



## Getting Ready for Adult Genetics Care

UHN

### **Congratulations!**

You are graduating from The Hospital for Sick Children (Sick Kids) and will soon be receiving care at the Adult Genetics Program at Toronto General Hospital (TGH). Both of our health care teams will work together to make sure your move from Sick Kids to TGH goes well. Our two hospitals have a close and strong relationship, and we are all committed to giving you the best care possible. This information booklet has been prepared to give you an idea of what to expect at Adult Genetics at TGH.

### **Getting Ready**

As you get older you may be expected, or want, to take on more responsibility for keeping yourself healthy. This can be an exciting and scary time. Most patients have been followed at Sick Kids for many years. Moving from the people and places you know to a new adult health care team can bring about many different feelings - excitement, fear, relief or sadness. Knowing how things work in Adult Genetics may make this move easier.

### **Continued Care is Important**

Becoming an adult involves many changes. One of these changes is where you receive your health care. As an adult with a genetic condition, you will continue to have health care needs throughout your life. Regular visits with a genetics team are still important to monitor your health and to plan for the future.

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## How Will My Care Change?

This is a common question. It is true that the routine at TGH is somewhat different from what you are used to at Sick Kids. The biggest change is that the responsibility for watching and reporting on your health is placed on you. As a result, the adult health care team is more likely to talk with you first about your health, rather than with someone in your family.

You may also have new questions about becoming an adult with a genetic condition. Some common ones have to do with:

- Becoming more independent
- Finding a job
- Living on your own
- Being in a relationship
- Starting a family
- Psychological concerns, feeling different, finding social support

These questions and concerns are not unusual and you should feel free to talk to us about them. We can then try to find you resources and support for these issues.

## How To Prepare for Your Clinic Visits

Plan ahead and take responsibility for what you will need to bring to the appointment. Each time you come for an appointment, it is important to bring:

- Your health card
- Your Toronto General Hospital card, we also call this your "blue hospital card" (you will get one at your first appointment)
- All bottles of medication that you are taking
- A support person/family member, if this makes you feel more comfortable
- Name and address of your family doctor
- A list of your questions

Find out how to get to the clinic and where parking is available. Make sure you give yourself enough time to get to your appointment.



## Who Will You Meet at Your Appointment?

The Adult Genetics Program is made up of a team of doctors, genetic counsellors, and other health care providers. We all have experience, and a strong interest in working with individuals with genetic conditions. The number of team members you will meet with at your visit depends on what your health care needs are and what questions you have.

**REMEMBER... YOU are  
the most important part of your  
health care team.**

## We look forward to working together.

### How to reach the Adult Genetics Program:

Toronto General Hospital  
200 Elizabeth St.  
East Building, 3rd Floor, Rm. 401C  
Toronto, Ontario  
M5G 2C4  
Phone: 416-340-4800, Ext. 6632  
Fax: 416-340-3709

This information booklet was prepared in collaboration with the staff in the Genetics Clinics at The Hospital for Sick Children and the Toronto General Hospital.

Materials were adapted from:

1. Getting Ready for Adult Metabolic Care. A transition information sheet prepared in collaboration with the staff in the Metabolic Genetics programs at the Hospital for Sick Children and the Toronto General Hospital.
2. Getting Ready for Adult Cardiac Care. A transition booklet prepared in collaboration with the staff in the Cardiac Programs at The Hospital for Sick Children and the Toronto General Hospital.
3. Getting on Trac - A Workbook for youth (1999). On Trac. A transition service at Children & Women's Health Centre of British Columbia.

Please visit the UHN Patient Education website for more health information:

[www.uhn.ca/patient/health\\_info](http://www.uhn.ca/patient/health_info)



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