

Congratulations on the arrival of your baby! While you may have been surprised to learn your baby has Down syndrome, know they will be a wonderful addition to your family.

Babies with Down syndrome need what all babies need – cuddles, nourishment, and love. They will grow, learn and develop, reaching childhood milestones – just at their own rate. Although your baby may have some physical characteristics common to people with Down syndrome, he or she will also look like members of your family.

Your baby also needs health care, a rich, stimulating learning environment and the company of family and friends. This brochure explains some of the common characteristics of individuals with Down syndrome, including possible health and development issues.

You are not alone – approximately 500 babies are born with Down syndrome each year in Canada. There are 50 Down syndrome groups associated with the Canadian Down Syndrome Society, offering information and support.



# Your Child With Down Syndrome



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Canada's national voice for  
individuals with Down syndrome



Down syndrome is not a disease, disorder, defect or medical condition. It is a naturally occurring chromosomal arrangement. Down syndrome has always existed; it happens in all races, geographic areas, socio-economic communities and genders. Today, one in every 800 babies born in Canada has Down syndrome.

Nothing you or your partner did before or during pregnancy caused the Down syndrome. It happens in the early stages of cell division at conception – something we still do not fully understand.

There are three types of Down syndrome: Trisomy 21, translocation and mosaicism. About 95 per cent of people with Down syndrome have Trisomy 21, with three copies of the 21st chromosome in every cell in their body instead of two.

Two to three per cent of people with Down syndrome have a translocation pattern. During cell division, a part of the 21st chromosome breaks off and attaches itself to another chromosome, usually the 14th. About two-thirds of translocations occur spontaneously; the rest are inherited from a parent.

In mosaicism, some cells have 46 chromosomes and some have 47. The percentage of cells with 47 chromosomes varies from person to person.

What is Down syndrome?  
You likely have lots of questions.



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 as a child first. Down syndrome is just a part of who they are.

Many people are surprised to hear that 80 per cent of children with Down syndrome are born to women younger than 35 years old. While the chance of Down syndrome increases with maternal age, a baby with Down syndrome can be born to any woman of child-bearing age. Younger women have more babies than older women, so they have more babies with Down syndrome.

The word syndrome refers to a collection of symptoms. Down syndrome was named after Dr. John Langdon Down who identified the collection of symptoms in the mid-1800s. In many countries, including Canada, we say Down syndrome, not Down's syndrome. Unlike Lou Gehrig's disease (also known as ALS), John Langdon Down did not have Down syndrome – therefore it is not possessive, as in Down's. Other countries like England refer to it as Down's syndrome.



## Newborn

You may have known before your baby's birth that they have Down syndrome, or you may have found out after they were born.

There are several indications in a newborn which would make health care professionals think your baby might have Down syndrome, but only a diagnostic test (karyotype) confirms it. Some of the symptoms have no medical connection – they include:

- \* almond shaped eyes
- \* light spots in the colored portion of the eyes
- \* a crease across the palm
- \* small, low set ears and nose
- \* low muscle tone

People with Down syndrome have extra genetic material associated with the 21st chromosome; how this genetic material will affect them is unique to them. There is way no of knowing how healthy your child will be, or how he or she will develop socially or intellectually, just as with all children!

Down syndrome itself does not require either treatment or prevention. However, the extra genetic material in your baby's cells can affect their health so it is important that your baby is receiving good medical care. Your baby will be weighed to ensure they are gaining adequate weight as often babies with Down syndrome are smaller.

Heart problems are common, including congenital heart disease (a heart problem present at birth). Every newborn with Down syndrome should have an EKG and an ECHO cardiogram before the age of four months. Many heart defects can be reversed with surgery. Your baby will be checked for any stomach and bowel problems. Most problems usually occur after birth and can be corrected surgically. Your physician will also check your baby's thyroid function, vision and hearing.

