable characteristics occurring together. A 'congenital' syndrome is one present at birth, one which cannot be 'caught' later on.

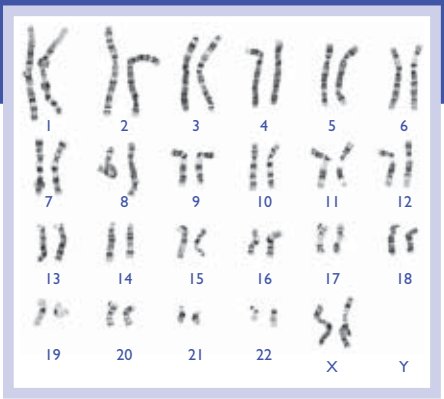
The name 'Trisomy 21' is also used, and will be explained later. However, Down's syndrome or DS is the most widely known term.

The outlook has changed radically since DS was first described. Today, most children with DS lead healthy and fulfilled lives, and are integrated successfully into family and community life.

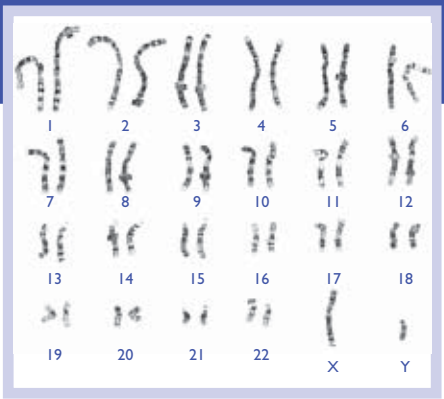
WHAT CAUSES DOWN'S SYNDROME?

DS is caused by an extra copy of chromosome number 21 inside each of the body's cells. It is a chromosomal accident, not caused by anything the parents have done before or during the pregnancy, and is only very rarely inherited.

Our bodies are made up of billions of cells. Within each cell lie the fundamental units of inheritance, known as genes. These are bundled into packages called chromosomes, which can be seen under the microscope.



Female Chromosomes



Male Chromosomes

These pictures show sets of normal chromosomes, from the cells of a man and a woman. Both have 46 chromosomes, made up of 23 pairs. The difference between males and females lies in the 23rd pair, known as the sex chromosomes. Females have two X chromosomes, while males have a large single X and a smaller Y chromosome.

The body's cells are continuously dying and being replaced. Each 'parent' cell divides into two 'daughter' cells. During this process chromosomes are faithfully replicated so that a complete set of 46 is passed on to each new cell.

However, a special type of cell division called meiosis takes place for the production of egg and sperm cells which can together form a new baby. In order for the baby's cells to have 46 chromosomes only 23, one from each pair, are passed on to each sperm and egg.

Inexplicably, meiosis can go wrong, and the sperm or egg receives an incorrect number of chromosomes. The technical term for this is non-disjunction.

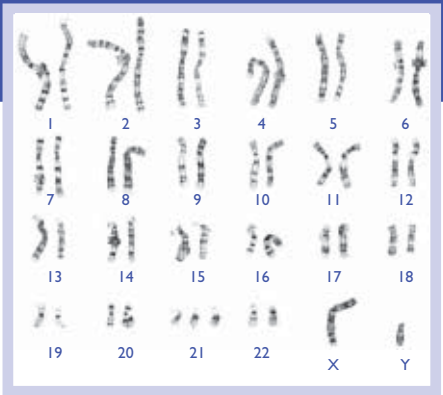
This means that in the parent cell a pair of chromosomes has failed to disjoin equally into separate daughter cells – sperm or egg.

When a pregnancy starts with a chromosome imbalance it usually miscarries. If the pregnancy does continue, the baby is born with a chromosomal syndrome. DS is the most common such syndrome, resulting from an extra chromosome 21.

There are now three copies of chromosome 21, instead of two. This explains the alternative name for DS, 'Trisomy 21', from the Greek words 'tri' and 'soma' meaning 'three' and 'body'.

