Information about Down Syndrome

FOR EXPECTANT PARENTS

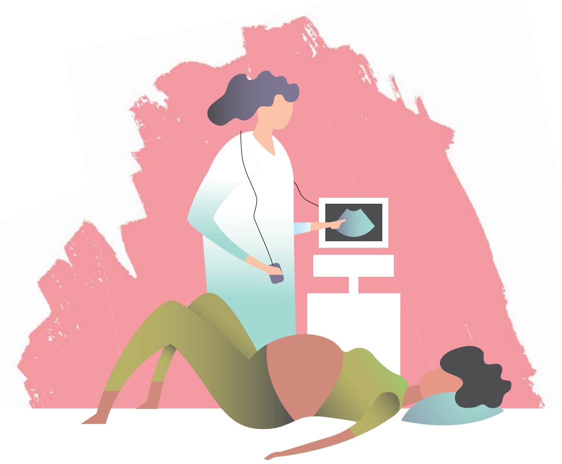
Canadian
Down Syndrome
Society

Société
canadienne de la
trisomie 21

INFORMATION ABOUT DOWN SYNDROME FOR EXPECTANT PARENTS

Undergoing prenatal screening and diagnostic testing for Down syndrome is a very personal decision. The Canadian Down Syndrome Society has developed this resource for women who are considering having prenatal screening or they have recently learned of the possibility of their child having Down syndrome and are seeking more information about Down syndrome.

The Canadian Down Syndrome Society respects the right of women to make decisions about their pregnancy that are aligned with their own personal values and beliefs. We support informed decision making by ensuring that women have access to accurate and up to date information about Down syndrome.



INFORMATION ABOUT PRENATAL TESTING

The following section provides an information overview about prenatal screening and diagnostic testing for Down syndrome. **Screening** tests are used to estimate the **chances** of your baby having Down syndrome. **Diagnostic** tests can provide a **more conclusive** diagnosis of Down syndrome.

Prenatal screening is an option available to everyone during pregnancy. Prenatal screening is non-invasive and determines the chance of having a baby with Down syndrome and does not provide a definitive diagnosis of Down syndrome. It is your choice whether or not to have a prenatal screening test. If your screening test results indicate that there is an increased chance (screen positive) your baby has Down syndrome, you can decide if you would like to undergo further diagnostic testing, the choice is yours.

Diagnostic testing will tell you if your baby **has or does not have** Down syndrome. With more invasive medical procedures that involve obtaining a sample of the baby's genetic material, an amniocentesis and chorionic villus sampling (CVS) can provide a **more conclusive diagnosis** of Down syndrome, but there is an increased risk of miscarriage (less than 1%).

For more in depth information on the types of tests available in Canada and the information these tests provide, please consult with your prenatal care provider or a genetic counsellor.

THE CHOICE IS YOURS

Women can choose to undergo prenatal screening and diagnostic testing for their own reasons including preparing for the birth of the child; learning more about the condition and what it is like to raise a child with Down syndrome; learning about the resources available in your area and working with your health care team who will be involved in the pre and post-natal care of your child.

If the diagnostic tests determine that your baby has Down syndrome, your health care provider can offer and discuss the choices expectant parents have about continuing or ending the pregnancy. It is imperative to take some time to understand and consider all of the information available on Down syndrome and make the decision that is right for you. It is reported that women have lower levels of regret surrounding their decisions when they have access to high quality, up to date information, don't feel pressured, and have access to non-directive counselling and support by health care providers.

Your medical team is available to provide support, answer questions and discuss the results of the Down syndrome diagnosis while you are considering the available options.

When you are ready, there are local Down syndrome organizations and community support groups who can provide current information and resources about Down syndrome.

WHAT IS DOWN SYNDROME?

Down syndrome is a genetic condition. It is not an illness or disease.

All people with Down syndrome have an extra copy of chromosome 21. It is largely unknown why some babies are born with the extra copy of chromosome 21, but it does occur at the point of conception. Down syndrome crosses all barriers and affects people from all age, race, gender and socioeconomic backgrounds and almost always occurs randomly. The chance of having a baby with Down syndrome increases with the mother's age; however, about half of babies born with Down syndrome are born to mothers under 35 years old simply because more young women are having babies.[1]

People with Down syndrome might look similar and share some common physical features, but most of all, they will look like their family members and will have their own unique personality.

