



Down
Syndrome
Ireland

National Leadership Local Support

Student Information Booklet



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WHAT IS DOWN SYNDROME?

Down syndrome is a common congenital¹ chromosomal anomaly which is found worldwide. The condition occurs when there is one extra copy of chromosome 21 in cells in the body. The extra chromosome 21 material may affect the physical development and learning abilities of people with Down syndrome.

Down syndrome is the most common genetic cause of learning disability.

Down syndrome is not a disease or an illness that can be cured. People with Down syndrome do not suffer from it, nor is it anybody's fault.

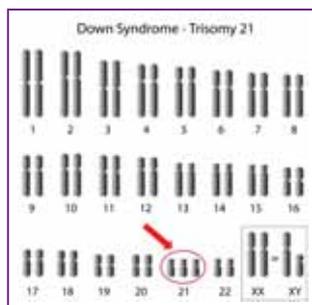
WHAT IS A SYNDROME?

A syndrome is a collection of several signs and symptoms that usually occur together.

WHAT IS A CHROMOSOME?

The human body is made of cells. Chromosomes are minute packages of genetic material found in the nucleus (the centre) of every cell. They are the building blocks which give us our individual characteristics i.e. they determine the colour of our hair, our eyes and other physical features.

Human cells normally contain 23 pairs of chromosomes, half of which are inherited from each parent i.e. one chromosome in each pair comes from your father, the other from your mother. Down syndrome occurs when some or all of a person's cells have an extra full or partial copy of chromosome 21. The most common form of Down syndrome is known as Trisomy² 21: an extra number 21 chromosome making 47 chromosomes in all. The condition results from an error in cell division called non-disjunction.



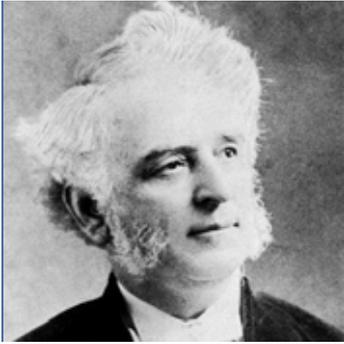
HOW IS DOWN SYNDROME DIAGNOSED?

The presence of Down syndrome is often identified soon after birth from the baby's clinical features and confirmed with a blood test. Sometimes babies with Down syndrome are identified during pregnancy as a result of pre-natal tests.

1 Congenital: Present at birth

2 Trisomy: having three copies of a chromosome in each cell rather than the normal number of two.

HISTORICAL BACKGROUND



Down syndrome was first described by Dr. John Langdon Down in 1866. While working in London in 1866, he noticed that some of his patients, though not related, had similar physical characteristics that made their condition different from other types of intellectual disabilities.

Langdon Down thought that their facial features resembled those of the Mongolian people and so, he introduced the term Mongol. People with Down syndrome were once referred to as having "mongolism" or being "mongols". These terms are inappropriate and are no longer used when referring to a person with Down syndrome.



It was not until 1959 that Dr. Jerome Lejeune, a French physician, made the discovery that Down syndrome was the result of a chromosomal anomaly. His research led him to the fact that the cells of people with Down syndrome had 47 chromosomes, compared to the typical 46 chromosomes. Shortly after, it was discovered that chromosome number 21 contained an extra partial or complete chromosome, thus the term Trisomy 21 was born.

TYPES OF DOWN SYNDROME

There are three types of Down syndrome:

Trisomy 21 (97% of cases) Down syndrome is caused by trisomy 21. A child with trisomy 21 has three copies of chromosome 21 instead of the usual two copies in all of his or her cells. This form of Down syndrome is caused by abnormal cell division during the development of the sperm cell or the egg cell.

Translocation (2% of cases) Down syndrome can also occur when part of chromosome 21 becomes attached (translocated) onto another chromosome, before or at conception. Children with translocation Down syndrome have the usual two copies of chromosome 21, but they also have additional material from chromosome 21 attached to the translocated chromosome. In approximately half of the babies with this type of Down syndrome; it is a unique occurrence. In the other half, the translocation occurs because one or other parent happens to have a number 21 chromosome translocated or stuck onto another chromosome. Either parent can carry a translocation without showing any symptoms, because he or she still carries the correct amount of genetic material, although some of it is out of place (by translocation). In the latter situation, there is a risk of reoccurrence of Down syndrome. In this situation chromosome studies would be carried out to ascertain the size of the risk.