TYPES OF DOWN'S SYNDROME

Nowadays, every baby born with DS has a blood chromosome test to confirm the diagnosis. There are basically three types of DS:

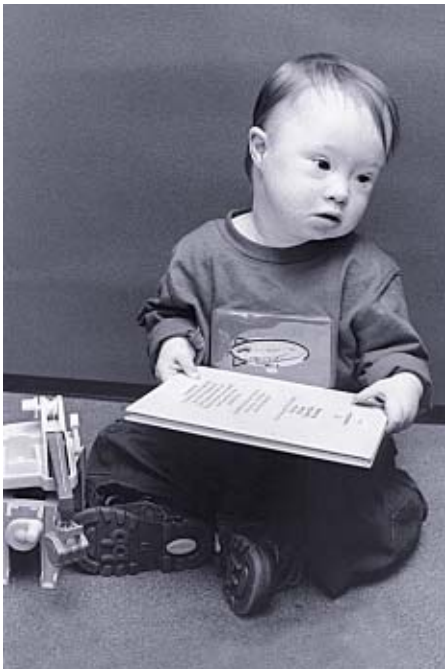


Male Chromosomes with Trisomy 21 DS

Trisomy 21 DS

This most common form accounts for about 95% of all cases. It arises when one of the parents, through non-disjunction, gives two of chromosome 21 to the sperm or the egg instead of one. This gives the child an extra chromosome 21 in every cell.

The reasons for non-disjunction are not known. One factor does appear to be the mother's age as older mothers are more likely to have a baby with DS. However, babies with DS are born to parents of all ages. In general, the majority of women have their families whilst in their twenties and early thirties, so most babies with DS are born to this group, who have no known predisposing factors.



Trisomy 21 is usually not hereditary. The chance that a couple might have a second affected child is low, about 1 in 100. This is, however, higher than in the general population. In subsequent pregnancies, some couples choose to take a prenatal test. Such tests are discussed later.

Translocation DS

In about 4% of people with DS the extra chromosome 21 is translocated or joined on to another chromosome. People with Translocation DS are physically indistinguishable from those with Trisomy 21 but they have 46 chromosomes not 47, and one chromosome is larger because it carries the extra 21.

Couples who have a child with Translocation DS should have their own blood chromosomes checked because this type is sometimes hereditary and can recur in a family or more distant relative. Families concerned about a history of DS should seek specialised genetic counselling.

Mosaic DS

In about 1% of individuals there is chromosome mosaicism. This means that some cells in the body carry an extra chromosome 21 while other cells have two as usual. Depending on the proportion of cells affected (impossible to check throughout the many different types of cells), the degree to which the person is affected may sometimes, but not always, be lessened.

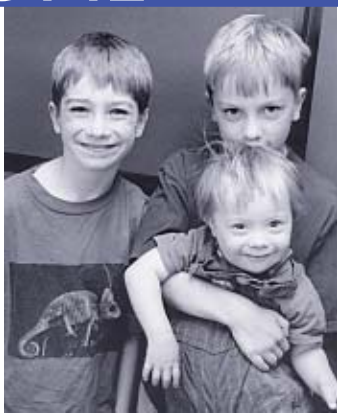
STATISTICS

There are no accurate figures for the number of people with DS living in Scotland today.

Current estimates are based on local surveys. UK estimates of people with DS in 1991 suggest a figure of over 26,000. This has grown in line with an increase in life expectancy. Many individuals with DS now live to 50-60 years or older as compared with life expectancies of 9 in 1929, and 15 in 1958. This is largely due to improvements in health care, modern surgery and improvements in quality of life.

It is fairly unusual for women with DS to become pregnant because of ovarian abnormalities and difficulties in producing eggs. However, there have been occasional cases of women with DS becoming mothers. There has only been one recorded case of a man with DS possibly fathering a child.

Recognising DOWN'S SYNDROME



People with DS do have features in common, but they also closely resemble their parents and family. Many characteristics are attributed to DS, but any individual will have only some of them. Children and adults with DS should not be categorised as a group. Each person is an individual, with a unique appearance, personality and set of abilities.

There will be a degree of learning difficulty and certain common facial features. No other characteristic is present in every individual.

