

Transition

TRANSITIONING TO ADULT HEALTHCARE
A GUIDE FOR PARENTS/CAREGIVERS



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

Lifelong support: Requirement for ongoing care due to challenges navigating the adult healthcare system and areas of adulthood independently. This dependence on others could be due to cognitive impairments, psycho-social issues, complex medical needs, etc. The way in which a person will depend on others will be different for everyone.

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

“Adulthood” skills: Life skills that allow a person to navigate adulthood (i.e. budgeting, finding work, doing groceries, forming relationships). No one is born with these skills, but they can learn them over time at a pace that feels comfortable and with support from trusted adults. Some teens and young adults may be ready to do these tasks earlier, while others may start at a later age. Not all tasks are applicable to everyone.

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

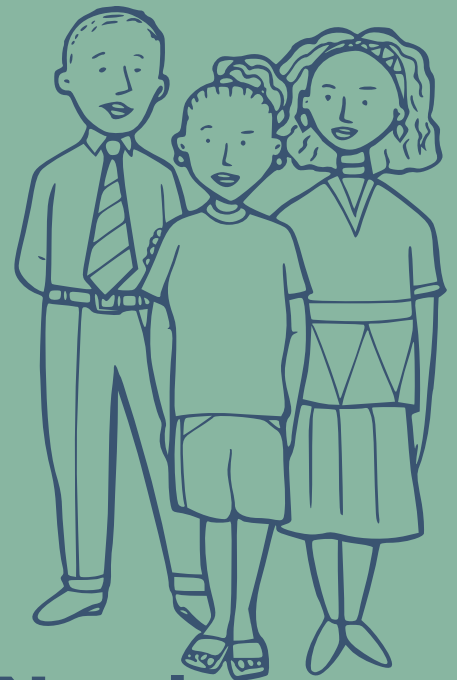
Self-reflection: Ability to think about your own thoughts, feelings, and behaviors

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

OUR POLICY

Dear parent/caregiver,

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

Once your teen turns 18, they will be transferred to an adult doctor. We can help make the change easier in different ways. This might mean helping them find a doctor, sending their medical records, and discussing any special needs with their new healthcare provider. We may also provide your teen with information on community resources and specialty care, if necessary. Since their privacy is important to us, your teen's health information will only be shared with you if they 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

TRANSITION is a process that 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 is unique. In this booklet, you will find different ways to support your teen throughout their transition process.

Keep in mind that the transition process continues well into young adulthood. While we refer to teens in this booklet, the information here is also applicable to parents of young adults.



Foundations of Transition

Take action to help your teen achieve their goals and track their progress.

Support your teen to practice their self-care skills and encourage them to ask questions to find information about their health condition.

Collaborate with your teen's healthcare team to determine the best transition plan for them.

Transfer to adult healthcare system and provide feedback.

SUPPORT CHECKLIST

Use this checklist to track and complete age-related tasks to better prepare for the transition from pediatric to adult healthcare. **If your teen will require lifelong support, please refer to page 14 for a Transition To-Do List.**

Ages 12-14+

APPLY FOR

- Social Insurance Number (SIN)
- Bank account
- Family doctor (see page 11 for more information)

PREPARE BY

- Having your teen help with meals, grocery shopping, and household chores
 - Encouraging your teen to participate in medical decisions
 - Encouraging your teen to start asking and answering questions during their appointments
 - Completing the Transition Readiness Assessment each year with your teen
 - Organizing your teen's health information and keeping it in one location
-

Ages 14-16+

APPLY FOR

- Government issued photo ID
- Driver's license
- RAMQ

PREPARE BY

- Helping your teen set up a routine for taking their medications independently
- Encouraging your teen to spend some time during appointments speaking with their doctor on their own
- Helping your teen to start keeping track of important health information

SUPPORT CHECKLIST

Ages 16-17+

PREPARE BY

- Helping your teen update their medical equipment/supplies
- Having your teen ensure pediatric clinic visits are scheduled
- Encouraging your teen to consult their doctor on their own
- Supporting your teen in filling/refilling their prescriptions
- Encouraging your teen to practice daily life skills (e.g. calling for appointments, using public transportation, budgeting/money management)

