



Down
Syndrome
Ireland

National Leadership Local Support

Down Syndrome – What is it all about?



An easy-to-understand
guide to Down syndrome



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SECTION 1

Down Syndrome



Down Syndrome



Down syndrome is something that happens in babies when they begin to grow in their mum's tummy before they are born.



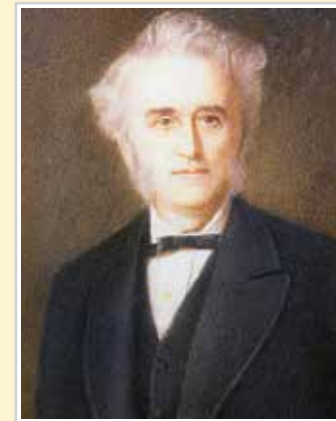
In Ireland, 1 in every 444* babies born has Down syndrome.



Nobody knows why Down Syndrome happens.

*Eurocat, 2010

Why is it called Down syndrome?



Down syndrome is called after Doctor John Langdon Down.

Doctor John Langdon Down noticed that some of his patients looked alike.

This happened a very long time ago in 1866.

What is a syndrome?

A syndrome is the name given to a collection of different things grouped together in your body.

Down syndrome is not an illness.

Down syndrome is not a disease.

Sometimes you can have health problems and learning difficulties when you have Down syndrome.

Many people with Down syndrome are very healthy and can learn lots of different things.



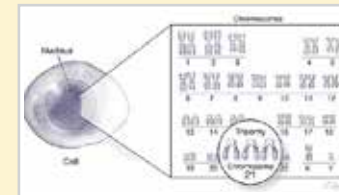
It's simple, really...
I'm a person, not a syndrome.

Down Syndrome Ireland
National Leadership Local Support

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

How does Down syndrome happen?

Down syndrome happens when you are born with an extra **chromosome** inside your body.



Chromosomes are tiny thread-shaped things inside your body.

Chromosomes are inside the cells of your body.

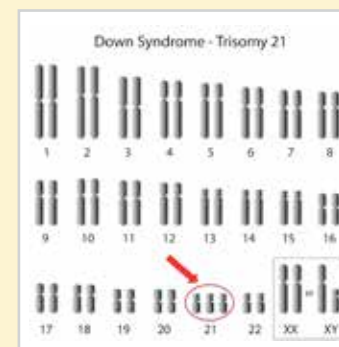
Chromosomes contain the instructions that tell your body how to grow.



These instructions will tell your body what colour your eyes and hair will be.



These instructions also decide how your heart, lungs and brain develop.



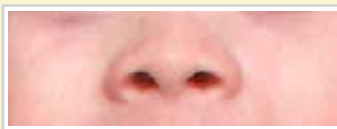
People with Down syndrome are born with an extra copy of chromosome number 21.

This extra chromosome 21 makes people with Down syndrome look and learn a little differently.

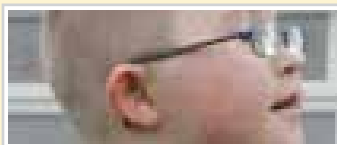
Things you notice about people who have Down syndrome



Eyes are sometimes shaped like almonds.



Nose can be flat and small.



Ears can be small.



A line across the palm of the hand.



People with Down syndrome can be shorter in height than other family members.

These things can be found in many people but are more common in people who have Down syndrome.

Am I like others?



You may look a bit like others who have Down syndrome.



You will also look like your parents, brothers and sisters.



There is no one in the world just like you, this means that you are **unique**.

SECTION 2

Down syndrome – The way you learn



The way you learn

Most people with Down syndrome learn things more slowly and in different ways.



You might like to learn from pictures or the computer.

You might have some difficulty remembering things.



Many people who have Down syndrome can read.

Some people who have Down syndrome find it difficult to read.

You will learn new things all your life.

Everybody is smart in his or her own way.