DS is recognisable at birth. The child usually has a rounded face with a flattish profile. The child's head is often smaller than average, caused by underdevelopment of the facial bones. The back of the child's head may be slightly flattened and the neck may appear short.

A child with DS may have a small mouth, with a flattish roof. This gives the tongue less space, making it more likely to protrude initially. This tendency is increased by weakness of the tongue and jaw muscles.

The eyes of nearly all people with DS slant slightly upwards. The 'epicanthic fold' is a small fold of skin often present at the inner corner of the eye. It becomes less prominent as the child grows older. There may also be small white speckles on the edge of the iris, 'Brushfield spots'. Neither of these features affects vision.

Arms and legs are often short in relation to the body, and hands may be broad with short fingers. The little finger may have one joint instead of two, curving in towards the other fingers. The palm often has only one crease across it. Feet tend to be broad with short toes, and a space between the big toe and the second.

At birth some babies will have poor muscle tone (hypotonia), and may feel floppy. There may also be loose-jointedness (hyperflexibility), which adds to this impression. Tone is always lowest during the early years. It improves spontaneously as the child gets older and is seldom a problem by adolescence.

Children with DS are often light at birth and may not gain weight as rapidly early on. Body length is also less than average. During childhood growth is slow but steady with adult height being near the bottom of the normal range. Specific charts are available for measuring growth in children with DS, and these should be used to gauge progress rather than general growth charts.

HEALTH PROBLEMS associated with Down's Syndr

The following problems can be experienced by any child, but are more common in those with DS. However, many children with DS do not experience most of these difficulties. This section is for reference, and it is important to note that the serious conditions described are rare.

MINOR CONDITIONS

Upper respiratory tract infections

Most pre-school children are prone to coughs, colds and ear infections. Children with DS are especially so, because of their relatively narrow ear and nasal passages. Antibiotic treatment may be necessary.

Ears

Accumulation of fluid in the ear is common in all small children, especially those with DS because of their narrow eustachian tubes. These passages run from the bottom of the middle ear to the throat, allowing secretions to drain. If they become blocked, fluid accumulates causing hearing loss. Often this will clear spontaneously or with antibiotic treatment.

Sometimes a more chronic condition with sticky, heavy secretions may develop, known as 'glue ear'. Treatment by the insertion of tiny plastic tubes or grommets into the eardrum to drain off fluid may be advised, if the child is having persistent pain or hearing loss.

It is important to speak clearly and directly to a child with glue ear. The problem becomes less common by the age of about 10, but hearing should still be monitored throughout life.

Eyes

Vision in children with DS should be regularly checked because of a tendency for long or shortsightedness to develop. Squints are also more common.

Children with DS sometimes look as if they have a squint because of the wide spacing of their eyes and the epicanthic folds. True squints are caused by imbalance in the eye muscles. When vision in one eye is defective, the child suppresses its use, and that eye becomes 'lazy'.

rome

Squints can be remedied by use of a patch on the 'good' eye, to encourage the vision in the other eye to improve. Occasionally surgery is required to correct the eye's position.

Another common condition is nystagmus (jerkiness in the movement of the eye). This is due to poor muscle co-ordination. Nystagmus can be slightly improved by wearing spectacles. It tends to improve spontaneously in later childhood.

Cataract (clouding of the lens) occurs rarely. If it interferes with vision it can be remedied by an operation and spectacles. Small tear ducts sometimes cause 'sticky eyes', for which a saline wash is helpful.

Eating and Drinking

Poor muscle tone can cause a young child with DS to have sucking problems or reflux (regurgitation of feeds). Although eating and drinking skills develop, this can continue to be an area of difficulty. Your Speech and Language Therapist will advise at any stage in a person's life where there are concerns.

Muscle tone and hernias

Protruding tummies and hernias (swellings) especially at the umbilicus (tummy button) are common and are exacerbated by poor muscle tone. These often look dramatic, but rarely cause problems and usually resolve on their own. Hernias affecting the groin are less common, but do usually require treatment.

Sometimes young children with DS have minor postural foot abnormalities because of poor muscle tone whilst in the womb. These are treated by simple stretching exercises.