Ages 17-18+

CONSIDER

- Private health insurance
- Adult funding
- Post-secondary education, employment and/or volunteer opportunities
- Scholarships and bursaries
- Adult home support (CLSC)
- Supported decision-making

Other ways to support your teen's participation

ENCOURAGE BY

- Having them book their own adult clinic appointments
- Having them prepare for their clinic visits
- Encouraging them to attend appointments on their own and/or take the lead during appointments
- Co-creating a personal directive
- Having them request copies of pediatric reports, physician letters and medical transfer summaries
- Nurturing self-awareness (e.g., journaling, meditation)

Helping Your Teen Reach Their Goals

Use the **My Self-Reflection** tool in the **Teen Transition Booklet** to help your teen identify skills they want or need to develop to manage their health more independently.

As a parent you can help your teen to break down tasks into smaller, more manageable and achievable steps. Here are three strategies you can use to support your teen to build skills and independence as they transition to adult healthcare.

1 SETTING SMART GOALS

S - specific (define goal in detail)

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

A - attainable (challenging but achievable)

R - relevant (meaningful and important)

T - time-based (pick a deadline!)

Use this tool to help your teen set achievable and meaningful goals to develop their health care skills.

Example: By next month, I will be able to call the doctor's office to book my own appointment.

You can also break down big goals into smaller 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 call the pharmacy to refill my prescription on my own.	<ul style="list-style-type: none">• Pharmacy phone number• Names of my medications• Prescription	<ol style="list-style-type: none">1. Locate my prescription2. Practice what I will say3. Call the pharmacy	My mom or dad	Tuesday

2 CHAINING STEPS FOR LEARNING












To teach your teen a new skill, break it down into smaller, more manageable steps. Your teen can then learn one step at a time. Start with either ① the **first** or ② the **last** step with your teen to help them become independent with the full sequence of steps. **Example goal:** I would like to refill my prescription.

1

Forward chaining

Your teen starts with taking the prescription from the doctor. You complete all of the following steps (i.e., steps 2-4). Once your teen has mastered the first step, they can tackle the next step.



A	1. Take the prescription from the doctor. 	Pick up prescription from the pharmacy.	Take daily medication.	Organize medicines for the week. 
B	1. Take the prescription from the doctor. 	2. Pick up prescription from the pharmacy. 	Take daily medication.	Organize medicines for the week.
C	1. Take the prescription from the doctor. 	2. Pick up prescription from the pharmacy. 	3. Take daily medication. 	Organize medicines for the week.
D	1. Take the prescription from the doctor. 	2. Pick up prescription from the pharmacy. 	3. Take daily medication. 	4. Organize medicines for the week. 

2

Your teen starts with organizing medicines for the week. You complete the other steps. Once your teen has mastered that step, you move on to the next.

