

Transition

TRANSITIONING TO ADULT HEALTHCARE



Hôpital de Montréal
pour enfants
Centre universitaire
de santé McGill



Montreal Children's
Hospital
McGill University
Health Centre

Acknowledgement

This Transitioning to Adult Healthcare booklet was developed by McGill University Master's of Occupational Therapy students and the Pediatric-Adult Transition Hub-Espace de transition adulte-pédiatrique (PATH-ETAP) team at the Montreal Children's Hospital (MCH):

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Thank you!

Disclaimer

This booklet was created to support you along your transition journey. It covers many topics related to building your independence and managing your healthcare. Keep in mind that every person's journey is unique. Some parts of this booklet may not be relevant to you. If you have any questions that come up along your transition journey please reach out to path-etap@muhc.mcgill.ca and/or speak to your healthcare team.

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GLOSSARY

Pediatric care: Healthcare for kids and teens (usually ages 0–18).

Transition: The ongoing, evolving journey from pediatric to adult healthcare (happens at the same time as the journey from adolescence to adulthood).

Transfer: The graduation from pediatric healthcare and move to adult healthcare (a one-time event that usually happens at age 18).

Independence: Being able to do things for yourself and make your own decisions. It involves building practical skills and asking for help when needed.

Healthcare: The whole set of services provided by doctors and other medical professionals to improve or maintain your health, or even prevent disease or disability.

Healthcare management: Strategies and techniques to improve organization of different areas of your healthcare, including appointments, treatments, and medication.

Healthcare professionals: People who are trained and specialized in caring for your health. This can include your doctor, nurse, physical therapist (PT), occupational therapist (OT), speech-language pathologist (SLP), social worker (SW), nutritionist (RD), psychologist and child life specialist.

Self-care skills: Everyday tasks to take care of your mind and body (e.g., hygiene, nutrition, medication management, rest and relaxation, sleep).

“Adulting” skills: Life skills that allow you to navigate adulthood (i.e. budgeting, finding work, doing groceries, forming relationships). No one is born with these skills, but you can learn them over time at a pace that feels comfortable to you and with support from trusted adults.

Adult-centered care: Healthcare for adults (usually starts at age 18).

Self-reflection: Ability to think about your own thoughts, feelings, and behaviors.


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This section is for teens (and young adults) who feel ready to manage more of their health care independently and take on added responsibilities.

A NOTE FROM THE MONTREAL CHILDREN'S HOSPITAL PEDIATRIC-ADULT TRANSITION HUB (PATH)

OUR POLICY

Dear patient,

We care about you and your health. As you grow older, your healthcare needs will change. We will support you along the way. While you are at the Montreal Children's Hospital, your parents are involved in making decisions regarding your health care. During your teenage years, you will be more involved in making your own choices. We will work with you and your parents/caregivers to prepare you for the upcoming changes.

Once you turn 18, you will be transferred to a doctor for adults. We can help make the change easier in different ways. This might mean helping you find a doctor, sending your medical records, and discussing any special needs with your new healthcare provider. We may also provide you with information on community resources and specialty care, if necessary. Since your privacy is important to us, your health information will only be shared if you agree. We want you to feel supported and prepared for the transition to adult health care.

OUR VISION

The Montreal Children's Hospital hopes all teens feel empowered in their journey to adulthood. Our healthcare teams will support patients and their families, providing tools and guidance to successfully move from pediatric to adult healthcare.

TRANSITIONING TO ADULT HEALTHCARE

Foundations of Transition

TRANSITION begins around the age 14 in the pediatric system and continues until **TRANSFER** to adult care, which occurs at the age of 18.

Everybody's transition to adult health care will be different, and each person may have different goals.

Learning

Learn about and discuss your health care rights as you get older.
Take action to achieve your goals and keep track of your progress.

Readiness

Practice self-care skills and ask questions to find information about your health condition.

Planning

Collaborate with your healthcare team to determine the best transition plan for you.

Transfer of care

Transfer to adult-centered care and give feedback.



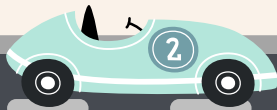
TRANSITION TIMELINE

YOUR PATH TO DEVELOPING THE SKILLS TO GROWING UP

Learning to take care of your medical needs on your own can be overwhelming. Here are some ways you can get started with practicing the skills you will need!