Mosaic 1% of people with Down syndrome have a mosaic pattern. They have a mixture of cells, some with an extra chromosome 21 and some normal cells. This mosaic of cells is caused by abnormal cell division after fertilization. Some of these babies may present with less of the physical characteristics typically associated with Down syndrome.



HOW IS THE TYPE OF DOWN SYNDROME DETERMINED?

When a child with Down syndrome is born, or if Down syndrome is suspected, a chromosomal analysis is carried out (by blood tests) to confirm the diagnosis and determine the type of Down syndrome the child has.

IS DOWN SYNDROME HEREDITARY?

A very small percentage of all translocation trisomies are inherited. Parents whose child has this type of chromosomal abnormality are advised to seek genetic counselling.

INCIDENCE AND PREVALENCE

It is estimated that there are approximately 7,000 people in Ireland with Down syndrome. One baby with Down syndrome is born out of every 547 live births (Johnson et al., 1996). Approximately 110 babies with Down syndrome are born in Ireland each year.

Women aged 35 and older have an increased risk of having a child with Down syndrome, however a baby with Down syndrome can be born to a parent of any age.

CHARACTERISTICS

Typical Facial Features:

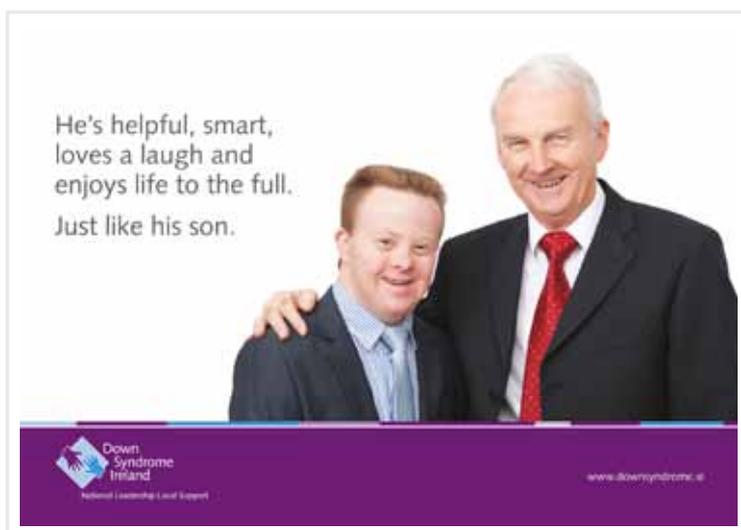
- Face tends to be round and flat.
- Eyes slant upwards and have an extra fold of skin on the upper eyelid known as an epicanthic fold or the epicanthus. This skin fold covers the inner corner of the eye next to the nose.
- The mouth cavity is slightly smaller than average and the tongue slightly larger causing the person with Down syndrome to sometimes protrude his/her tongue. With speech and language therapy from an early age, tongue protrusion can be managed through exercises that strengthen the lips and tongue.
- The back of the head (called the occiput) is slightly flattened.
- Nose may be small with a flat and low bridge.
- Ears may also be small and low-set.



Other Physical Features

- The neck in new-born babies may have excess skin; this is called the nuchal fold. Older children and adults tend to have short broad necks.
- A single crease across the palm of the hand.
- Hands tend to be broader and shorter and the little finger can sometimes curve inwards.
- A bigger than normal space between the first and second toe (the 'sandal gap').
- Low muscle tone or 'hypotonia' is common among babies and very young children with Down syndrome. Hypotonia generally improves over time, and most children with Down syndrome will have physiotherapy in infancy and childhood to help improve their hypotonia.
- Babies may have a low birth-weight.
- The average height of a child or adult with Down syndrome is less than that of the rest of the population.
- Most people with Down syndrome have a slow metabolism and put on extra weight more easily than their peers (metabolism refers to how quickly or slowly your body uses up the calories from the food you have eaten). Research suggests that children with Down syndrome have a lowered resting metabolic rate than their peers. This means that children with Down syndrome use fewer calories when they are asleep than children of the same age. This generally doesn't change as they get older. Weight gain can be a problem for a person with Down syndrome but with a healthy diet and plenty of exercise this can be avoided.