Backward chaining

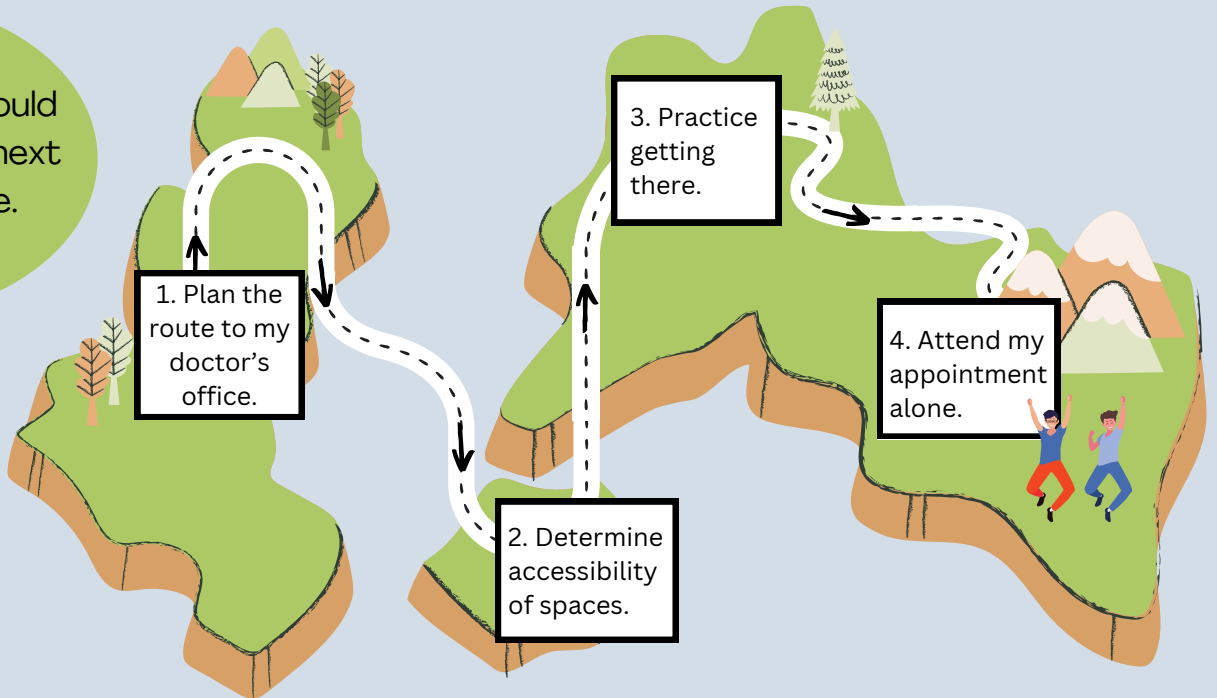


	Take the prescription from the doctor.	Pick up prescription from the pharmacy.	Take daily medication.	1. Organize medicines for the week. 	A
	Take the prescription from the doctor.	Pick up prescription from the pharmacy.	1. Take daily medication. 	2. Organize medicines for the week. 	B
	Take the prescription from the doctor.	1. Pick up prescription from the pharmacy. 	2. Take daily medication. 	3. Organize medicines for the week. 	C
	1. Take the prescription from the doctor. 	2. Pick up prescription from the pharmacy. 	3. Take daily medication. 	4. Organize medicines for the week. 	D

3 NAVIGATION MAP

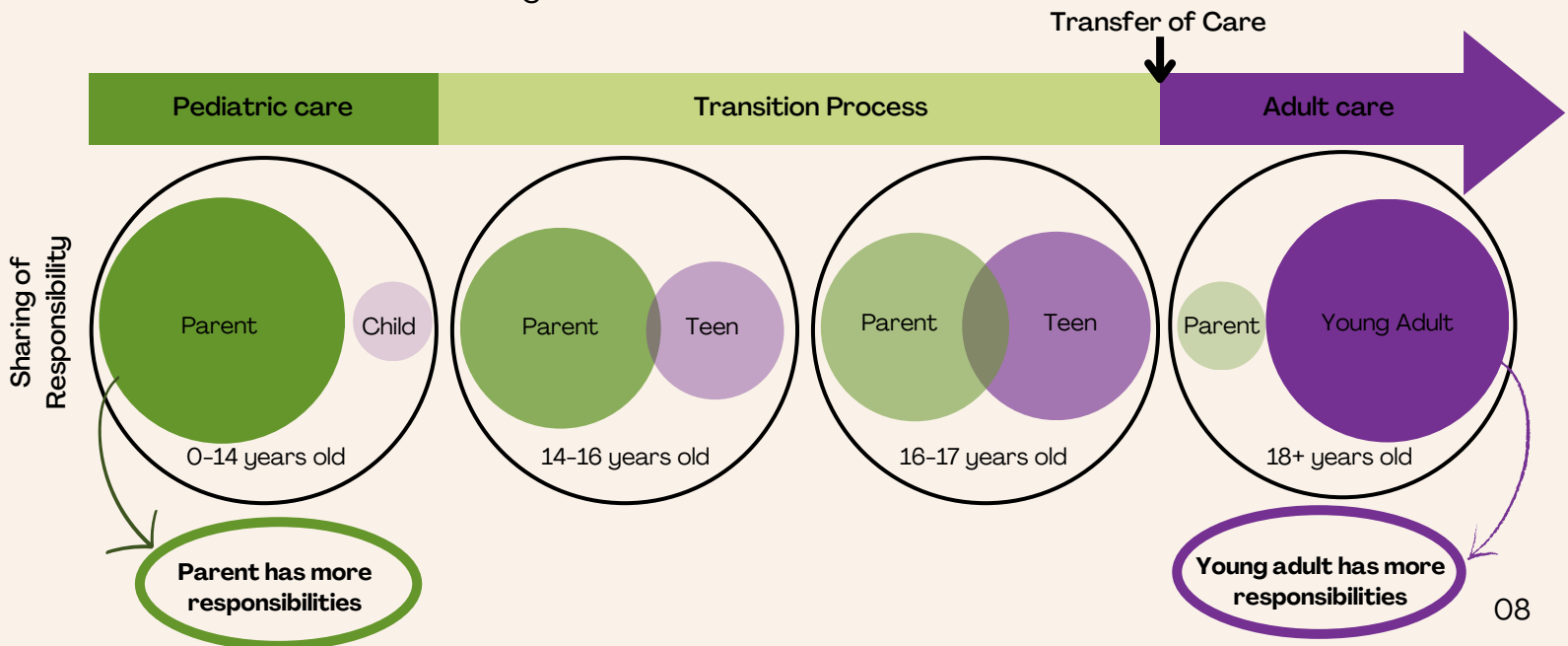
This visual strategy helps break down bigger tasks into smaller steps. Have your teen fill out the map and label the steps needed to achieve their goal. This can also help them identify useful strategies.