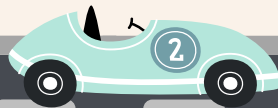
On Your Mark...



(Can start around age 14)

- **SPEAK UP!** Ask for help if you feel sick, know who to call in case of an emergency, and let others know how they can help you
- Practice by asking one question during your medical appointments
- Explore the **3-Sentence Health Summary** - learn about your medical condition and diagnosis, your medications and when to take them, and your allergies
- Start the process to find a family physician
- Begin reflecting on your own path to adulthood
- Start **My Self-Reflection**

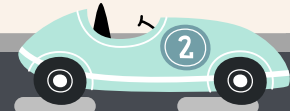
Get Set...



(Usually around ages 14-16)

- Ensure you are signed up for a family physician, if you don't already have one
 - Manage your own self-care (e.g., knowing your limits, resting when you need to, managing your own hygiene, exercising)
 - Start taking your medications independently
 - Make a list of questions to ask your healthcare providers during appointments
 - See your healthcare provider alone for part of the visit
 - Talk to your healthcare team about sexual and/or emotional health issues if needed
 - Understand how drugs, cigarettes, or alcohol can affect your health
 - Start making a list of specialists, care providers and services who follow you
 - Start making a list of medications, supplies, and equipment you need
 - Explore post-secondary school options and funding opportunities
-
- Reflect on balancing different life priorities (health, relationships, school, work)
 - Explore transportation options for upcoming appointments
 - Start calling the pharmacy to refill your prescriptions
 - Create a healthcare plan if moving away for school or if you are going on vacation
 - Apply for accommodations for all conditions if attending post-secondary school
 - Talk to your healthcare team about having a copy of important medical documents
 - Assess and update all equipment and supplies
 - Make final appointments with different services (OT, PT, RD, SLP)
 - Put your 1st appointments with adult specialists on your calendar
 - Discuss/confirm legal guardianship and signing of consents
 - Understand how your private insurance may change when you turn 18

Go!



(Around age 18 +)

- Make medical appointments on your own
- Take and refill medication without assistance
- Confirm with healthcare providers that they have received your medical file
- Call medical team independently if you have any changes in your health
- Confirm adult insurance (medical, dental)
- Confirm adult suppliers for supplies and equipment
- Identify community services and supports
- Explore education and job opportunities, scholarships and bursaries
- Apply for adapted transport and disability parking permit if needed
- Explore savings options and tax credits available to you
- Understand the impacts of your condition on your daily activities and leisure



Knowing Your Rights

Up until you turn 14, your parents/guardians have been making health care decisions for you. As of 14, you are allowed to visit healthcare professionals on your own and decide on the confidentiality of your medical information. You can talk to your healthcare provider about whatever concerns and feelings you have without your parents being in the room.

However, remember that at any age, people you trust can help support you in making decisions about your health care.

3-SENTENCE HEALTH SUMMARY



AN EASY WAY TO DISCUSS HEALTH INFORMATION WITH YOUR TEAM AT EACH VISIT

SENTENCE 1: MY AGE, MY DIAGNOSIS, MY MEDICAL HISTORY

EXAMPLE: I AM 16 AND I HAVE ASTHMA. I HAVE BEEN HOSPITALIZED TWICE, BUT NOT IN THE LAST FIVE YEARS.

YOUR TURN:

SENTENCE 2: MY TREATMENT PLAN

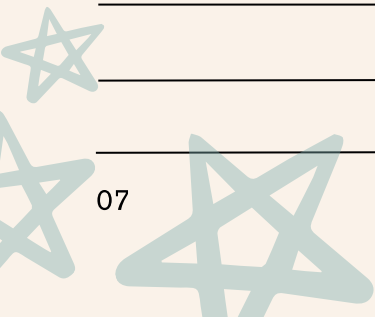
EXAMPLE: I HAVE BEEN TAKING VENTOLIN AND FLOVENT SINCE I WAS 3.

