



Down Syndrome and You

A booklet for people
with Down syndrome

*Canada's national voice for
individuals with Down syndrome*





Do you have Down syndrome? Then this booklet is for you.

Down syndrome is something that happens in babies even before they are born. About one of every 800 babies born in Canada will have Down syndrome. So far, no one knows why.

The Canadian Down Syndrome Society has written this booklet to tell you some things about the syndrome. We hope we have answered some questions you may have.

We hope you enjoy this booklet.

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How did Down syndrome get its name?

The name came from Dr. John Langdon Down, who wrote about it in 1866.

What is a syndrome?

A syndrome is a group of different things that can happen in your body. Down syndrome is not an illness or a defect, but sometimes you can have health problems or difficulties because of it.

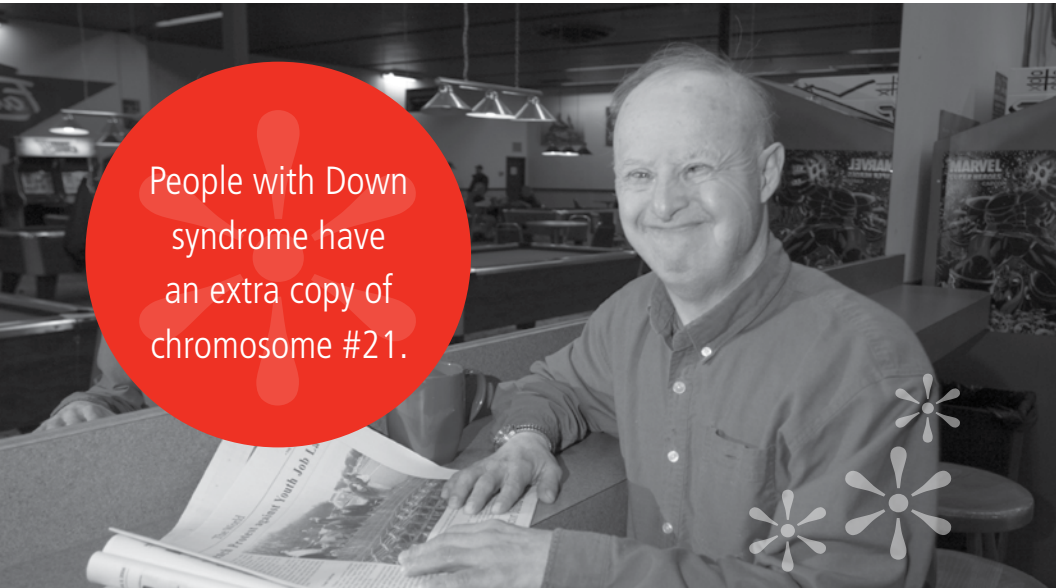
Who has Down syndrome?

Anyone can be born with Down syndrome. It does not matter:

- * If you are a boy or a girl
- * The colour of your skin
- * Where you were born
- * If you were born into a poor home or a rich home
- * If your mother and father had lots of education or very little.

Down syndrome just happens. It is important to understand that your parents could not have done anything to make sure you did not have Down syndrome. It does not go away.

How does Down syndrome start?



People with Down syndrome have an extra copy of chromosome #21.

Down syndrome happens when you are born with an extra chromosome (*sounds like krome-o-soam*) in each cell in the body. People with Down syndrome have an extra copy of chromosome #21.

Chromosomes are the tiny parts of cells that carry genes (*sounds like jeans*); and cells are the tiny parts that make up the body. Chromosomes come from your mother and father. Chromosomes carry all the information that makes you just who you are, such as the colour of your eyes and hair, how tall you are and the shape of your nose.

Some things about Down syndrome that can be seen

- * Your eyes may be shaped like almonds and have beautiful light marks in the coloured part, called Brushfield spots.
- * Your nose may be flat and small.
- * Your ears may be small.
- * You may have a gap between your first and second toes.
- * You may have a line across the palms of your hands that is different from other people's.
- * You may be a little shorter than other people in your family.

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

If you have Down syndrome, you may look a bit like others with Down syndrome. But you will also look like your parents, brothers and sisters. There is no one in the world just like you.

Down syndrome and the ways you learn

Most people with Down syndrome learn things more slowly. You may learn a little slower, or you may find it hard to learn. People with Down syndrome often learn in different ways. Maybe you like to learn from pictures. Maybe you have a great memory and do not need to write things down to remember them.



You will
learn new things
all your life.

Many people with Down syndrome can read. Some cannot read well, and some can read very well. No one can tell how well you will learn to read, or how long it will take. There are different kinds of smart and you are smart in your own way. You will learn new things all your life.

Your body

As a person with Down syndrome, your body and health may be a bit different. There are some big problems and some small. No one has all of them. Here are things that some people with Down syndrome may have.

Muscles (*sounds like muss-els*)

People with Down syndrome often have muscles that work more slowly, so it is harder to do some activities such as climbing or running.

Heart

Your heart's job is to pump blood to your lungs and around your body. This keeps you strong and well. Some babies with Down syndrome are born with hearts that are a little different. Most of the time doctors can fix heart problems.