Constipation

Older infants and children are treated by ensuring an adequate intake of fluid and dietary fibre, with laxatives as prescribed. In young babies, constipation should be assessed by a paediatrician.

Skin

Many children with DS have dry, flaky skin which may crack or itch. Frequent use of soap and water, and exposure to the weather, can make this worse.

A handful of bicarbonate of soda in a half full bath can help but try not to use soap as this dries the skin.

Bath oil is not advised as it prevents the water from hydrating the skin.

Using aqueous cream or applying an oily substance to the skin after bathing can be helpful.

MORE SEVERE CONDITIONS

These conditions can affect any baby or child. They are more likely to occur in children with DS, but nonetheless are rare.

Gastro-intestinal (bowel) complaints

Complete blockage:
Duodenal atresia
This affects about 10% of babies with DS and means that a short part of the bowel is completely blocked. It becomes apparent soon after birth and is readily diagnosed by the paediatrician. Treatment is by surgery, removing the blocked segment and restoring bowel continuity.

Partial blockage:
Hirschsprung's disease
This very rare complaint is usually diagnosed later than duodenal atresia. A lack of certain nerve cells in the bowel wall prevents regular, easy emptying of the bowel, and causes very severe constipation, vomiting and dramatic distension of the abdomen. Again the condition is treated by surgery.

Thyroid gland underactivity (hypothyroidism)

This causes deficiency of a hormone called thyroxine, produced by the thyroid gland in the neck and secreted into the blood. The amount of thyroxine must remain at a certain level for proper functioning of the mind and body.

Affected newborn babies are diagnosed through the Guthrie blood screening test performed on all babies born in this country. Older children and adults can he affected without obvious signs of illness, so regular blood checks of thyroid function are recommended (see Maintaining Good Health). Treatment is by prescribed thyroid supplements in tablet form.

Leukaemia

About 1 in 100 children with DS develop leukaemia, which is a cancer of the white blood cells. Its onset is usually between 1 and 4 years, with symptoms being skin

pallor, bruising and general malaise. Modern drug treatment can bring leukaemia under control, and can even cure it permanently in many cases.

Cervical Spine Instability (Atlanto-axial instability)

In about 10 – 20% of children and adults with DS there is increased mobility of the joint between the two bones directly under the skull, the atlas and the axis. In extreme cases, abnormal pressure on the neck can cause dislocation of these bones, leading to neurological symptoms such as altered sensation in the fingers and hands or occasionally paralysis.

Currently there is no screening procedure that can predict those at risk. Until recently, special neck X-rays were used in an attempt to detect any possible problems. It is now felt that these X-rays are not a reliable test for atlanto-axial instability and are therefore discouraged.

The symptoms of cord compression are neck pain, restricted neck movement, unsteadiness in walking and deterioration in bladder and/or bowel control. Urgent medical care should be sought if these symptoms develop.

Examinations for signs of slow cord compression should be part of the annual medical review.

Treatment for cord compression is surgery to fuse the back of the atlas to the back of the axis. Although this may reduce the mobility in the neck it may prevent life-threatening dislocation of the atlanto-axial joint.

Children and adults with DS should not be barred from sporting activities (but should avoid intensive trampolining, intensive horse riding and high diving) as there is no evidence that participating in sports increases the risk of cervical spine injury any more than for the general population. In fact, regular exercise is to be encouraged.

When undergoing any treatment requiring anaesthesia, a collar should be used to keep the neck stable and avoid cervical injury whilst the head and neck are being manipulated. Collars should also be used if a person with DS is involved in a road traffic accident, until examination has taken place.

The HEART

INCIDENCE OF HEART DISEASE

About 1 in 3 children born with DS have a heart defect which, because it is present at birth, is called congenital heart disease (CHD). If no problem is detected in early life it will not develop later on.

As part of the neo-natal check, the paediatrician examines the new born baby's heart and blood vessels for any problems. It can be difficult to detect heart disorders this early, so there is a further check at age six weeks.

One of the two following diagnostic tests may be performed:

- Echocardiograph or ultrasound scan: the structure of the heart is examined by passing a small pad over the chest, to direct ultrasound waves at the heart. The results appear on a screen. This is now a very accurate examination and a normal ultrasound result is extremely reassuring.
- Electrocardiogram or ECG: small electrodes are placed on the child's body and connected to a machine which picks up the electrical currents produced by the heart pumping, and records them on paper as a graph.