Every person is an individual and this is no different for the person with Down syndrome. People with Down syndrome may share certain physical characteristics as a result of the extra chromosome. However, each child also inherits many family features, traits and characteristics. A person with Down syndrome will therefore be more like his/her family than like any other person with Down syndrome.



HEALTH

Having Down syndrome does not guarantee any medical conditions or health problems. Most children and adults with Down syndrome are healthy and active and will benefit from a variety of opportunities just like other children in the family. However, it is established that people with Down syndrome have a higher incidence of certain health issues such as:

- Congenital heart defects
- Susceptibility to infection
- Hearing (e.g. recurring middle ear infections), vision, thyroid and respiratory problems
- Obstructive digestive and neurological problems and leukaemia
- Dementia in later life [some individuals with Down syndrome may experience dementia/Alzheimer's disease in later life. Research indicates that the incidence of dementia in people with Down syndrome is similar to that of the general population only that it occurs 20-30 years earlier. (www.downs-syndrome.org.uk)].

Down Syndrome Ireland produced and published the internationally recognised 'Medical Management of Children & Adolescents with Down Syndrome in Ireland'. These medical guidelines are a road map for parents and healthcare professionals to ensure the best possible medical care for people with Down syndrome. These guidelines can be downloaded from www.downsyndrome.ie

The life expectancy of people with Down syndrome is increasing, thus, the importance of life-long living and learning needs to be supported.



STRENGTHS AND NEEDS

All children with Down syndrome experience some degree of learning disability. They make progress in many areas, but it may be at a slower pace. There are recurring patterns in the development of children with Down syndrome which can suggest a 'profile' of characteristic strengths and needs.

STRENGTHS

» Social interaction

Most children with Down syndrome are very sociable; they enjoy and learn from social interaction with family and friends. Socially acceptable and age-appropriate behaviour should however, be encouraged and expected at all times. People with Down syndrome can often be 'babied' as a result of their smaller stature and often immature speech and language.

» Visual learning

Children with Down syndrome will generally learn better through demonstration rather than learning through verbal instruction alone. They often find it easier to take in information presented with the support of pictures, gestures or objects.

» Gesture, mime and imitation

Children with Down syndrome are often particularly good at using their hands, faces and bodies to communicate.

» Reading ability

Reading is often a strength, possibly because it builds on visual learning skills.



NEEDS

» Speech and language development

Children with Down syndrome are typically good communicators. They are keen to interact socially from infancy but they have to rely on non-verbal skills such as gesture for longer than other children because they usually experience significant speech and language delay. People with Down syndrome can have specific difficulty with learning grammar and with developing clear speech.

Developing clear speech for a child with Down syndrome is impacted by;

- Hearing difficulties
- Their anatomical and physiological differences (that is their hypotonia, small oral cavity, high arched palate, respiratory difficulties)
- Phonological difficulties
- Weak processing of auditory information.

Since speech and language skills are fundamental to the development of mental abilities such as thinking, reasoning and remembering as well as to social inclusion, it is important that speech and language is a focus for parents, teachers and therapists from infancy through to adult life.

» Hearing and vision

Hearing difficulties are common and can contribute to speech and language difficulties and learning. 50% of children with Down syndrome wear glasses. However, both hearing and vision difficulties can usually be treated effectively or managed, with appropriate medical intervention and therapy.

» Movement

The skills needed to move around and explore, like reaching, grasping, sitting, crawling, standing and walking, tend to be delayed compared with other children. However, given time, most children become mobile and learn to be independent with feeding, dressing and toileting.

» Number skills

Some children with Down syndrome experience difficulties with number skills and learning to calculate.

» Reduced immune system

Some children with Down syndrome get many colds and blocked sinuses as a result of having a weakened immune system.