Example goal: I would like to attend my next appointment alone.



Shifting of Roles

Transition from pediatric to adult care occurs over a period of time. By starting early, you can support your teen as they learn how to manage their healthcare more independently. Below is a visual model to show the shifting of roles and responsibility that will occur as your teen moves towards the adult healthcare system.



HEALTH MANAGEMENT

Your Teen's Rights

Until your child turns 14, you will be making all their healthcare decisions. As of 14 in Quebec, your teen is allowed to visit healthcare professionals on their own and decide on the confidentiality of their medical information. Your teen now has the right to talk to the healthcare provider about their questions and concerns without you being in the room.

However, we recognize that every family is different. We encourage you to have an open discussion about medical confidentiality with your teen.

Medical Information

Health Care Record

A health record is opened the first time you visit any health institution and is used by healthcare providers to communicate important information regarding medical care. According to the law, if your teen is 14 years or older, they can access their health record for free. They should contact the Medical Records department of their institution to obtain their health record.

Health Booklet

By registering to this Government Health Platform, your teen will be able to access their health information online, including their medications, medical imaging results, and sampling results (<https://carnetsante.gouv.qc.ca/portail>).

Medication

Managing medication can be more difficult than expected. That's why building these skills early on is so important. This may involve:

- Helping your teen learn how to organize their medication(s) for the week
- Determining the best way to remind themselves to take medication(s) on time
- Helping them call the pharmacy to ask for a refill

By starting early, your teen can become more confident and familiar with managing their own medications by the time they transfer to adult care.

HEALTH MANAGEMENT

Medical Insurance

Public Insurance

As a 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). You should own a health insurance card (also known as a Medicare Card or Carte Soleil) to prove you are covered. You will be sent a notice to renew your card a couple of months before it expires, and it is important to renew it for continuous coverage.



Private Insurance

Private health insurance provides additional coverage. There are many different private insurance companies and what they cover varies. This may include:

- Type of services covered
- Maximum amount of money that can be reimbursed
- The age until which your teen is covered under your parental policy (usually until 21 or 25 for students)

It is important to know what goods and services are covered by your insurance, and what kind of documentation you need to provide when submitting your claim (e.g., doctor’s prescription).

Some insurance companies are billed at the time of your appointment, while for others you need to pay upfront and apply for reimbursement.

Medical Appointments

Medical Forms

Remind your teen that their healthcare professional is not there to judge them and that it is better to answer questions truthfully to ensure their healthcare professional gets the right information.

Talking About Symptoms

It may be helpful for your teen to write down their symptoms before their appointment and bring the list with them. You can also encourage your teen to practice describing their symptoms to you.

Asking Questions

Asking questions is an essential skill to understand and manage health. You can help your teen by having them prepare a list of questions they want to ask during their appointment and have them practice asking those questions with you.