Sometimes the paediatrician will report hearing a 'murmur', the sound of blood flowing abnormally through the heart. Many murmurs turn out to be trivial and eventually disappear. An echocardiograph will always be performed on a baby who has a heart murmur, and often whether a murmur has been heard or not.

Not every child with a heart disorder will need surgery. Many lead full lives despite a heart disorder, and merely return to the consultant periodically for check-ups.

TYPES OF CONGENITAL HEART DISEASE

Atrio-ventricular septal defect (AVSD defect)

This is the most common heart defect in children with DS, affecting 1 in 6. It is a hole between the two atria, and in some cases between the two ventricles as well. Both 'partial' and 'complete' canal defects can be corrected by surgery in infancy.

Ventricular septal defect (VSD)

This occurs in about 1 in 10 infants with DS, and is a hole between the two ventricles. In some cases the hole is so small it causes no problem, and some small holes close themselves. Holes causing problems can be repaired by surgery.

Persistent ductus arteriosus (PDA)

This occurs in about 1 in 50 children with DS. A duct lying above the heart fails to close after birth, allowing excess blood to flow into the lungs. The duct is closed by surgery.

Tetralogy of Fallot

Only about 1 in 100 children with DS have this combination of four heart defects, including a large hole between the ventricles and a narrowing in the blood vessel from the heart to the lungs.

Repair involves a complex open heart operation. Total correction is difficult in an infant, so temporary repair is often carried out until the child is older.

ANTIBIOTIC PRECAUTIONS

Precautions should be taken when a child with a heart defect has any operation, particularly where bacteria may enter the bloodstream. For example, drilling or extraction of teeth may allow bacteria in the mouth to enter the bloodstream, causing infection in the heart (endocarditis).

Dentists should always be informed of any heart defect, so that antibiotic cover can be arranged if necessary.

Maintaining GOOD HEALTH

People with DS now live longer, healthier lives because of improved diagnosis and treatment of conditions which used to cause illness.

RECOMMENDED HEALTH CHECKS

Physical and developmental check: At birth, 6 weeks, 6-8 months and then annually, to monitor growth and developmental progress. Length and weight should be checked frequently using the DS growth chart from 3 months until 18 months of age, and at least annually after this. Later checks are available through Child Health Clinics.

Vision test: From birth visual behaviour should be monitored by a paediatrician. A formal opthalmology review should occur in the 2nd year of life and again in the 4th year. Standard vision testing at least once every 2 years throughout life is recommended.

Hearing test: Neonatal screening if available locally and audiological review as soon as possible after 6 months and not later than 10 months. There should be a full audiological review between 15-18 months, repeated yearly until the age of 5. Hearing should then be tested **at least** once every 2 years of life and more frequently if indicated.

Dental examination: At 2 years, then every 6 months.

Thyroid function test: At birth (routine Guthrie test) then at 12 months to check for thyroid antibodies. Then at least once every 2 years and annually for people with thyroid antibodies.

Neck X-ray: As advised by doctor.

IMMUNISATION

Children with DS should follow the usual immunisation schedule. Whooping cough could be experienced by children with DS as a very serious illness, so vaccination is recommended.

DENTAL CARE

The teeth of children with DS erupt later, so milk teeth often stay longer and suffer more wear. Gum disease is more prevalent than in the rest of the population.

Dental care is important. Brushing should be started when the first tooth appears, and excessive sugar avoided. Fluoride supplements should be given in the usual way. An orthodontist should be consulted about any problems with the spacing of teeth.

DIET

Children with DS benefit from a healthy lifestyle, like anyone else. Some children and adolescents with DS tend to become overweight, so exercise and diet are particularly important.

CONTROVERSIAL treatments

A healthy and fulfilling lifestyle can often be achieved through appropriate care, but DS cannot be cured. Various therapies make claims to a cure or at least dramatic improvement. The SDSA keeps up-to-date information, and will provide further details if required.