YOUR TURN:

SENTENCE 3: MY QUESTIONS/CONCERNS TO TALK ABOUT DURING THE VISIT

EXAMPLE: I AM HERE TODAY BECAUSE I CAN'T RUN ANYMORE, I WHEEZE TOO MUCH AND CAN'T BREATHE

YOUR TURN:



MY SELF-REFLECTION

A TOOL FOR YOU TO REFLECT ON YOUR TRANSITION SKILLS AND GUIDE YOUR GOALS

VOICE

I ask healthcare providers questions about my health

I meet with healthcare providers on my own

I can describe my health conditions to others

When my symptoms are getting worse, I know who to ask or call for help

I know what patient confidentiality means

I ask questions to better understand the risks and benefits of treatments before consenting

I know who to ask for information about sexual health

I know who to talk to about the effects of alcohol, drugs and tobacco on my medications and health

I talk to others about my feelings and concerns about transferring to adult care

ACTION

I know what I am allergic to (food, medication)

I know the names of my medications, why I am taking them, and their side effects

I take my medications on my own and/or do my own home treatments. Or I have a support system in place to help me

I know how to fill my own prescriptions

I know the reasons for my tests

I have an emergency plan and carry my emergency information with me

I have a family physician or I am on the waitlist for one

I can make and get to my own appointments

CONNECTIONS

I have support in managing my health and my plans for transition

I have people to talk to when I am feeling sad, anxious, down, hopeless or having difficulty sleeping

For fun I like to...

HOPES & DREAMS

I know there is planning to do around my health before I go away for school, work or travel

I have thought about what I want to do in the future. Some of my hopes and dreams are...

MY THOUGHTS & FEELINGS

MY SELF-REFLECTION SPACE

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GOAL SETTING TIPS

SETTING GOALS WITH YOUR HEALTH CARE TEAM IS PART OF YOUR TRANSITION JOURNEY AND DEVELOPING YOUR INDEPENDENT “ADULTING” SKILLS.

Use the **My Self-Reflection** to guide your goals and consider the following:

- What is your healthcare goal? Where/how do you want to build upon your skills?
- What **information** do you need to reach your goals?
- What **items/supports** do you need to reach your goals?
- Are there any factors that may make it **difficult to reach** your goal?
- Who can you **ask for help**?
- What can you **start doing tomorrow** to work towards reaching your goal?

Little ways to build your healthcare skills:

- Manage and take your medications independently
- Book your own appointments
- Figure out transportation to next appointment

SETTING S.M.A.R.T. GOALS

S - specific (define your goal in detail)

M - measurable (how can you measure your success, consider quantities)

A - attainable (challenging but achievable)

R - relevant (meaningful and important to you)

T - time-based (pick a deadline!)



SETTING GOALS

My Goal	What I Need	Steps I Will Take	Who I Can Ask for Help	I Would Like to Complete My Goal By...
Example: I will go to the pharmacy to fill my prescription	<ul style="list-style-type: none">• Pharmacy address• My prescription	<ol style="list-style-type: none">1. Locate my prescription2. Practice what I will say3. Go to the pharmacy	My parents or a trusted adult	Tuesday

KNOWING THE SYSTEMS

Pediatric Healthcare	Adult Healthcare
Possibly a team approach to your care	Services divided by specialty, may be at different locations
Playful and child-focused environment	The space may feel less inviting and more structured
Parents/caregivers help keep track of your medical care, file and medication	Patient responsible for their own medical care and scheduling their own appointments
Seeking information about treatment and care options is the responsibility of the parents/caregivers	Patient responsible for seeking information about treatment and care options
Parents/caregivers are responsible for Medicare and insurance	Patient may be responsible for Medicare and insurance
Healthcare professionals will talk with patient and parents/caregivers about their care	Healthcare professionals talk directly to the patient about their health care and decisions
Many support services may be offered	Patients may need to ask and/or advocate for support services



Transition 2.0

The Bonus Section



MANAGING MY HEALTH

Medical Information

There are many benefits to taking responsibility for your health, however, this involves mastering many skills. It is important to have a strong foundation of knowledge regarding your condition, the symptoms, the treatments and medications involved, and the ability to seek out further information as required.