HEALTH MANAGEMENT

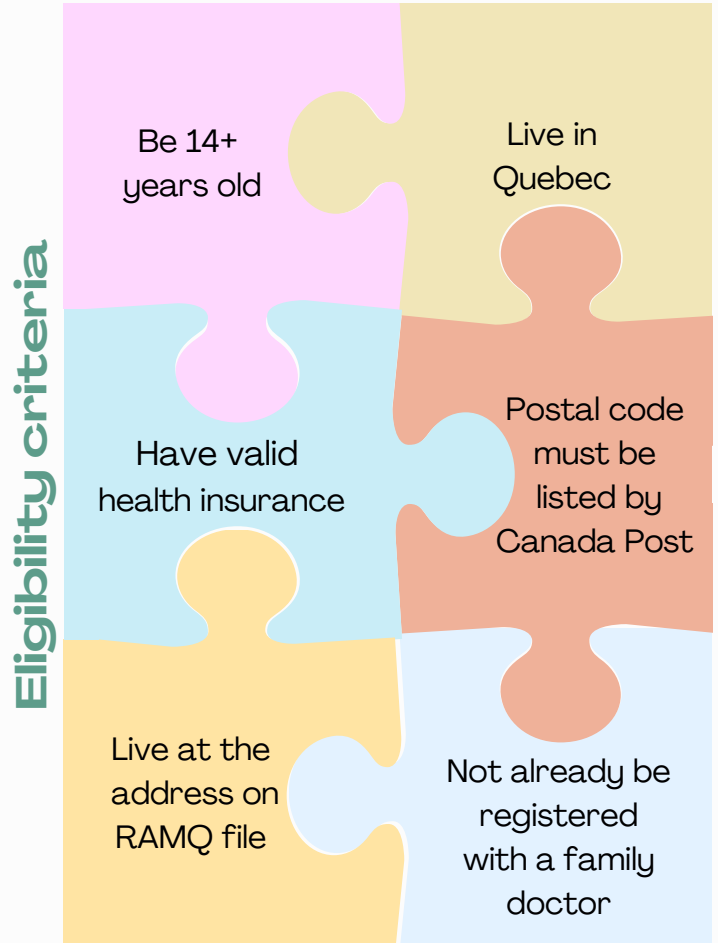
Finding A Doctor

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



Priority Waiting List

After registering on the waiting list, the request will be evaluated, and priority will be assigned based on your teen's health condition. Waiting times vary 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).

KNOWING THE SYSTEMS

AS A PARENT / CAREGIVER

Pediatric Healthcare	Adult Healthcare
Possibly a team approach to 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 to help keep track of your teen's medical care, file and medication	Patient is 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 parents/caregivers and your child about their care	Healthcare professionals talk directly to the patient about their health care and decisions
Many support services may be offered	Patient may need to ask and/or advocate for support services
Longer appointment times	Shorter appointment times

CARING FOR A TEEN WHO WILL NEED LIFELONG SUPPORT

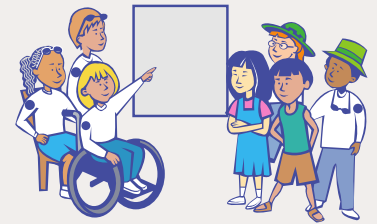


TRANSITION TO-DO LIST

For the parent/caregiver of a teen who will require lifelong support, use this guideline to prepare for a successful transition to adult healthcare.

Ages 14-15

- Register for a **family physician** if your teen does not already have one
- Start obtaining a copy of their **medical records**
- Obtain a **social insurance number** if your teen does not already have one
- Ensure a **psychological evaluation** is completed before transfer to adult care
- Apply for financial resources:
 - Federal and provincial **Disability Tax Credit**
 - Provincial **Supplement for Handicapped Children**
 - Compassionate Care Benefit**
- Apply for **adapted transportation** and/or a **disabled parking permit**
- Obtain a **medical exemption certificate** if your teen is not able to provide a photo or signature for Medicare or Passport
- Open a **Registered Disability Savings Plan** with the assistance of a financial advisor
- Apply for **Residential Adaptation Assistance Program** for transportation funding to medical appointments