Some people with Down syndrome may need to take medication (*probably pills*). Some of you may have had an operation; while others may have no heart problems at all. Some of you may need to take heart pills before you visit your dentist.

Sleep

Sleep apnea (*sounds like ap-nee-ah*) is very common. This means you may not sleep well. You might snore, sleep sitting up or with your head between your knees. You may wake up often at night.

We all need sleep to feel rested and to have energy to work, learn and have fun.

When we do not sleep well, it can lead to other problems.

To help you sleep well, you may need extra pillows, or a machine to help you breathe. This is called a CPAP (*sounds like see-pap*) machine. Lots of people use a CPAP machine.


Stomach (*under your ribs*) and belly (*your guts*)

People with Down syndrome are mostly healthy, but you may need to take medication (often pills) or pick different foods to eat in order to keep your stomach and belly well. Your doctor can tell you what to do. Here are some things you may notice.

- * You may burp a lot.
- * You may throw up.
- * You may have pain in your stomach or belly.
- * You may need to run to the bathroom often. When this happens, you may have diarrhea (*sounds like dy-a-ree-a*).
- * On the other hand, you may not have a bowel movement for many days. When this happens, you have constipation (*sounds like con-sti-pay-shun*).
- * You may find you are often very thirsty.

Eyes

You may need to wear glasses to see well – this is very common. It is important to have your eyes checked each year.



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Ears

You may need a hearing aid; this is very common for people with Down syndrome. If you need people to talk louder so you can hear, tell to your doctor.

Thyroid

Our bodies make thyroxine (*sounds like thy-rocks-in*) to help us learn, grow and stay healthy. Your body may make too much or too little. Doctors need to check often for this, so that you can get pills if you need.

Skin

If your skin is itchy or cracked, show your doctor. Your lips can get dry and cracked too. Sometimes your head itches and you may need to use dandruff shampoo. Remember not to take really hot baths. That can dry out your skin.

If you use a public swimming pool, remember to shower well after swimming. Swimming pool water has chemicals in it that can dry out your skin.

When you use sunscreen, use one that does not have PABA in it, as PABA makes many people itchy.

Feet, knees and hips

It is important for your feet and legs to feel good so you can walk, run, do sports and get out to meet friends. Always wear shoes that fit well and are comfy.

If you have problems with your feet or legs, tell your doctor. You may need an X-ray, or need to see a physical therapist. You may need different shoes, or supports in your shoes.

Neck

The bones in your neck help keep your head up and allow messages to go from your brain to the rest of your body. If the messages cannot reach your body, you may have problems with your feet and legs. You may also not be able to control your bladder or bowel. Tell your doctor. Your doctor may want you to have some X-rays or other tests, so that the problem can be fixed.

Germs

It is easy to catch germs and get sick. Keep away from people with colds if you can. Remember to wash your hands before you eat and after a visit to the bathroom. When you keep your hands clean, it is easier to stay well.

Tiredness

You may get tired easily. You may feel tired even when you sleep a lot. You need to exercise and eat healthy food to give your body the energy it needs.

Some questions you may have

Am I sick?

No, not at all. You may get sick sometimes, but you will not have all the problems we have listed here. Most people with Down syndrome lead lives that are healthy and happy.

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



Some people may call you disabled and not see all the things that you can do.

Am I disabled?

Everyone in the world can do some things better than others. If people cannot do things, they are called disabled. It is not a bad thing to be disabled.

Some people may call you disabled and not see all the things that you can do.

Dating and relationships

Can I have a boyfriend or girlfriend?

Yes, yes. Like everyone else, people with Down syndrome want to have close friends and people who love them.

Can I have babies?

If you are a woman with Down syndrome, you can usually get pregnant and have babies. But if you are a man with Down syndrome, you may not be able to make babies. Most men with Down syndrome do not have many sperm (which you need to make babies).

It is a very big job to look after a baby. You must think carefully before you plan to become a parent. It is OK if you think you do not want a baby.

If you want to be a parent, but you cannot have a baby, you may feel very sad. It can be good to find someone you trust to talk to about this.

Will my baby have Down syndrome?

Maybe. Half of the babies with mothers who have Down syndrome also have Down syndrome.

Stories about Down syndrome that are not true

Many people do not know much about Down syndrome and say things that are not true. Do not listen to everything you hear about Down syndrome.

- 1 Many people think that everyone with Down syndrome is happy and easy to get along with.

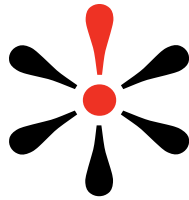
Not true. Like all people, this is only true some of the time. Even if you are easy to get along with, you probably want your own way at times. There are times when you may be angry or hurt. You do not need to be happy all the time.

- 2 People with Down syndrome are not as good as other people.

Not true. This is *very* wrong. You are an important part of your family and the community where you live.

- 3 People with Down syndrome cannot have a boyfriend or girlfriend or go out on dates.

Not true. Like everyone else, you can have close friends, go on dates and have people you love in your life. You can marry someone, if you meet the right person, or live together as partners. There is no reason why you can't, even if you need some support.



*This booklet is for general information only.
It does not take the place of professional help
when you need it.*



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