What you should know

Here is a list of tips to help with clear communication about your health condition:

- Summarize your medical history (see 3-Sentence Health Summary)
- Track your medical information including your symptoms, active treatment plan, current medication, and allergies
- Keep an updated list of relevant phone numbers, including your personal emergency contacts and healthcare professionals
- Keep your health insurance information

Where you can get the information

Your Health Care Record

It is opened the first time you visit any health institution and is used by healthcare providers to communicate important information regarding your care. According to the law, if you are 14 years or older, you can access your health records for free. Contact the Medical Records department of your institution to fill out the forms to obtain your health records.

Health Booklet

By registering to this Government Health Platform, you will be able to access your health information online such as your medications, medical imaging results, and other results

(<https://carnetsante.gouv.qc.ca/portail>).

MANAGING MY HEALTH

Medical Insurance

Provincial Insurance Coverage

When you are resident of a Canadian Province, you have free access to basic provincial insurance coverage. In Quebec, the insurance is provided by “*La Régie de l’Assurance Maladie du Québec*” (RAMQ) and you must have a health insurance card to prove you are covered. You will be sent a notice to renew your card before it expires, and it is important to renew it for continuous coverage.



Private Insurance

Private insurance provides different coverage and complements your public coverage. There are many different private insurance companies and what they cover can vary greatly. This may include the type of services covered, the maximum amount that can be reimbursed, and the age until which you are covered under parental policy. It is important to know what is covered by your health insurance, and what kind of documentation (such as a doctor’s prescription) you need to provide when submitting your claim. Some insurance companies can be billed at the time of your appointment; for others you need to pay and apply for reimbursement.

Medication management may involve learning how to organize your own medication for the week, determining the best way to remind yourself to take medications on time, or calling the pharmacy to ask for a refill.

Tips for Managing your Medications

Educate Yourself

Why do you take this medication?

What are the **side effects** of your medication?

What are the **consequences** of your medications interacting with one another? With **drugs or alcohol**?

Are there any **food restrictions** for those medications?

Write down any questions you have about your medications.

Get Into A Routine

Find a routine for taking your medications that is **easy to follow and works for you.**

Some people find it helpful to take their medication when they first wake up or at mealtimes.

Create reminders!

This could be a visual schedule or alarms on your phone.

Use an app!

There are many options that can help you keep a schedule and remember your appointments.

Communicate Your Needs

Listen to your body. If you experience any new symptoms or side effects, make sure to inform your healthcare provider.

If you are having a tough time figuring out how to manage your medications, don't be afraid to **share your concerns with a healthcare provider.** They can help you find strategies that suit your needs.



MANAGING MY HEALTH

Medical Appointments

Preparing for Appointments

If you feel you would be more comfortable with someone at the appointment, arrange to have a family member or support person attend.

Always aim to arrive 30 minutes in advance in case of unforeseen events. Also, think about how you are going to get into the building or clinic.

Note: Completing medical forms can be a scary part of attending appointments. Remember that your healthcare professional is not there to judge you. It is better to answer questions truthfully to ensure your healthcare professional gets the right information.

Communicating during Appointments

Asking Questions

You may want to prepare a list of questions before your appointment about your symptoms or health concerns to better understand your health. If the healthcare professional is telling you new information, it is important that you have a good understanding.

Talking About your Symptoms

It can be difficult to describe your symptoms to others. It may be helpful to write down your symptoms before your appointment and bring the list with you.



MANAGING MY HEALTH

Finding a New Doctor

Registering on the waiting list

Registration can be done online through the Québec Health Booklet (<https://carnetsante.gouv.qc.ca/portail>). Registration can also be done by telephone by contacting your territory waiting list.

Note: If you are in the Nunavik and Cree Territory of James Bay regions, you must contact your health centre:

- Nunavik: (819) 964-2905
- Cree Territory of James Bay: (819) 855-2744

Eligibility criteria

Be 14+ years old

Live in Quebec

Have valid health insurance

Postal code must be listed by Canada Post

Live at the address on RAMQ file

Not already registered with a family doctor

Priority waiting list

After registering on the waiting list, your request will be evaluated, and priority will be assigned based on your health condition. Waiting time varies depending on the availability of doctors in your region and the number of people on the waiting list.

What can I do if I need to see a doctor, but I am still on the waitlist?

Check out the Bonjour-Santé website (<https://bonjour-sante.ca/>), which allows you to easily make appointments the night before with doctors and specialists in walk-in clinics (0-20\$ fee).