People with Down syndrome have:

- Some level of intellectual disability
- Some delay in development which may include delays in speech development and motor skills
- Some characteristic physical features, including a recognizable facial appearance and short stature[2]

With appropriate medical interventions and treatment, most people with Down syndrome can have healthy lives. In 1983, people with Down syndrome only lived to about 25, now the average is 60 years old. However, as with anyone else, there is no definitive life span and some people with Down syndrome have lived well into their 70s.

Some health concerns for people with Down syndrome may include:

- Congenital heart conditions
- Gastrointestinal issues
- Increased risk of developing childhood leukemia
- Respiratory infections
- Sleep issues
- Thyroid problems
- Vision and hearing problems

It is important to remember that not all people with Down syndrome will experience these health concerns. Most health issues associated with people with Down syndrome also occur in the general population and in many cases, the health conditions can be successfully treated and managed by careful monitoring.[2]

There are three types of Down syndrome and the type is identified from the chromosome studies done at birth to confirm the diagnosis of Down syndrome:

Trisomy 21 is the most common type of Down syndrome- it includes 95% of the Down syndrome population.

Translocation occurs in only 2-3% of those born with Down syndrome. After a child is born with translocation Down syndrome, the parents can have their chromosomes tested to see if there is a risk of future children having Down syndrome in subsequent pregnancies.

Mosaicism is the least common type of Down syndrome. In about one percent of children with Down syndrome there is an extra whole chromosome 21 in only a percentage of their body cells- the rest of the cells do not have the extra chromosome.

> ***No matter which type of Down syndrome your child has, the effects of the extra genetic material will be unique to them. They will have their own strengths, likes, dislikes, talents, personality and temperament. Think of your baby first as a child. Down syndrome is just part of who they are.***

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[1] https://www.ndsccenter.org/wp-content/uploads/2017-PTP-Eng.pdf

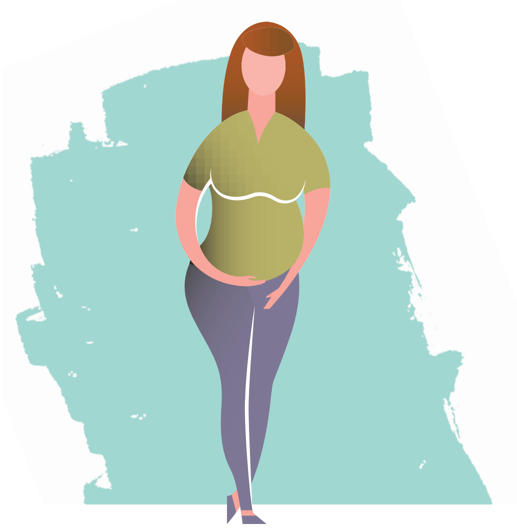
[2] www.downsyndrome.org.au/documents/resources/prenatal/DSA_AGuideForExpectantParents_Resource.pdf

DEALING WITH INITIAL FEELINGS AND ADJUSTING

People will react differently to learning that their child has or may have Down syndrome. Personal reactions can vary and can be dependent on their personal values, beliefs and their expectations of having a baby.

All parents have different feelings when they find out their child may have or has Down syndrome. Some expectant parents feel happy and excited while some will experience feelings of disbelief, sadness, guilt or disappointment. Many feel a lot of uncertainty and doubt regarding their child's future. All of these feelings are perfectly normal and there is no right or wrong way to feel. You should know that there is absolutely nothing that you did to cause your child to have Down syndrome.

No matter how you feel, remember that you are not alone on this journey. Your partner, other children, and other family members may be experiencing feelings and emotions similar to yours. Take as much time as you need in your journey as you will probably have a lot of questions and concerns. Be patient and kind to yourself and if you feel like you are not able to cope, seeking help from friends, family or other professional supports may be helpful.



> ***"What you are feeling is natural and normal. Be gentle with yourself. There will be bumps and worries along the way, but that's part of parenthood, period. There are lots of parents who have walked in your shoes and they are happy to support you."***
>
> *– Parent of a child with Down syndrome*

COMMON MISUNDERSTANDINGS ABOUT PEOPLE WITH DOWN SYNDROME

✗ People with Down syndrome are limited on what they can achieve in life

People with Down syndrome participate in school, sports teams, performing and visual arts programs, volunteer and are employed in the community. They are able to achieve life goals and participate in their communities just like everyone else. People with Down syndrome may face some challenges in his or her life but with the proper supports and resources, he or she will be able to continue to learn, contribute and live a meaningful life.