EARLY DEVELOPMENT

Infants with Down syndrome present with an uneven profile of expected development. Strengths in social understanding, self-help skills and behaviour can be identified with weaknesses evident in motor development and speech and language skills. Visual processing and visual memory skills are areas of strength and can be used by parents and therapists to support children's learning.

Early intervention is both a philosophy and a service. It simply means, intervening early in a child's life to encourage growth and development. Many different professionals are involved in providing early intervention services, including speech and language therapists, physiotherapists, occupational therapists, early educators and early development nurses.

While each baby with Down syndrome is unique; the presence of extra genetic material almost always causes recognisable developmental delays. While early intervention is individually tailored, it is also based on research into effective treatments for specific problems such as low muscle tones and speech and language delays.

Families can experience great anxiety in relation to the amount of therapies/ interventions recommended for children with Down syndrome; while specific teaching and therapies will help, there will be no greater influence on the progress of a child with Down syndrome than to be absorbed into the everyday life of the family and community. (Buckley & Sacks, 2001)



FAMILY LIFE

In the past it was assumed that the effects of having a child with Down syndrome in the family were negative. Since the 1970's and 1980's children are more likely to be brought up in the family home and attend mainstream education.

There is no evidence that having a child with Down syndrome in the family automatically produces ill effects. Most families accept the challenge of raising a child with this condition and report it as being rewarding and strengthening.

Research also tells us that siblings of children with Down syndrome are often very tolerant people, with remarkable understanding and maturity in their dealings with others.



There's no place like home

“The most powerful influence on the progress of a baby with Down Syndrome is to be loved, wanted and absorbed into the everyday life of the family. Therapists will definitely help, but must be kept in perspective and not allowed to create stress and anxiety for families.”

— Sue Hoolby & Sue Tuckey 2009

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EDUCATION

Research has shown that children with Down syndrome gain academic, social and behavioural advantages from being educated with their typically developing peers in mainstream schools.

Research has also shown that students who were educated alongside a student with Down syndrome are found to demonstrate maturity, compassion and understanding in their later professional lives.

Inclusion promotes the academic and social well-being of the student, whether or not s/he has Down syndrome. Opportunities to interact with typically developing children and teenagers on a daily basis provide the student with Down syndrome with models for age-appropriate behaviour. Mainstream educational settings also provide opportunities for the person with Down syndrome to participate in a stimulating environment with good models of speech and language.

Children and teenagers with Down syndrome require additional resources to help them with their literacy, numeracy and the curriculum in general.

Children and teenagers with Down syndrome are now completing primary and second level education, with some progressing to further education and employment.



ADULTS WITH DOWN SYNDROME

By their late teenage years, individuals with Down syndrome vary widely in terms of their health, abilities and behaviour. Their life experiences and successes cover a wide range from those who complete second/third level education to those who have little or no education; from those who are in care facilities to those who work in the open labour market and enjoy a typical adult life.

With appropriate support from an early age and with education, individuals with Down syndrome can develop a high degree of independence in adulthood.

However, there is a long way to go and much work needs to be done in the areas of further education and employment before all people with Down syndrome enjoy the same rights and opportunities as other adults to participate fully in society.



Yes,
I can run errands.
But give me
half a chance and
I'll run the company.

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The image shows a young man with Down syndrome standing at the front of a meeting room, gesturing as he presents to a group of four people seated around a table. A whiteboard with some text is visible behind him. The scene is set in a professional environment, illustrating the potential for individuals with Down syndrome to participate in the workforce.

ATTITUDES IN SOCIETY

In *To Kill a Mockingbird* Atticus Finch tells us “You never really understand a man until you stand in his shoes and walk around in them”.

Living with Down syndrome involves certain shared experiences in society including; the stares of people, the change in tone of voice when strangers and sometimes family members converse with them, and the exclusion they sometimes experience in society.



HOW YOU CAN HELP

Down Syndrome Ireland runs awareness campaigns aimed at challenging societal views and perceptions of the condition of Down syndrome.

Please visit www.downsyndrome.ie for further information on these campaigns and find out ways that you and your school can get involved and support our goal of working towards an improved quality of life for our members and a respect and acceptance of people with Down syndrome as valued members of Irish society.