TAKING ON NEW ROLES

Transitioning to adulthood requires the development of new skills and an increase in responsibilities. By reflecting on and planning for those changes ahead, you will be better prepared for transition.



School



Planning For After High School

- Know your learning strengths and what supports you need
- Get a copy of your IEP
- Contact your upcoming institution to learn about the services they offer for students with disabilities and how to get the support you need

As you start to think about your future, it is a good idea to become the expert on you! Knowing your learning needs and your strengths will allow you to fully participate in life as a young adult.

Individualized Education Plans (IEPs)

What is an IEP?

It is an individualized plan which details the special supports and services you need to succeed. This can include how information is given to you (printed or electronically) and the types of assistive technology you might need to access the material (dictation software or computer).

Why is an IEP useful?

These plans allow you to participate fully in your education.

Do I need to update my IEP?

IEPs should be updated as needed, as your needs may change over time.

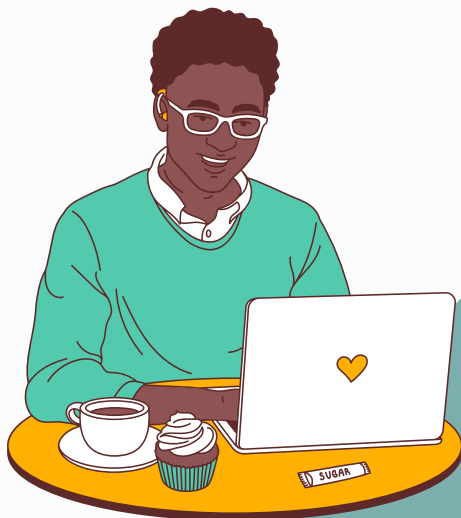
TAKING ON NEW ROLES

Employment Rights

The provincial government of Québec has an act to ensure a barrier-free environment for persons with disabilities within the workplace. This means no one should be denied an opportunity for employment due to their disability and that special measures and accommodation should be provided.

Support within the Workplace

There are many resources to support persons with disabilities within the workplace. Emploi-Québec explains the assistance you can get as a person with a disability when training for a job and working (<https://www.quebec.ca/en/people-with-disabilities/employment-and-adapted-jobs>).



Work Volunteer

Volunteering is an excellent way to connect you to your community and develop the skills for a future career.

It can be a great way to engage with others, meet new people and make a difference.

You can volunteer with your family, friends or by yourself.

Hospitals, shelters, and libraries are great options for volunteering experience. Check out <https://www.cabm.net/benevoles/offre-benevolat> for more opportunities in the Montreal region.

TAKING ON NEW ROLES

Social Life and Recreation

Having a strong support system is important. Connecting with caring friends and family members, as well as participating in community activities can help strengthen your support system.

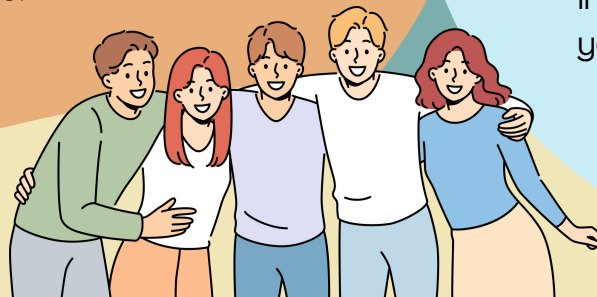
Note: All families are different. This section may include information that is not relevant for you.



Friends

Positive peer pressure is when your friends motivate you to be your best and go after your goals.

Negative peer pressure usually involves risk-taking actions, such as taking drugs, drinking alcohol and having sex before you feel ready or without feeling comfortable.



