

When You're 18

YOU ARE IN CHARGE OF YOUR HEALTH



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This Book

This book is about you and your life...who you are now and what you want to do in the future. It also includes some information and gives you some activities to do that will help you understand what it means to be legally in charge of your health care, and help you be active, healthy and able to do more of the things you want to do now and in the future.



Your New Rights and Responsibilities

Since you are reading this booklet either:

You will turn 18 soon, and want to learn more about what new rights and responsibilities you will have when you are legally an adult

----- **OR** -----

You have already had your 18th birthday and want some more information about what it means to be an adult and in charge of your own health care.

This booklet will help you be prepared to work effectively with your doctor and other health care providers, to understand health insurance and to have your parents and others as involved in your health care as you want them to be.



On the next page is a short quiz about what rights and responsibilities you have when you turn 18 and are, legally, an adult.

Quiz #1

To test your knowledge about the legal rights of young adults (age 18 -20) in Canada, answer the following questions. (The answers and additional information about your adult rights and responsibilities are on page 5 but don't look yet!).

True or False??

In Canada, individuals age 18 to 20...

1. T F Can vote in provincial and local elections
2. T F Cannot vote in federal elections until age 21
3. T F Can sign a contract (like a lease on an apartment) but legally must have a parent co-sign
4. T F Can sign by themselves for a loan (for example to pay for school or a car)
5. T F Have to sign for themselves to give "informed consent" for medical procedures
6. T F Control who can see (and cannot see) their personal medical information
7. T F Cannot get medical treatment unless a parent is informed and also gives consent
8. T F Can live where they want
9. T F Are not responsible for their own debts (like credit card payments) if they do not have enough money to pay them
10. T F Can purchase and drink alcohol
11. T F Can purchase cigarettes
12. T F Can serve on a jury

Your New Rights and

Answers

1. True. If you are age 18 or older, and register, you can (and should) vote in provincial and local elections in Canada.

2. False. If you are age 18 or older, and register, you can (and should) vote in federal elections.

3. False. At age 18, you can sign a contract, like a lease, by yourself. You do not need to have your parents co-sign.

4. True. At 18, you can sign a loan agreement (and you are responsible for repaying the loan).

5. True. If you are age 18 or older, health care providers must get informed consent from you in order to carry out a medical procedure. Of course you can ask for advice from your parents, but you are the one who must be informed and give consent. Your parent cannot make medical (or other decisions) for you.



Responsibilities

to Quiz #1

6. True. If you are age 18 or older, doctors, nurses and other health care providers cannot share information about you unless you have given permission. More about this later...



7. False. Once you turn 18, your parents do not need to be told about or give permission for your medical care. In fact, medical information cannot be released to your parents unless you say so.

Your New Rights and Responsibilities

Answers to Quiz #1

8. True.

9. False. At 18, you are financially responsible for yourself. You can live where you want, but you also have to pay your



own way. Once you turn 18, your parents no longer have a legal responsibility to support you financially.

10. True and False, depends on the province you are in. In Alberta, Manitoba and Quebec you may legally purchase and consume

alcohol at age 18. In the other provinces and territories the legal age to purchase and consume alcohol is 19.

11. True and False, depends on the province you are in. In Alberta, Manitoba, the Northwest Territories, Nunavut, Quebec, Saskatchewan and the Yukon you can purchase cigarettes at age 18. In the other provinces you must be 19.

12. True. To serve on a jury, you have to be at least 18 years old.



Your Life as an Adult

Having and working toward goals is an important part of being an adult. Below are some questions about what you would like to accomplish by the time you are 25 years old.

Circle or check the answer that is true for you.

By the time I am 25 —

Education and Work

- | | | | |
|--|-----|-------|----|
| I will finish my vocational training | Yes | Maybe | No |
| I will complete college..... | Yes | Maybe | No |
| I will have a job | Yes | Maybe | No |

What kind of work would you like to do? _____

Where I Will Live

When I am 25, I want to live...

- In my own house or apartment (with roommates or by myself)
- With my parents
- With other members of my family (brother, sister, aunt)
- Another place (specify): _____



Your Life as an Adult

Where I Want to Live

When I am 25, I want to live...