Some therapy (treatments) may actually be harmful to the child, both physically and psychologically. They may also be detrimental to the care parents can offer their child with DS and to the rest of their family.

The merits of any scheme should be weighed up, and professional advice sought. If any programme is started, there should be definite objectives and a timescale set. If the desired improvement is not achieved, treatment should cease.

Vitamin and mineral supplements

It has been recommended that children with DS are given vitamin and mineral supplements, sometimes in very high doses. The evidence that such supplements benefit children is inconclusive. Indeed there is evidence that high dose vitamin and mineral supplements may cause harm.

Plastic surgery

Surgery can be performed on children with DS, to alter and 'normalise' their appearance. This can be available on the NHS. The risks of each operation should be weighed up against any possible benefits. Most parents are not prepared to put their child through a general anaesthetic and surgery for cosmetic reasons.

SDSA would urge parents/carers who decide to take this course of action to wait until their son or daughter is old enough to make an informed decision for themselves. If they are happy with the way they look, then don't ask them to change. If they are not happy, then they should be given the respect that any other teenagers or young adults would be given and be allowed to make an informed decision.

Prenatal SCREENING and TESTING

Before the 1980's no blood or screening tests were available to pregnant women to assess the chances of their baby having DS. It was then recognised that a low level of alpha-fetoprotein (AFP) in the mother's blood was more common where babies had chromosomal abnormalities, including DS.

More recently, several blood screening tests have been developed which indicate whether a pregnant woman has an increased chance of having a baby with DS. At the time of writing, different tests are routinely available in different parts of the UK and new, improved tests are being developed.

Screening is imperfect – not all mothers carrying a baby with DS will be identified and will 'screen positive'. Moreover, most mothers who do screen positive turn out to have an unaffected foetus when further tests are performed. Screening causes anxiety if it is not properly explained or understood. It is advisable for up to-date advice on local practice to be sought.

If screening suggests an increased risk, expectant mothers can go on to a diagnostic test, showing definitely whether or not the baby has DS. The two diagnostic tests currently available are amniocentesis and chorionic villus sampling (CVS). These are also sometimes sought by couples who already have one child with DS.

Amniocentesis is the most common form of antenatal diagnosis. When it is done a thin needle is inserted into the womb, and a sample of the amniotic fluid surrounding the foetus is withdrawn for examination. This fluid contains some cells from the foetus. Results are usually available in three weeks. There is a small risk, reported at 1%, that amniocentesis might cause miscarriage.

An alternative is CVS. The procedure is similar to amniocentesis, but cells are collected from the developing placenta. CVS is performed earlier in the pregnancy than amniocentesis, at about ten weeks. The results are available after about two weeks. Like amniocentesis, CVS carries a risk of miscarriage, commonly reported to be 2-3%.

Further information about these tests can be obtained from regional genetic counselling centres. Couples who have a history of Translocation DS also may wish to seek specialist advice concerning family screening and prenatal testing.

The growing CHILD

At birth, it is impossible to predict any child's potential. There is certainly no significant relationship between the number of physical characteristics associated with DS and intellectual ability.

The types of health care described above can help ensure that nothing hinders the child's ability to learn. Even mild hearing or visual impairment can interfere with learning ability, language acquisition and the development of social skills.

Children with DS often have particular difficulties with their understanding and expression of language. The Speech and Language Therapist would advise on the introduction of a 'Total Communication' approach, which would include the use of gesture, facial expression and formal signing systems i.e. Makaton or Signalong and the use of symbols.

A loving and secure home environment is very important. Children with DS develop and learn throughout life, increasing skills in the same way as other children, but at a slower pace. Progress in learning is not always smooth. A child may seem to 'stick' at a certain stage, but during such phases new skills are being consolidated, and the foundations laid for the next step.
Children with DS do not have particular behaviour problems. Difficulties occurring are similar to those in other children. However, they often appear later. For example, 'toddler tantrums' may not start until a child reaches that developmental stage, perhaps at about four. As with all children, rewarding good behaviour and ignoring bad is often effective.

