Getting ready for adult health care

Learn how things work.



Holland Bloorview Kids Rehabilitation Hospital

Getting ready ...a time of transition



Becoming an adult brings many changes. One change is where you receive health care.

Moving to a new adult health-care team can bring mixed emotions including excitement, fear, relief or sadness. You have probably gotten to know many of the people who work at Holland Bloorview Kids Rehabilitation Hospital. When making the switch to new service providers, it helps if you know more about how things work.

- Children's health organizations provide family-centred care.
 We involve your family in decision making.
- Adult care is patient-centred. It focuses on your needs and wishes. You are the one making the decisions.
- You can expect to be alone when you see your adult health-care providers during your visit. If you want your parents or someone else to be with you, you can request that.

Tips for adult health care



Give information

Know about your medical history and current medications. Tell your team what works best for you.

Listen to suggestions

Your new team knows a lot about adult health care.

Ask questions

Write questions down before your visit so you don't forget. If you don't understand something, ask again. There are no silly questions. Get all the information you need.

Decide on a plan

Choose a plan that is good for your health and works best with your lifestyle — for school, work and family.

Do it!

Get involved with your care. Stay involved. Always take your medications and attend your medical appointments.

GLADD is from "Talking with Your Doctor and Other Health-care Professionals" and used with permission from the author, John Reiss, PhD (Health Care Transition Initiative at the University of Florida): http://hctransitions.ichp.ufl.edu/gladd

It's important to continue your care

You probably already know from your own experience that catching problems early makes a big difference. People with physical disabilities stay healthier if they have lifelong follow up. It is important to keep in contact with your primary care provider regularly (at least once a year — even when you are healthy). Your primary care provider might be your family doctor or a nurse at a community clinic.

After you turn 18 you will no longer be able to use the emergency services at children's hospitals. Talk to your health-care team about the best place for you to go in an emergency.

You may have questions about becoming an adult



Some common concerns are:

- Relationships and sex
- Family planning: contraception, planning a healthy pregnancy/ fathering a child, parenting options
- Health insurance (to pay for medications and personal care supplies)
- Post-secondary education
- Managing finances (working, income supports, funding)
- Moving out on your own
- Managing health care
- Where to get community supports and services

These questions and concerns are normal. Discuss them with your health-care team.

TIP: Carry your health card with you at all times. It's also a good idea to keep your MyHealth Passport with you. You can make a MyHealth Passport by visiting: www.sickkids.ca/myhealthpassport

Preparing for adult clinic visits

Remember this is **YOUR** health-care appointment. Your questions and concerns are important.

Plan ahead and take responsibility for what you need to take to the appointment.

Plan ahead

- Bring a support person or family member to the clinic if this will make you feel more comfortable.
- Make sure you have everything you need use the Appointment Checklist (page 6).
- Think about how you will get to your first appointment.
- Find out how to get to the building and into the clinic.
- Ask about parking if you will be driving.
- Give yourself enough travel time to get to your appointment and to check in when you arrive.

Be in charge of your medications

- Keep a list with names and dosage amounts of your medications including vitamins, supplements and over-the-counter medications.
- If you are put on a new medication write it in your MyHealth Passport.
- Before your appointment check your prescriptions for the number of repeats. If you only have a few repeats be sure to ask your doctor for a refill prescription.

TIP: If you use special transit services such as Wheeltrans or ParaTransit, allow extra travel time in case of traffic or appointment delays. Before booking your rides, call ahead to the clinic to find out how much time you will need for your appointment. Let the staff know your pick-up time when you check in for your appointment.

Appointment checklist

Hospital or clinic card (if you have them)
Name and address of primary care providers and specialists
A list of questions or issues you want to talk about
Your current medication list with your pharmacy's phone number
Any medical or personal supplies you may need
Knowledge about:

— Your condition

Your health card

- Your past procedures and surgeries
- Your medications
- Any other medical problems you have

Don't be afraid to write information down to help you remember

- ☐ Your MyHealth Passport (you can create this by visiting www.sickkids.ca/myhealthpassport)
- A book or a magazine to help pass the time while you are waiting.
- A snack or some cash to buy something to eat or drink.
- ☐ Your phone

TIP: You will be asked to make decisions and give consent to treatments. Bring a support person or family member with you if this will make you feel more comfortable.

Taking charge of your health-care appointments

- If you realize an appointment time is not convenient for you, it is your responsibility to book a new appointment time.
- Make sure you keep track of your appointments (phone, agenda, calendar, etc). You most likely won't get reminder phone calls. (You could ask about this if reminders help you.)
- If you miss an appointment it will be your responsibility to rebook.
- Make a list of all the team members at the clinics you visit. Know their names, their roles, and how to contact them.
- Ask who is in charge of scheduling appointments. Talk to this person if there is more than one health-care provider that you would like to see on the same day.
- Follow-up after two weeks if you have not heard about things you discussed during your visit: test results, referrals, or new tests bookings.

We wish you the very best in this important step towards adulthood!

From your health-care team at Holland Bloorview Kids Rehabilitation Hospital

TIP: If taking charge of appointments sounds hard to you, talk with your health-care team.

Resources

Community Care Access Centre (CCAC) Website: **www.ccac-ont.ca** Phone: 310-CCAC (310-2222) Connects people with health care and support services

Ontario Disability Support Program Website: www.mcss.gov.on.ca/en/mcss/ programs/social/odsp 'Income support' and 'employment supports' programs for eligible people with disabilities

March of Dimes Canada Website: www.marchofdimes.ca Services, resources and funding for people with disabilities

National Education Association of Disabled Students (NEADS) Website: http://www.neads.ca/en Services and resources for post-secondary education, scholarships and employment

Developmental Services Ontario (DSO) Website: **www.dsontario.ca** Phone: 855-372-3858 Connects adults with developmental disabilities to services and supports in their communities

Centre for Independent Living (CILT)

Website: **www.cilt.ca** Phone: 416-599-2458 Resources for people with disabilities including information about attendant services in the GTA and Ontario-wide

The Anne Johnston Health Station Website: **www.ajhs.ca** Phone: 416-486-8666 Community-based primary health care services and health promotion programs for people with physical disabilities Healthcare Connect Website: www.health.gov.on.ca/en/ms/ healthcareconnect/public Phone: 800-445-1822 Helps Ontarians find a family health care provider

211 Ontario Website: www.211ontario.ca Phone: 211 Information and referral to community and social services

Easy for You to Say: Q&As for Teens Living with Chronic Illness or Disability (2005) Author: Miriam Kaufman, Key Porter Books. Available at public libraries or through major booksellers

Spinal Cord Injury Ontario Website: www.sciontario.org Phone: 877-422-1112

Persons with Disabilities Online Website: www.pwd-online.gc.ca

Resources about transition to adult health care

Good 2 Go Transition Program, The Hospital for Sick Children Website: www.sickkids.ca/good2go

Health Care Transition Initiative Website: http://hctransitions.ichp.ufl.edu/gladd Information on how to talk with health-care professionals

Got Transition.org Website: www.gottransition.org

Acknowledgements

This "Getting ready for adult health care" booklet is revised and reproduced with permission from the Good 2 Go Transition Program, Division of Adolescent Medicine at The Hospital for Sick Children.

Developed by: The Anne Johnston Health Station; the Good 2 Go Transition Program, Division of Adolescent Medicine at The Hospital for Sick Children; Holland Bloorview Kids Rehabilitation Hospital; Spina Bifida & Hydrocephalus Association of Ontario