## Babies Two to 12 Months

It's recommended within the first three to six months of your baby's life that he or she is enrolled in an infant stimulation program to help your baby's development. A developmental evaluation is recommended at one year – occupational, feeding and speech therapy can help determine your baby's areas of strengths and needs.

Just as when your baby was a newborn, your doctor will weigh your child to make sure they are gaining proper weight. Many children with Down syndrome are prone to ear, nose and throat infections – if your baby has recurring infections, talk to your doctor about a referral to an ENT (ear, nose and throat) specialist. Some children with Down syndrome also have sleep apnea – problems with sleeping. Let your doctor know if your baby has problems sleeping or snoring.

If your baby's vision was not checked as a newborn, an eye exam should be done before your baby is six months old. Indications of poor vision are common among babies with Down syndrome, and can be determined through eye exams. Talk to your doctor if you suspect any vision problems.

Regular visits to your physician can help ensure your baby's health if there are any medical concerns.

## One Year to Adolescence

Your child with Down syndrome will grow and develop much like other children without Down syndrome. During this time period, there are some health concerns to be aware of.

An annual check-up with your physician is important. Review with your doctor any infections, ear problems, constipation, eye problems, or snoring (possible sleep apnea). Discuss with your doctor any possibilities of congenital heart disease, hypothyroidism, low caloric intake, etc.

Similar to when your child was a newborn, annual thyroid tests are recommended. Ear tests are beneficial, especially if your child has a history with ear infections. Talk to your doctor about screening for Celiac disease, if you suspect your child has digestive difficulties.

A neck X-ray at three to four years of age (and then again between 10 to 12 years old) can determine if your child has Atlantoaxial instability (instability where the neck connects to the spine). Radiographic screening is also recommended between ages two to three to assess for Atlanto-axial instability.

Like other children, an initial dental examination before two years old is recommended, with follow-up at six- to 12-month intervals. A balanced diet and regular exercise program are important to avoid childhood obesity.

Continued speech and motor therapy assessments are beneficial to monitor your child's development. A complete education assessment is recommended every three years, especially before your child enters school. Community supports like respite and counselling are available if beneficial to your family.

Children with Down syndrome benefit from quality inclusive education settings, and the opportunity to learn from and with their peers. Early intervention programs used to identify and support the learning needs of each individual will ensure better and more frequent inclusion in our community schools.

## Adolescence to Adulthood

Your teenager should continue having annual physical exams, including a pelvic and pap smear for women with Down syndrome. Annual eye, thyroid and hearing monitoring is recommended. Talk to your kids about smoking, alcohol and drugs.

Your physician should refer an X-ray for Atlanto-axial instability at 18 years of age, and after the age of 30. A neurological exam can assess problems with seizures and symptoms of dementia which, in some individuals, can appear as early as 30 to 40 years of age.

Twice yearly dental exams, a low-calorie diet and daily exercise are always important. Your child's school program should include plans for employment, independent living and sexual education. Attention to these issues can help ensure a life of contribution, engaged citizenship and meaningful relationships for your child.

## Additional Assessments

The following additional assessments are recommended for children with Down syndrome:

**Heart:** Congenital (defects existing from birth) heart disease occurs in many children with Down syndrome. It can be present even when a murmur is not heard. An ECHO cardiograph is worthwhile. Many children born with heart defects can have these problems reversed with surgery.

**Hearing:** Most children with Down syndrome tend to have small ear canals, making ear infections and structural ear problems common. Many children have some hearing loss, often due to fluid build-up. This can begin as early as the newborn stage. Regular ear exams can monitor your child's hearing. A brain stem evoked

response (ABR) is also recommended. This test measures responses in brain waves that are stimulated by a clicking sound to check the central auditory (hearing) pathways of the brainstem.

**Vision:** About half of children with Down syndrome have eye problems or vision loss. Eye exams from birth can ensure your child's vision is properly monitored and supported.

**Endocrinology:** Individuals with Down syndrome commonly experience thyroid disease, which can occur at any age. Blood tests can best monitor that your child's thyroid levels are normal.

