



*What to expect  
when you are*

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# **EXPECTING A BABY WITH DOWN SYNDROME**



Surrey Place Centre  
Centre Surrey Place



## **Dealing with the Diagnosis:**

If you have been told that you will be having a baby who will have Down syndrome you will likely be feeling confused, overwhelmed and afraid. It is likely you will be in denial of this information for a period. It is important that you allow yourself time to feel these emotions and to process the feelings of disbelief, anger, and often grief you may have. These are natural feelings and ones which will help you to begin to move towards acceptance.

## **Get the Emotional Support and Help you need:**

Tell all your family and friends or just tell a couple of people. It is up to you. When you do tell them you just need to let them know that your baby has Down syndrome. If you don't want to talk about, tell them. If you do, go ahead. You decide. But let them be a source of strength and support.

Some parents may want to consider attending a Prenatal Parent Counseling Service that can provide supportive specialized counseling for pregnant parents who have learned that their baby will be born with Down syndrome.

You may want to join a support group and one of the many Down syndrome Associations / Society's (see links below). These provide you with opportunity to learn, laugh, share, gain and provide support with other parents of children with Down syndrome.

- » Canadian Down Syndrome Society - <http://www.cdss.ca/>
- » Down syndrome Association of Ontario - <http://www.dsao.ca/>
- » Down Syndrome Association of Toronto - <http://www.dsat.ca/>
- » Circle 21 - <http://circle21.com/>
- » National Down Syndrome Congress - [www.ndsccenter.org](http://www.ndsccenter.org)

## **Get the Information you Need:**

You will probably go home and have many questions you need to have answered. You should speak with your doctor or clinic.

It is important to ask questions of the medical professionals who are giving you this information if anything is unclear or confusing. You may want to write down questions you may later have to ask them.

It is likely that you were provided with some information about Down syndrome and some lists of services and resources available to families. Support Groups and

Associations as list above provide many great books and articles that will help you learn about your baby.

### **Find Out about the Types of Financial Supports Available:**

There are some financial help available to families' who have a child born with Down syndrome. The amount your child receives sometimes depends on different things such as your income and/or your child's needs. These include Assistance for Children with Severe Disabilities (ACSD), Special Services at Home (SSAH), and the Disability Tax Credit (DTC). <http://www.oeyc.edu.gov.on.ca>

Additionally information about the Register Disability Saving Plan (RDSP) is available at the Government of Ontario website [www.cra.gc.ca/disability](http://www.cra.gc.ca/disability)

Others include the Easter Seals Incontinence Supplies Grant Program, and Charitable Foundations, President's Choice® Children's Charity (PCCC) and Jennifer Ashleigh Charity.

### **Find Out What Services will be Available for your Baby:**

When you child is born, the hospital will referred you to an agency such as Surrey Place Centre. Where an Intake/Service Coordinator will begin the process of you to services and facilitate additional referrals as needed. They will also help you understand the services and supports available for infants, children and adults with Down syndrome.

You will want to ask the doctor of the pediatric nurse for the name of a Paediatrician for your baby. Also ask for a list of the medical appointments that will need to be booked.

While you are waiting for your baby to be born, you may want to visit the following websites:

- » [www.mothercraft.ca](http://www.mothercraft.ca) - CITYKIDS is a network of agencies offering single point access, coordinated intake and service delivery to children with special needs and their families. Phone: 416-920-6543.
- » <http://www.healthykidstoronto.ca> The Toronto Early Childhood and Family Resource System: Pathway and Resource Listing, a tool that helps link families to appropriate community services and programs that promote development, reduce risks, and address developmental concerns.
- » <http://www.tpsls.on.ca> - Toronto Preschool Speech and Language Services and

the Infant Hearing Program

- » <http://www.oeyc.edu.gov.on.ca> - Ontario Early Years Centre (OEYC) is a place for children up to the age of six and their parents and caregivers to take part in programs and activities together. Parents and caregivers can also get information about their children's development and about services to support that development. The programs and services are free to all parents and caregivers of young children.

## **What to Expect**

All persons born with Down syndrome will have some degree of intellectual delay and also some physical features that are part of the syndrome. But, as with all children, no two children with Down syndrome are alike. Each will be unique and each will be affected in these areas in varying degrees.

There will likely be a number of medical professionals involved in your child's life and some medical testing and screenings may be recommended at some point for your child when they are young and as they age. It is important to follow your baby's doctor's advice to ensure optimum health.

Create an information binder that can be used to keep all the important information about your baby that you will need. This can include the names and phone numbers of doctors, clinics, people and agencies who will be involved with your child. Keep a list of appointments, any assessments or reports in this binder as well.

Finally, if you are feeling overwhelmed or just in need of support consider counseling services. Counseling services for expecting parents and for parents of a baby with Down syndrome can assist parents looking for guidance in dealing with the diagnosis, how to talk to family and friends, information about the condition, and what to expect from services. For more information call 416-925-5141 or visit [www.surreyplace.on.ca](http://www.surreyplace.on.ca)

Raising children is never simple! Getting the help you need is the first step to get adjusted to your new baby and becoming parents. Most families make good use of the services which are available to them and continue on a positive path of happy family life.