Growing UP

The changes of puberty occur in adolescents with DS at about the same age as others, and follow the same pattern. In teenagers with DS though, the changes are occurring when the individual is less intellectually mature, and this may cause problems.

Increased hormone levels in the blood during puberty can cause changes in behaviour. Teenagers may become more tired and listless, more irritable and defiant. Professional advice can help during this period, and prevent behaviour problems from becoming too deep-seated.

HEALTH CARE IN ADOLESCENCE

Diet

Puberty is a period of rapid growth, marked also by an increase in appetite. If obesity is a problem, and once thyroid hormone deficiency has been excluded as a cause, calorie intake should be reduced. The advice of a dietician may be helpful.

Exercise

Sport and exercise are important in adolescence, for keeping weight down and for providing opportunities for teenagers with DS to mix with others of the same age.

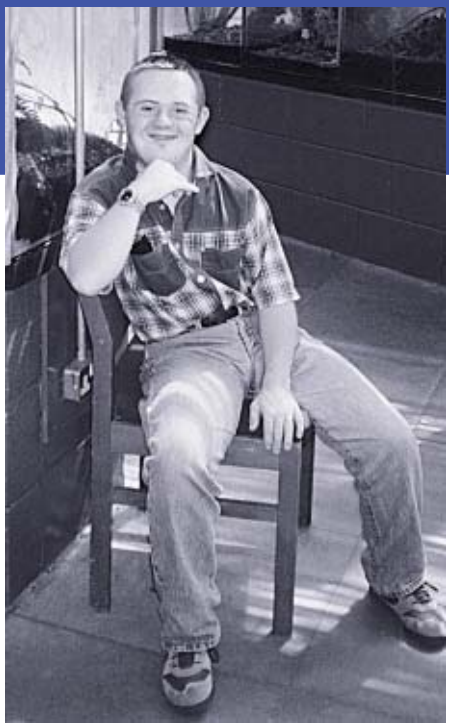
In the past, adolescents with DS often lacked peer contact, socialising mainly with their parents' friends. Sport, activity clubs and holiday camps encourage peer contact and also teach skills for coping away from home, a vital part of growing up.

LEARNING ABOUT LIFE

During adolescence all children learn about themselves, their bodies and emotions. Parents and teachers should spend time discussing relationships and sex, appropriate and inappropriate behaviours, hygiene, and the dangers of sexual abuse.

Individuals need help to understand how DS has affected their own development. Self-esteem is important. Clothing and haircut should be up-to-date and age-appropriate.

Parents should continue the process, begun in childhood, of teaching the skills for independent living. Taken gradually and with plenty of opportunities for practice, the young person will not face situations unprepared, and risks will be minimised.



INTO ADULTHOOD

If teenagers are allowed some independence, occasionally staying away from home, their eventual move from home will be made easier. Once they leave home, adults with intellectual disabilities tend to live in houses in the community, with support staff, and not the large institutions of the past.

The quality of accommodation is improving, and so too are the opportunities for employment – either part-time paid employment in an ordinary job, or within a job coaching scheme. Leisure and further education opportunities are also expanding.

Adults with DS do not stop learning when their school years are over. Given the opportunity they continue to acquire new skills. An increasing number of colleges offer courses for people with learning difficulties to continue school subjects and learn new skills.

Adults should have a number of health checks to monitor specific problems more common in people with DS. It is recommended that vision and thyroid should be checked every two years. Hearing should be checked every two years and more frequently where appropriate. Teeth should be checked every six months.

Growing OLD

There is a common misconception that people with DS age prematurely but there is no firm evidence to support this. Ageing is a poorly understood process, but it is known that people who lead full and active lives usually age more slowly, whilst people who have very little physical or mental stimulation, tend to age more rapidly.

Older adults with DS experience all the usual problems associated with ageing, such as deterioration in vision, hearing and mobility. In addition, the following conditions are becoming more common as people with DS are living longer.

Dementia

There are different causes of dementia. One of the most common is Alzheimer's disease. This is the dementia to which people with Down's syndrome are susceptible. However they can develop other forms of dementia in the same way as the general population.

