

## **Welcoming your new baby with Down Syndrome**

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Congratulations on the birth of your new baby. As you welcome your new baby into your family, you may have many questions and concerns. This information sheet can help you learn about the support available to you and your family.

### **What will my new baby be like?**

Your child is unique. Your loving relationship with your baby can help him or her grow and develop. As your child grows, his or her needs will change.

Your new baby will behave just like other babies, but may need extra help with feeding.

You may notice that your new baby resembles a family member or a sibling, as well as having some of the features of Down syndrome.

### **What feelings are common for parents at this time?**

Parents have described many feelings when they first learned that their baby had Down syndrome. Some common feelings are:

- feeling overwhelmed
- sadness or grief
- shock or disbelief
- feeling alone
- wondering what the future will bring

It is not easy to adjust to the birth of a baby with special needs along with all the other physical and emotional changes that happen with childbirth. Try to get some rest. You may find it helpful to share your feelings with your partner, a close family member or friend. If you become overwhelmed by your feelings, please ask to speak with the Social Worker in the nursery.

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## What help is available for my family?

There are many sources of information and support for you and your family. These resources are available in the Hamilton-Wentworth area (if you live outside this area, see page 4).

### McMaster Children's Hospital

Your doctor or nurse may refer you to the **Developmental Pediatrics and Rehabilitation Service** at the Ron Joyce Children's Health Centre (RJCHC) or you can call Lori Tomalty-Nusca (Parent Therapist) at 905-521-2100, ext. 77286 to discuss services. She may meet with you while you are at the hospital or in your home after you leave. She will discuss future services such as the Infant-Parent Program and a developmental pediatrician.

The **Infant-Parent Program** at the RJCHC can provide you with support around child development and parenting. The program has health care providers that work with young children with special needs and their families.

The health care providers can visit you at home to:

- encourage positive relationships in your family through home visits, learning workshops and support groups
- listen and talk about your questions and concerns
- help you learn about your child's needs and development
- help you learn ways to encourage your child's learning
- connect you with the services you may need at home, at the RJCHC and in the community

You may be referred to a Developmental Pediatrician at the RJCHC. The Developmental Pediatrician has special training and experience in development of children with special needs. He or she will help monitor your child's health and development, from infancy to 18 years of age by using a care path developed specifically for children with Down syndrome. The Down Syndrome Care Path helps you know what to do for your child and when to do it.

For more information about services at McMaster Children's Hospital go to:  
[www.mcmasterchildrenshospital.ca](http://www.mcmasterchildrenshospital.ca)

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For information, the **Family Resource Centre** on the first floor of the RJCHC has books, videotapes, and other materials on parenting and child development. There is also a computer with access to the Internet.

A book you may wish to borrow is: **Babies with Down syndrome: A new parent's guide**, by Karen Stray-Gunderson.

To contact the Family Resource Centre:

- Call 905-521-2100, ext 77243
- Go to [www.mcmasterchildrenshospital.ca](http://www.mcmasterchildrenshospital.ca)  
Click "Patients, Families & Visitors", then click "Family Resource Centre" on the left.

### **Community resources**

The **Down Syndrome Association of Hamilton** is made up of parents like yourself. This self-help group meets each month to discuss issues related to parenting, development, community resources and services. There are opportunities to meet others and "network" at meetings or social events such as summer barbeques or holiday parties. If you wish, a member of the association can visit you at the hospital or at home. You or your doctor may call Sylvia at 905-388-2349 or Lisa at 905-527-8455. The website is: [www.dsah.ca](http://www.dsah.ca)

**Healthy Babies, Healthy Children** is a community-based program operating under the leadership of public health nurses. A public health nurse or a family home visitor may provide in-home support to your family. They will be able to provide you with information about community services that support families during pregnancy and through the first six years of your child's life. Call 905-546-3550 for more information about this program.

The **Hamilton Family Network** can help you get information and support from other families who have had the same experience. You may find it helpful to meet a Resource Parent who also has a child with Down syndrome. You can reach them at 905-526-7190. The website is: [www.hfnet.ca/](http://www.hfnet.ca/)

## What help is available to families living outside the Hamilton-Wentworth area?

If you live outside the Hamilton-Wentworth area:

- Speak with your family doctor or pediatrician about services in your community.
- Visit the **Family Resource Centre** online. Go to [www.mcmasterchildrenshospital.ca](http://www.mcmasterchildrenshospital.ca) and click on “Patients, Families & Visitors”, then click “Family Resource Centre” on the left.

### For more information



Canadian Down Syndrome Society: [www.cdss.ca](http://www.cdss.ca)

Persons with Disabilities Online:

[www.pwd-online.gc.ca](http://www.pwd-online.gc.ca)