Ages 16-17

- Discuss resources** for adult health care with your teen's medical team
- Open a **bank account** for your teen
- Continue to obtain a copy of all pertinent **health care information**
- File income taxes** for your teen prior to 17 years old
- Prepare for **curatorship** or a **will** (including preparing for **estate planning & Henson trust**)
- Explore **community resources**

Age 18+

- Ensure you have completed all **government forms** indicated in this checklist
- Familiarize yourself with the **adult health care providers**
- Request financial assistance through **Social Solidarity Program** if your teen is unable to work

MY TEEN'S CARE TEAM CONTACT INFORMATION

Keep track of the names and contact information of the professionals and services involved in your teen's healthcare.

	Healthcare Provider (Name/Role)	Contact Information (Phone/Email)	Pediatric	Adult
1			<input type="checkbox"/>	<input type="checkbox"/>
2			<input type="checkbox"/>	<input type="checkbox"/>
3			<input type="checkbox"/>	<input type="checkbox"/>
4			<input type="checkbox"/>	<input type="checkbox"/>
5			<input type="checkbox"/>	<input type="checkbox"/>

MY TEEN'S CARE TEAM CONTACT INFORMATION

	Healthcare Provider (Name/Role)	Contact Information (Name/Role)	Pediatric	Adult
6			<input type="checkbox"/>	<input type="checkbox"/>
7			<input type="checkbox"/>	<input type="checkbox"/>
8			<input type="checkbox"/>	<input type="checkbox"/>
9			<input type="checkbox"/>	<input type="checkbox"/>
10			<input type="checkbox"/>	<input type="checkbox"/>
11			<input type="checkbox"/>	<input type="checkbox"/>
12			<input type="checkbox"/>	<input type="checkbox"/>

MY TEEN'S TECHNOLOGY, EQUIPMENT, AND SUPPLIES

List of Technology, Equipment & Supplies

- 1 _____
Wheelchair
- 2 _____
- 3 _____
- 4 _____
- 5 _____
- 6 _____

Suppliers on Adult Side (name & contact info)

I will need to call

Constance-Lethbridge

514-XXX-XXXX ext. 1234



**SELF-CARE FOR
PARENTS & CAREGIVERS**

SELF-CARE FOR PARENTS & CAREGIVERS

Taking Care of Your Health

Guiding your teen as they transition to adulthood may be challenging or feel overwhelming. By caring for yourself and your wellbeing you can be an even better support and role model for your teen.

Things to Consider

Build a Self-Care Routine

Take care of your wellbeing

- **Physical**
- **Mental**
- **Emotional**
- **Spiritual**

What makes you **happy**?

What do you like to do for **fun**? What makes you **feel good**?

Have you considered **respite care**? Remember that **taking time for yourself** is important.

Recognize Signs of Distress

Are you...

- Feeling fatigued or having difficulty sleeping?
- Worrying all the time?
- Becoming easily irked/angry?
- Misusing alcohol or drugs?
- Gaining or losing weight unintentionally?
- Losing interest in things you used to enjoy?
- Forgetting to prioritize yourself?
- Feeling sad?

Know When to Seek Help

Seek and accept help

From your support network and/or professionals)

Focus on what you can do

You are doing the best you can!

Set realistic goals and know your boundaries

Get Connected

Join a support group or reach out to your friends/family

Take care of your health

Build a self-care routine



My personal notes:

SELF-CARE FOR PARENTS & CAREGIVERS

Building a Support System

YOU ARE NOT ALONE

Transition to adult healthcare is a long process and getting support can be very beneficial to you and your teen's overall wellbeing. Everyone needs help and support sometimes, and remember **you are not alone.**

People you can reach out to

Your healthcare team

Your family doctor
Your teen's family doctor
Specialist(s)
Social worker

Your Teen's Healthcare Team

Your teen's family doctor
Your teen's pediatrician(s)
Occupational therapist
Physical therapist
Social worker

Community Resources

CLSC
Call 811 (Info-Sante)
Call 211
(free information service)