Speech and Language

Most people with Down syndrome have some difficulty with their speech.

Sometimes it is hard for people with Down syndrome to say all of their words clearly.

You might get help from a speech and language therapist.



A speech and language therapist will help you to learn how to **communicate**.

When you **communicate** you share information or ideas with other people.

Most people with Down syndrome can talk.

Some people with Down syndrome use other ways to communicate.

Some people with Down syndrome will talk and use other ways to communicate also.

Other ways to communicate



Sign Language.

Sign language is when people use their hands to communicate.

In Ireland, many people with Down syndrome use Lamh signs.

Lamh signs are used with speech to communicate important words in sentences.



Some people with Down syndrome use pictures to communicate.



Some people with Down syndrome use **gesture** to communicate.

Gesture means moving part of your body or your head to communicate.



Some people with Down syndrome use their phone to communicate.



Some people with Down syndrome use a tablet computer to communicate.

A tablet computer is a small touchscreen computer.

An I-Pad is a type of tablet computer.

Phones and I-Pads have pictures that help a person communicate.

Some phones and I-pads have programmes that use a voice to help a person to communicate.



People with Down syndrome can understand a lot of words and learn new words all of the time.

Some people with Down syndrome can speak very clearly.

SECTION 3

Your Body

Your body and health may be a bit different when you have Down syndrome.

In this booklet there is information about:

- Muscles
- Heart
- Eyes
- Ears
- Thyroid
- Weight
- Sleep Apnoea



Muscles



People with Down syndrome may have muscles that work more slowly.



It can be hard to do some activities such as climbing or running.



People with Down syndrome can be very good at a lot of sports



A physiotherapist can show you exercises to do, to help make your muscles stronger.



A physiotherapist is a person who can give you exercises to do if you have weak muscles.



Exercise is very important to keep your muscles strong and healthy.

Heart



Your heart has to pump blood to your lungs and around your body.



The right side of your heart pumps blood to your lungs

The left side of the heart works hard to pump blood all around your body

Some babies with Down syndrome are born with hearts that don't work properly.



Doctors can often fix these heart problems.



Some people take pills to help their heart to work better.

Eyes



A lot of people with Down syndrome wear glasses.

Glasses help you to see better



It is important to have your eyes checked each year.

Ears

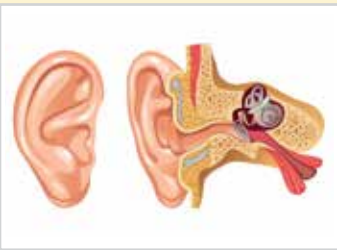
Tell your doctor if you need people to talk louder.



Tell your doctor if you always need to turn up the sound on the TV.

Your doctor will be able to help.

Some people with Down syndrome have hearing loss.



Hearing loss means that sound cannot pass through the ear very well.

This might be because the tubes in the ear are very narrow.

Ear wax can block the sound getting through the ear.

The doctor can clean your inner ear if there is a lot of wax in your ear.

Sometimes the nerves in the ear do not work properly and sound cannot get through the ear.

People with a hearing loss might need a hearing aid.

A hearing aid helps a person to hear better.



Thyroid



The thyroid gland is found in the front of the neck.

Your thyroid controls how fast or slow your body grows.

The thyroid makes thyroxine.

Thyroxine helps you grow and learn.

The thyroid might make too much or too little thyroxine.

An under-active thyroid is more common in people with Down syndrome.

An under-active thyroid can mean that you slow down, gain more weight and have more difficulty learning.



Your doctor needs to check your thyroid each year to check if there is a problem.



You can take pills to help fix the problem.

Weight Management



Your body needs food.

Food gives your body energy to do things every day.

If you do not **exercise** all of the food you eat is not used up by the body.

The body then keeps it as fat.



If you carry too much fat then you can be **overweight**.

If you are overweight it can damage your heart.

People with Down syndrome can put on weight quicker than other people.

This happens because your body takes longer to use up the food you eat.