PERSON FIRST LANGUAGE

The words or phrases people speak and write plus the order in which they are sequenced greatly affects the images that are formed about individuals with Down syndrome and the negative or positive impressions that result.

Words reflect attitudes, beliefs and values and they affect how people feel about themselves.

Words can create barriers and reinforce stereotypes. Down Syndrome Ireland strongly believes in the importance of ensuring that correct language is used when talking or writing about individuals with Down syndrome.

A baby born with Down syndrome is not a “Down’s child” or a “Down syndrome baby.”

When describing an individual with Down syndrome, it is preferred that you say, he/she is a baby with Down syndrome. A person with Down syndrome is not a “Downs” / “a Down Syndrome”. Placing the person before the disability emphasises the person first and the disability second.

When referring to peers, the correct term is “typical” peers as opposed to “normal.”

It is also important to use correct terminology. A person does not “suffer” from Down syndrome, nor are they “afflicted”. It is not a disease. Down syndrome is a chromosomal condition.

To use person first language, simply say the person’s name or use a pronoun first, follow it with the appropriate verb, and then state the name of the disability. When referring to an individual, always describe them as a person with Down syndrome. The correct terminology is capital “D” for Down and small “s” for syndrome e.g. John is a person with Down syndrome...

Person First language emphasises respect for the individual.

A child is much more than a label.

Help to educate family, friends and professionals about the preferred way to refer to a person with Down syndrome.

Using person first language shifts our focus from the disability to the person who has dignity, feelings and rights. This subtle but powerful language shift helps us view people with Down syndrome as individuals.

I'm a Person First

Words create barriers and reinforce stereotypes.

Down syndrome is a medical diagnosis.
A baby is born with Down syndrome.
He/she is not "a Down syndrome".

Help us to break stereotypes by using **person-first language**:

Please don't call me a Down syndrome or a Down syndrome person.

I am an adult with Down syndrome.

I am a person first and foremost.

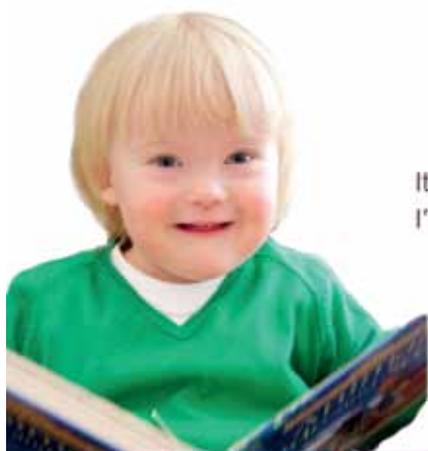
I was just born with an extra chromosome.



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It's simple, really...
I'm a person, not a syndrome.



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Please support our awareness campaign.
Visit www.downsyndrome.ie



HOW YOU CAN HELP

Visit www.downsyndrome.ie to download our 'Person-first' campaign materials.
Find innovative ways to spread the message in your school and local community.

ESTABLISHING THE FACTS!

MYTH 1 Children with Down syndrome are only born to older parents.

Many children with Down syndrome are born to women younger than 35. However, the likelihood of having a child with Down syndrome does increase with the age of the mother.

MYTH 2 People with Down syndrome are always happy.

Individuals with Down syndrome have the same emotions as everyone else. They respond to positive expressions of friendship and are hurt and upset by inconsiderate behaviour.

MYTH 3 People with Down syndrome are stubborn.

Children with Down syndrome may not be able to tell you how they feel or may require extra time to process new information or directions. This can lead to the false perception that they are being "stubborn." Behaviour is communication - individuals with Down syndrome typically face challenges with understanding and expressing language. By implementing strategies to support communication, this perceived behaviour can be greatly reduced.

MYTH 4 Having a sibling with Down syndrome will have a negative impact on other children in the family.

Many families report that siblings of a child with Down syndrome are more compassionate, patient, and tolerant because of their personal experience. The sibling relationship is generally a normal one - full of love with occasional arguments!

MYTH 5 Children with Down syndrome will never grow up to be independent.