Mental Health Resources

Psychologist
Spiritual care
Psychotherapist

Your Support System

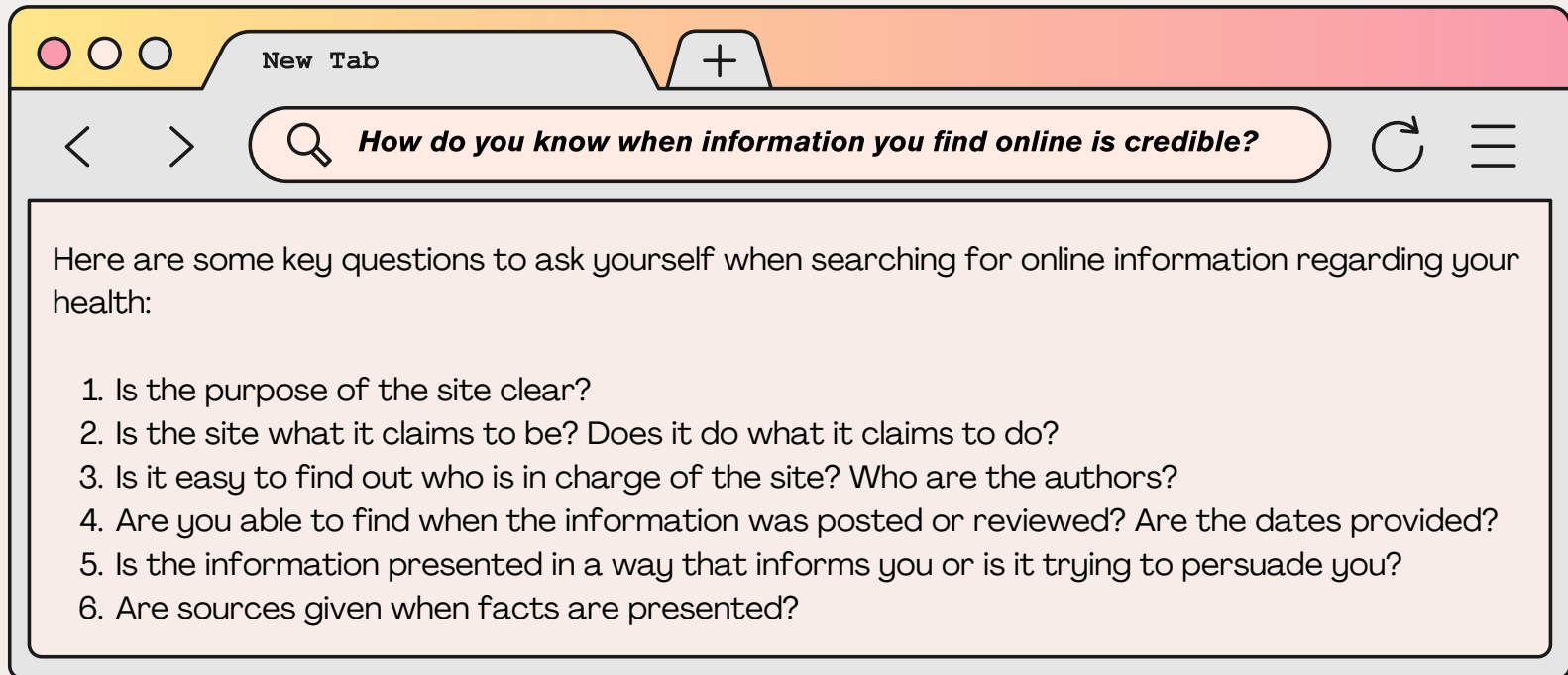
Family and friends
Community
Colleagues

Other Support



KNOW YOUR RESOURCES

Online Search - Health Information



Here are some key questions to ask yourself when searching for online information regarding your health:

1. Is the purpose of the site clear?
2. Is the site what it claims to be? Does it do what it claims to do?
3. Is it easy to find out who is in charge of the site? Who are the authors?
4. Are you able to find when the information was posted or reviewed? Are the dates provided?
5. Is the information presented in a way that informs you or is it trying to persuade you?
6. Are sources given when facts are presented?

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

- 1** *Montreal Children's Hospital Family Resource Centre and Library (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.muhealthlibraries.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>