As more people with Down's syndrome are living to middle age and beyond, the development of Alzheimer's disease is more apparent. Although Alzheimer's disease can occur earlier in adults with Down's syndrome than the general population, it is not inevitable and not everyone with Down's syndrome will develop the disease.

Seizures

Seizures (fits or convulsions) are caused by a temporary breakdown in the control of electrical activity in the brain cells. A person who suffers repeated seizures has epilepsy. Seizures are rare in children with DS (only 1-2%), but by the age of 50, 10% will have suffered a seizure. The condition is controlled by medication.

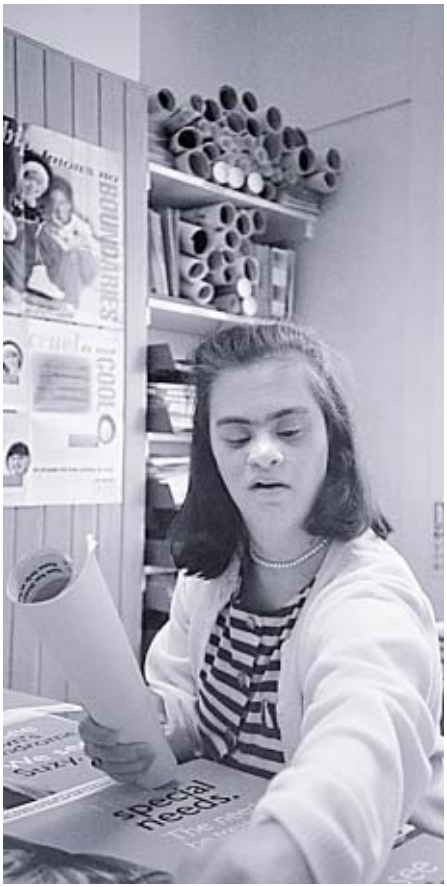
Current RESEARCH

Little is known about the fundamental cause of DS, but there is ongoing research. The special cell division called meiosis where chromosomes are distributed to the egg or sperm is being studied. This research is still at an early stage, and no 'breakthroughs' should be expected in the near future.

Another branch of research is working on a detailed genetic 'map' of chromosome 21, identifying areas within it which are important in producing associated medical problems such as congenital heart disease and Alzheimer's disease. Again, these studies are a long term investment.

A great deal is known about the way children learn, and psychologists and teachers are now looking at how children with DS acquire new skills. There is evidence to suggest that this may differ from the ways in which other children learn. The aim of such research is to discover which teaching methods are most suitable for children with DS.

Researchers are also looking carefully at how individuals fare in integrated settings, in schools and in the community. The aim here is to establish the types of environment and support that enable children and adults with DS to make best use of their intellectual and social skills, and to live their lives to the full.



Further READING

Down Syndrome: The Facts
Mark Selikowitz, OUP, 1997

A Parent's Guide To Down Syndrome: Toward A Brighter Future
Siegfried Pueschel, Paul H Brookes, 1990

Down's Syndrome, Adulthood And Ageing
Living with Down's Syndrome, SDSA, 1995

Living with DOWN'S SYNDROME

This booklet is one of a series produced by the Scottish Down's Syndrome Association for people with Down's syndrome, parents, carers, relatives, students, professionals, and anyone who has an interest in Down's syndrome.

The booklets are designed to help with the thoughts and questions that occur to parents and to answer some of the general queries we receive about Down's syndrome.

Some points to bear in mind while you read:

- The term Down's syndrome has been shortened to DS.
- People with DS are described as having learning disabilities or difficulties, rather than as having a mental handicap.
- In some of the booklets we refer to the person with DS as 'she' or 'her', while in others we refer to 'he' or 'him'. All the information applies equally to both sexes.
- We have written from a Scottish viewpoint, but the issues covered will be of relevance to readers elsewhere.

For details of other titles in the series, names of local contacts or any further information, please contact the SDSA at the address on the back page.

SCOTTISH
Down's Syndrome
ASSOCIATION
helping people realise their potential

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The SDSA provides support, advice and information to people with Down's syndrome and their families/carers, professionals and the general public in Scotland.

It also seeks to raise awareness and understanding of the potential of people of all ages with Down's syndrome.

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