Sleep Apnoea

Sleep apnoea is very common in people who have Down syndrome.

Sleep apnoea means that you may not sleep very well and wake up often during the night.

This can make you tired during the day.

You may need extra pillows to help you sleep better.

You may need a machine to make it easier for you to breathe while you sleep.

The machine is called a CPAP machine.

Many people use CPAP machines very well.



Real Life Story



My name is Shaun Bradley.

I am 26 years old.

I was diagnosed with sleep apnoea when I was a teenager.

Sleep apnoea is a disorder in which you have pauses in your breathing or shallow breaths while you sleep resulting in a disrupted sleep which leaves you very tired during the day.

I was given a machine to use to help me sleep at night.

At first I was worried and reluctant to wear it.

It was very uncomfortable and took some time to get used to it.

Ten years later, I find it strange going to sleep without my mask.

I get a better night sleep now and I don't feel as tired during the day.

My family noticed a difference in my mood when I started to use the mask and joke that I am not as grumpy in the morning.

Self Talk

People talk to themselves all the time.

Most of the time people talk to themselves silently in their heads.

People with Down syndrome often express their thoughts out loud.

People around you can then hear your private talk called self-talk.

Self-talk when done in a private place helps you to work out problems and make plans.

Self-talk when done in a private place helps you to express feelings

If you talk to yourself make sure you are in a private place.

Self-talk in a private place means that your thoughts you want to keep to yourself stay private.



Questions people ask about Down syndrome



Am I sick?

No.

You may get sick sometimes just like everybody else.

Most people with Down syndrome live healthy and happy lives.

Remember people who do not have Down syndrome have health problems too.



What can people with Down syndrome do for hobbies or a job?

People with Down syndrome can do many things;

Roisin passed her Leaving Cert with honours in some subjects and did all her subjects through Irish.

Emily sailed in the training ship 'Asgard' in force nine gales and walked from Slane to Glendalough.

Paul works in a pub.

Daragh works in supermarket.

Declan works in an office.

Conor works on the radio.

David travels to France each year for a holiday with his friends.

Shaun travels by himself to Philadelphia in the United States each year to visit his family.

People with Down syndrome can do many things and be very proud of themselves!

A NOTE TO PARENTS:

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”.

Parents are the closest observers of people with Down syndrome and know their child better than any person outside the family circle. Parents work extremely hard to provide therapies, stimulation and the means for their child to reach his/her full potential. Yet, there are times when the most important subject of Down syndrome is not discussed at all or only referred to as a special need.

When we began personal development work in Down syndrome Ireland we learned that teenagers and adults sometimes suggested that:

- » Down syndrome was a party they went to at Christmas time.
- » Down syndrome was something their mother had as she was often on the phone talking about it.
- » Down syndrome was an ice-cream party.
- » I only have a little bit of it.

These quotes illustrate the lack of communication about the condition.

Dave Hingsburger, International Disability Specialist, suggests that because Down syndrome is such a visible condition, parents need to explain it, as early as possible, both to the person with Down syndrome and their siblings. He further suggests that not addressing this issue leaves the person with Down syndrome further disadvantaged in the community.

When training a group of adults for the World Down syndrome congress in 2009 we discovered a hunger within that population to know more about what sets them apart from the general population. They notice 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.

All children with Down syndrome need good self-esteem in order to negate the messages coming from society. For all of us good self-esteem begins with accepting who we are. For people with Down syndrome that means accepting that they have Down syndrome. They cannot be proud of themselves if they cannot understand and accept their condition.

This can be done very successfully within the family but we must not underestimate the power of groups to inform, heal and educate. Children with Down syndrome may not have the expressive language required to ask questions the condition but they enjoy getting the information and understand much more than they say about it when they receive the information.

In Down Syndrome Ireland we hope this booklet will help to inform and provide facts about the condition in an easy to read format for our members.

Our family members with Down syndrome are unlikely to gain access to this information unless we, their parents, provide them with the opportunity.