✗ People with Down syndrome cannot attend regular public schools

All students including those with Down syndrome, have a right to be included and progress within an inclusive educational environment. Students of all abilities can learn together and are valued and participating students. Most children with Down syndrome have a mild to moderate level of intellectual disability, may have to work harder to reach the developmental milestones and may need some level of support. Some will have more significant educational and support needs and may require a specialized program. Early involvement from intervention specialists like speech language, physical and other developmental therapies as early as infants, toddlers and throughout childhood can help with developmental delays.

✗ People with Down syndrome cannot live independently and will depend on their parents for support for the rest of their lives

Many expectant parents worry about how a child with Down syndrome may change their lives and affect the rest of the family. They may have a hard time envisioning their family and the potential successes and challenges of raising a child with Down syndrome. A great deal of work has been done in improving advocacy and acceptance for people with Down syndrome. This has made it possible for people with Down syndrome to get a post-secondary education, find employment and a growing number are living independently or semi-independently. More opportunities are available today for education, employment and living options than ever before. With the proper support and preparations, people with Down syndrome can live an ordinary life with abundant opportunities and be a vital part of the community.

✗ Babies born with Down syndrome are not healthy

The effects from the extra genetic material vary from person to person, and there is an increased chance that babies born with Down syndrome will have health issues. During the pregnancy and after the baby is born, there will likely be careful monitoring to help manage and treat any health issues that arise. Although people who have Down syndrome can experience some health concerns, there are no guarantees that the baby will experience any or all of the common health conditions.

It is important to remember that babies with Down syndrome need what all babies need: cuddles, nourishment and love. They will grow, learn and reach developmental milestones — just at their own rate.

LIFE WITH DOWN SYNDROME

Things have changed for people with Down syndrome and the opportunities that are available to them have improved greatly. An increasing number of supports and resources are available to people with Down syndrome and their families. Children with Down syndrome now have the opportunity to attend their community schools and participate in inclusive learning environments with their peers.

The level of advocacy, awareness and acceptance for people with Down syndrome has improved drastically and has become an important part of many societies. It has opened up opportunities for people with Down syndrome to pursue post-secondary education, find employment and live independently.

Like raising a typical child, children with Down syndrome may face challenges throughout their lives, experience negative attitudes and low expectations. But with parents as their biggest advocates, it is important to challenge those perspectives, create opportunities and help people with Down syndrome live a fulfilling and meaningful life.

> “*Individuals with Down syndrome benefit from loving homes, early interventions, inclusive and accommodating education and being connected to appropriate community resources throughout their lives.*”

CONNECTING WITH OTHER PARENTS

Many parents find connecting with other parents and families who have a child with Down syndrome a helpful way to share feelings, concerns, and experiences and to learn about the resources available. Although no two families, children or experiences are exactly the same, talking to other people who have gone through similar experiences might be helpful.

When you feel ready, contact a local Down syndrome organization that can connect you with other parents, families and community supports who would be happy to talk with you.

SHARING THE NEWS WITH YOUR FAMILY AND FRIENDS

If you have recently learned that your baby may have Down syndrome, you may be dealing with difficult emotions. Sharing the news with family and friends can be very challenging as you may still be adjusting to the news yourself. You may want to share the news during the pregnancy or you might wait until the baby is born, but whenever you choose to, tell them when you are ready.

Some people may have inaccurate and outdated ideas about Down syndrome, but by offering them the most current information and an invitation to learn along with you, they can also be part of your support network.

> ***It is important to remember that raising a child with Down syndrome will be much like raising any child. There will be ups and downs, challenges, successes, smiles, laughs and tears.***

USEFUL LINKS AND RESOURCES

Canadian Down Syndrome Society: www.cdss.ca

21 Answers: https://cdss.ca/down-syndrome-answers/

Dear Future Mom: www.youtube.com/watch?v=Ju-q4OnBtNU

Down Syndrome Australia: www.downsyndrome.org.au/resources/prenatal.html

Genetics Education Canada: https://geneticseducation.ca/public-resources/prenatal-and-preconception-genetics/

Global Down Syndrome: www.globaldownsyndrome.org/about-down-syndrome/facts-about-down-syndrome/

Lettercase: https://resources.lettercase.org/

National Down Syndrome Congress, Prenatal Testing & Information about Down Syndrome pamphlet: https://www.ndsccenter.org/wp-content/uploads/2017-PTP-Eng.pdf

CANADIAN DOWN SYNDROME SOCIETY

The Canadian Down Syndrome Society partners with local support groups to provide comprehensive, in community and online support for people with Down syndrome and their families.

Please contact Canadian Down Syndrome Society at **1-800-883-5608** or visit our website at **https://cdss.ca/community/affiliates/** for more information on Down syndrome organizations near you.

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