Family

As you grow up, family roles may change

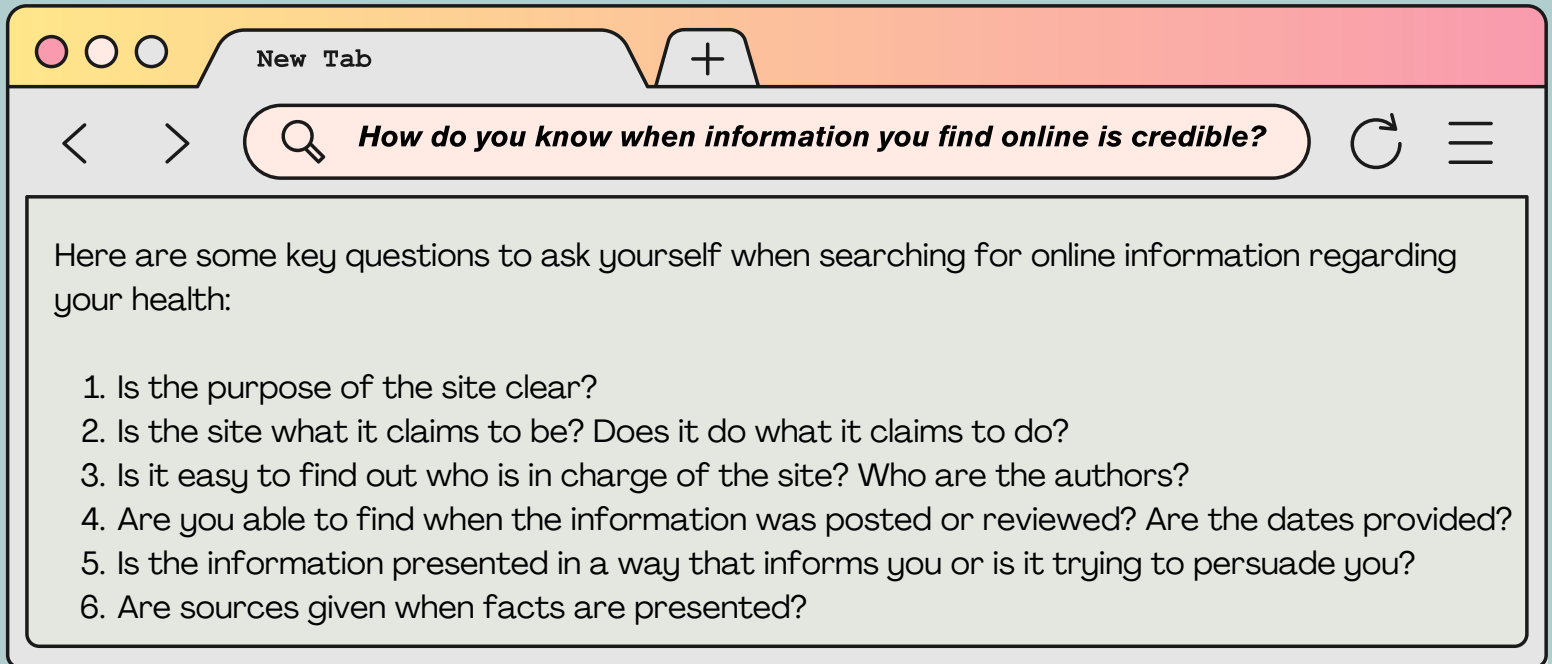
- Show that you can complete the tasks of your routine to demonstrate your desire to be more independent.
- Master “adulting” skills to demonstrate your abilities: learn about grocery shopping, cooking and cleaning.
- Learn to advocate for yourself. This involves honest conversations with your family members.

Community

There are many benefits to being part of a community! It can help you feel valued and become familiar with your neighbourhood, navigate around more easily, feel good about yourself, have a sense of belonging and create a social network. You may choose to participate in community activities and sports.

RESOURCES

Online Search - Health Information



If you don't know where to start, here are some reliable sources you can use to gather health information:

- 1** *Montreal Children's Hospital Family Resource Centre (ARC.1107)*
<https://www.thechildren.com/patients-families/restauration-et-services/national-bank-family-resource-centre>
You can also reach them by telephone (514-412-4400 ext. 22383) or email (bibliofam@muhc.mcgill.ca)
- 2** *McGill University Health Centre Library*
<http://www.muhclibraries.ca/patients/general-health-sites/>
- 3** *Online Health Information Aid*
<https://www.healthsanteinfo.ca/useful-websites/>
- 4** *Info-Santé 811*
Dial #811 for health or psychosocial advice
- 5** *Service 211 Grand Montréal*
Dial #211 to find social and community services near you or visit <https://www.211qc.ca>



NOTES

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