May Gannon

May Gannon

Parent & Former Director of the National Resource Team at Down Syndrome Ireland

TESTIMONIALS FROM ADULTS WITH DOWN SYNDROME

Prior to publication this booklet has been reviewed by Irish adults with Down syndrome. Listed below are testimonials from the group. Please note names used are fictitious but ages remained unchanged.

“I know I have Down syndrome but I am a normal person doing normal things in my life. My Dad explained Down syndrome to me, about chromosomes, and it's not a disease but it's in your body and you can't change that. You can go out and socialise with other people. A booklet like this helps us to understand our feelings. In this booklet are important issues for teenagers and adults to read”

Donal, 23 years

“When I was a baby I didn't know I had Down syndrome but my family told me I am so special and can do many things. I keep myself busy and do work and activities like sport. My life expands and is very interesting. My mam explained to me about Down syndrome and I know I am a unique person. We need this booklet to let people know what Down syndrome is about.”

Daithi, 27 years

“I don't remember when I found out I had Down syndrome. I heard about the extra chromosome on the Ambassador programme and the history of Down syndrome. It doesn't matter who you are, you are born with an extra chromosome and you need to be positive about Down syndrome. We need this booklet for parents to help explain what Down syndrome is about”.

Seamus, 27 years

“You should be proud of who you are. Don't look at the negative, look at the positive. The negative is when people stare at you and don't recognize you as a person. The positive is that we live our lives to the full and use our gifts and talents. We need the booklet to understand what Down Syndrome is all about”.

Tim, 30 years

“I like being myself, learning more skills and moving towards independence. Down syndrome did not stop me doing anything. The booklet explains Down syndrome”.

Mark, 29 years

“I felt fine when I was told about Down syndrome. I was nineteen when my mother told me. She wasn't ready to talk about it before then. I have my life and I enjoy it to the full. The booklet would help children to know they have Down syndrome and help parents to talk about it”.

Oonagh, 23 years

“I remember my Mum told me when I was thirteen. At first I was surprised and shocked. I shed a few tears and said Why Me? They told me I was a special gift. I have learned a few things about Down syndrome. I didn't know about the extra chromosome until the ambassador programme. I felt great when I learned that and relieved to know what it is about. It doesn't affect my life at all. I am independent. The booklet is good to have for teenagers and adults to understand what it means to have Down syndrome”.

Jack, 26 years

"I don't remember when I learned I had Down syndrome but I was probably around 11 or 12 years old. I know it's a condition I have and it's not a disease. My Dad told me I am a beautiful woman and I should have confidence in myself. Having a job makes me feel very important.

The booklet is a great idea to help us express what it is like to have Down syndrome. Lots of people don't have Down syndrome and they would be very interested to learn what it is like growing up with Down syndrome. This booklet will help children, whether they have Down syndrome or not, to talk to each other about living with Down syndrome and share their ideas.

Annie, 28 years



"I knew I had Down syndrome because I was special to everyone in my life. My family said "I need a little hand to do things". When I was younger I felt good and brilliant. Now I am older I still feel good. We need the booklet to help younger people and teenagers learn about their disability. I hope parents will read the booklet and explain to teenagers and adults about their feelings".

Paddy, 20 years

I'm proud of who I'm and all I have accomplished. I'm the youngest of 7 children. I was born in the National Maternity Hospital. My parents and siblings were involved in my education from Day one in my life. They learned to do all the muscle toning drills when I was three weeks old. Down Syndrome is part of my life which makes me very proud. Because of it I have met lots of people from across the world. I feel I know a lot about Down syndrome and can help others.

Tina, 28 years

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WEBSITES

www.downsyndrome.ie as of March 2015





National Leadership Local Support

Citylink Business Park,
Old Nass Road, Dublin 12.

T: 01 4266500 / 1890 374 374

E: info@downsyndrome.ie

www.downsyndrome.ie

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