There are now many more opportunities for individuals with Down syndrome to participate in all aspects of community life: education, recreation, employment, social, and family life. As community integration continues, we see more supports and services being developed that allow adults with Down syndrome to live an independent life.

Moving towards independence ideally needs to start when the person is young because like all people a large amount of learning needs to take place and along with this, increased experience. In people with Down syndrome learning may be slow and greater experience may be necessary in terms of opportunities.



MYTH 6 Adults with Down syndrome are unable to form close relationships.

Adults with Down syndrome can and do form close relationships such as friendships, close sibling/family relationships and sometimes romantic relationships. Adults with Down syndrome are people first and foremost with the same needs and desires as their peers with and without disabilities.

MYTH 7 Adults with Down syndrome are not suitable for employment.

People with Down syndrome want to work and represent a substantial source of untapped commitment and talent. People with Down syndrome are one of the most under-represented groups in the labour market. There is a misconception among employers that people with Down syndrome cannot cope with employment or are only able to undertake routine, methodical jobs. Down Syndrome Ireland urges employers not to make assumptions about what a person with Down syndrome can do. We ask employers to consider the skills, abilities and aspirations of each individual. Employers who do employ people with Down syndrome report that those employees are committed and motivated and often just need the chance to demonstrate their capabilities. Working alongside a person with Down syndrome can enrich the wider workforce and benefits a company in diverse and unique ways.



WORLD DOWN SYNDROME DAY

World Down Syndrome Day is a global awareness day which has been officially observed by the United Nations since 2012.



The date for World Down Syndrome Day is the 21st day of the 3rd month to signify the uniqueness of the triplication (trisomy) of the 21st chromosome which causes Down syndrome.

Join our cause to create a single global voice for advocating for the rights, inclusion and well-being of people with Down syndrome on 21 March.

HOW YOU CAN HELP

» Raise Awareness

Run a positive awareness campaign.

Make your school 'A Person-First' school by promoting the use of person-first language.

» Fundraising

There are many ways you, your family, your school or your company can help Down Syndrome Ireland. By participating in one of our events, organising an event of your own or making a donation you will help raise much needed funds that will help us to continue to provide essential services for people with Down syndrome and their families.

Please see www.downsyndrome.ie



DOWN SYNDROME IRELAND

Down Syndrome Ireland (DSI) is a national voluntary organisation supporting people with Down syndrome and their families in twenty-five branches nationwide.

Down Syndrome Ireland provides a nationally recognised voice for people with Down syndrome and their families. DSI provides information and advice, influences policy, raises public awareness and works towards the improvement of education and services for children and adults with Down syndrome.

Down Syndrome Ireland is substantially funded through donations and national fundraising events.

MISSION STATEMENT

Down Syndrome Ireland (DSI) is dedicated to being the primary source of information and support to people with Down syndrome, their families and the professional community, working towards an improved quality of life for our members along with a respect and acceptance of people with Down syndrome as valued members of Irish society.

LOCAL BRANCHES

DSI comprises a professionally staffed national office and twenty-five local branches servicing and supporting our members across the country.

The local branches are run on a voluntary basis by our members and offer a range of services, activities and supports. Branches are funded through donations and local fundraising. Each branch is unique in the type and range of services they offer. Samples of services include speech & language therapy, early development groups, adult literacy classes and drama classes.

For more information on your local branch see www.downsyndrome.ie

THE NATIONAL RESOURCE TEAM

Expertise and Understanding

The National Resource Team at Down Syndrome Ireland provides specialist support in the areas of early development, education, counselling, health, speech and language therapy and independence to our members and the professional community connected by Down syndrome.



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RECOMMENDED READING

Books

- Down Syndrome – The Facts 3rd Edition, Mark Selikowitz, (2008)
(Some pages accessible on Google Books)
- Down Syndrome – An Introduction for Parents and Carers, Cliff Cunningham,(2006)
- Early Communication Skills for Children with Down Syndrome – A Guide for Parents and Professionals, Libby Kumin, (2003)

Websites

www.downsyndrome.ie

www.downs-syndrome.org.uk/information

www.downsed.org

www.mosaicdownsyndrome.org







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