Transitioning to Adult Care: Neurology

Taking more responsibility for your health and your health care is a part of growing up. Another part of growing up is a change in where you receive health care. During your time with us at CHEO, we have gotten to know each other pretty well. Moving to the adult system is a big change, and you’re probably having mixed feelings about this. We think that you will find this transition much easier if you know how things work and what to expect.

As you transition into the adult system, you will notice some differences:

1. You will receive your care in an adult setting (this one is pretty obvious).

2. You, as a young adult with a neurological condition, will be primarily responsible for your health needs (and not your family). At CHEO, we provide family-centered care. Adult care is patient-centered. This means that care focuses on your needs and wishes and making sure that you’re part of decisions. But your family can still be involved, as much as you want them to be.

Key points:
- Because you are turning 18, your medical care will move to an adult medical center outside of CHEO.
- Before you turn 18, we will refer you to an adult neurologist.
- You will need a family doctor for health issues that may not be related to your neurological condition.
- Plan ahead before your first appointment with your adult neurologist.
- Your adult neurology team will help you to get the best care for your neurological condition.
- You are the most important member of your health care team. Don’t be shy to ask questions.
- If you have questions, you can still contact your CHEO team.

Continue with regular follow up visits with a neurologist. We’ll refer you to a specialist at The Ottawa Hospital (TOH) or in the community. It is very important to have a specialist monitor your health and to help you plan for the future. People with neurological conditions do better if they have regular follow-up visits. You probably know from experience that catching problems early can make a big difference.

Remember that once you turn 18, you can no longer be admitted at CHEO if you need to come into hospital. We will help to make sure that you’re connected with an adult facility that can admit you if needed.

Make sure you have a family doctor. Your health is not only related to your neurological condition. As you get older, you may develop health problems that are unrelated to your neurological condition. If you don’t have a family doctor, or if you are not happy with your family doctor, you need to find another as soon as possible. Your family doctor will help you with other non-neurological health issues. This is the person you will go to with your health concerns, and for preventative things like immunizations.

If your parents or other adult family members have a family doctor, maybe that doctor could become your family doctor as well. Or check with Health Care Connect, a program that connects patients with primary care providers.

1. Register by phone, at 1-800-445-1822 Monday to Friday, 9:00am to 5:00pm. You’ll speak to a representative who will ask you a few questions.

2. Register online, at http://www.health.gov.on.ca/en/ms/healthcareconnect/public. Once you register by phone or online, you will be linked with a Nurse Care Connector at Community Care Access Center who will help you find a doctor.
For Québec patients: You may register to find a family doctor accepting new patients.
1. Register by telephone by contacting the CLSC for your territory. Visit the ‘portail santé mieux-être’ to find the telephone number for your territory : http://sante.gouv.qc.ca/en/votre-gaco/#trouver-coordonnees.

2. Visit the Portail santé mieux-être website to register online at http://sante.gouv.qc.ca/en/programmes-et-mesures-daide/inscription-aupres-d-un-medecin-de-famille

You will notice some differences in the adult health care system. For example:
• You will be responsible for watching and reporting on your health.
• You can expect to see the doctor or nurse alone during your visit.
• Your new neurology team will probably discuss your health with you first (rather than with your family). If you want your parents or someone else to be with you and receive information, you can also request that. You may wish to bring a support person to appointments where you will be receiving a lot of information from your doctor.

It’s important to take an active role in your health and health care. You can really increase your chances for a healthy life if you:
• Understand your condition and what you need to do to take care of yourself;
• Get regular medical care;
• Follow your treatment plan and take your medications as prescribed.

Questions you may have for your health care team
Your new health care team will be very willing to talk with you about things like:
• Smoking, drugs and alcohol;
• Driving or getting your driver’s license;
• Feeling different, anxious or depressed;
• Relationships, dating;
• Fitting your health care in with school and work;
• Career planning and insurance (for example, insurance to pay for medications);
• Birth control and pregnancy;

These concerns are not unusual, please feel free to discuss them with your health care team.

What do I need to bring to my appointments?
Remember, this is your health care appointment. Your questions, concerns, opinions and ideas are important. Your new team will also expect that you will be the one consenting to any treatments. Make sure to bring:
☐ Your health card;
☐ Your hospital card (you will get one at your first appointment, if you’re seeing a neurologist at TOH);
☐ The name and address of your family doctor;
☐ A list of questions;
☐ A list of medications you’re taking (with your pharmacy’s phone number);
☐ A summary of important health information.

Tools like the MyHealth Passport will help you to keep track of your health information. You can create your personal passport at : http://www.sickkids.ca/Good2Go/Transition-Interventions-Tools/MyHealth-Passport

It will also be important that you can answer questions about:
• Your neurological condition;
• Procedures and surgeries you have had in the past;
• Medications you are taking;
• Any other medical problems you have.
Taking control of your health

Getting older means that you will start to take control of your health and personal goals. Your health care team can work with you to come up with a treatment plan that will help you reach these goals. Some good ways to start taking control of your health:

- **Write Stuff Down.** It's a good idea to write your questions down ahead of time, so you don’t forget to ask. Leave space to write down the answers.
- **Don’t be shy.** If you don’t understand something, let your care provider know and ask him or her to explain things. Keep asking until you understand. It is important that you get all the information you need and that you understand it.
- **Take charge of your medication**
  - Know the names and dosages of your meds.
  - Keep track of when you need refills and new prescriptions.
  - Before your next appointment, check to see if you are going to need a prescription or refill, so you can ask for it during your appointment.
  - Add any new medications to your MyHealth Passport (and keep this with you, in your wallet, purse, or bag).

**Tip!** To order refills on time, some people put a week’s worth of medication in a plastic bag. When they get down to the last loose pills in the bottle, they call for a refill, knowing that they have a week to get the medication.
Questions for my Adult Neurology Team

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__________________________________________________________________________
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The doctor I’ve been referred to: _____________________________________________

Your CHEO Neurology team and your new adult Neurology team wish you the very best in this important step forward!

Helpful resources

- http://www.cheo.on.ca/en/Transition-Adult-Care
- Epilepsy Ontario: www.epilepsyontario.ca
- Epilepsy Canada: www.epilepsy.ca
- Epilepsy Foundation: www.epilepsy.com
  - Seizures in youth - www.epilepsy.com/learn/seizures-youth
  - My epilepsy diary - www.epilepsy.com/get-help/my-epilepsy-diary