- In the same province I live in now
 - In a different province (What province? _____)
 - In a big city. (What city? _____)
 - By the ocean
 - In the country
 - Another place (specify): _____
-

Living independently

By the time I am 25, I want to

- Be financially independent;
support myself Yes Maybe No
- Have a car or other vehicle..... Yes Maybe No
- Get married or have
a steady partner Yes Maybe No
- Raise a family Yes Maybe No
- Have lots of friends Yes Maybe No
- Communicate well with
health care providers Yes Maybe No
- Arrange for and manage
my own health care Yes Maybe No
- Pay for my own health insurance Yes Maybe No



Being an Adult with a Special Health Care Need

Growing up with a special health care need and becoming an adult can present you with many challenges. However, many young adults with chronic health conditions and disabilities have successfully met these challenges and have reached their goals of being independent and having a good job. They say that to be successful they had to...

- Take responsibility for themselves
- Manage their own health care
- Be as physically fit and healthy as possible



Time Out for

1. **Chronic** – A word that means “lasts a long time”.
2. **Health condition** – Another way of saying disease or disability.
Sometimes people refer to those who have a chronic health condition as “people with special health care needs”. However, most young adults do not like the term “special” when it is used to describe them.
3. **Families**
There are all kinds of families. Some teens live with one or both of their birth parents; some live with adoptive, foster or stepparent(s). Some live with one or more grandparents, other relatives or family friends. There are all kinds of parents and families. If the terms used in the next sections of this book don't fit your family living situation, just substitute the ones that do.
4. **Pediatrician** – A doctor who is trained to take care of infants, children and teens.
5. **Family Physician** – A doctor who is trained to provide primary care to both children and adults.
6. **Health Care Transition** – The process of getting ready to leave your pediatric doctors and get your health care from doctors who are trained to care for adults.

Definitions

- 7. Specialist** – A doctor who treats one kind of health problem or treats problems with one part of the body.
For example, an oncologist is a specialist that cares for patients with cancer. A cardiologist takes care of problems with the heart. Specialists usually do not deal with health problems that are not in their area of speciality.
- 8. Nurse Practitioner** – A registered nurse (RN) with enhanced knowledge and skills.
They work closely with members of the health care team including physicians, pharmacists, other nurses, rehabilitation specialists and others.



Staying

If you have a chronic health condition (like diabetes, asthma, sickle cell disease, congenital heart disease and epilepsy) it takes a lot of planning and work to stay healthy.

On the next page are some things that, as a young adult with a chronic health condition, you need to be able to do. For each task, indicate if you already do this by yourself, or if you need to learn more, in order to do this independently.



Healthy

Check what is true for you...

Do independently

Need to learn more



- | | | |
|--------------------------|--------------------------|--|
| <input type="checkbox"/> | <input type="checkbox"/> | Take all my medications when I need to |
| <input type="checkbox"/> | <input type="checkbox"/> | Order my medications when I need more |
| <input type="checkbox"/> | <input type="checkbox"/> | Schedule appointments with my doctors |
| <input type="checkbox"/> | <input type="checkbox"/> | Go to my medical appointments |
| <input type="checkbox"/> | <input type="checkbox"/> | Tell the doctors about how I am feeling |
| <input type="checkbox"/> | <input type="checkbox"/> | Answer all the questions that doctors ask |
| <input type="checkbox"/> | <input type="checkbox"/> | Ask doctors questions about my condition |
| <input type="checkbox"/> | <input type="checkbox"/> | Take notes about what the doctors say |
| <input type="checkbox"/> | <input type="checkbox"/> | Remember what the doctors say to do |
| <input type="checkbox"/> | <input type="checkbox"/> | Read books to learn more about my condition |
| <input type="checkbox"/> | <input type="checkbox"/> | Look things up on the Internet about my condition |
| <input type="checkbox"/> | <input type="checkbox"/> | Keep a record about my condition and health care – (for example my diagnosis, medications I take, name and phone number of my doctors) |
| <input type="checkbox"/> | <input type="checkbox"/> | Do health insurance paper work |
| <input type="checkbox"/> | <input type="checkbox"/> | Pay health care bills |



Quiz

Now that you're 18

...and ARE in charge of your health care, you need to know about your health insurance and when you will be too old to go to your pediatrician or a children's hospital.

To test your knowledge about these important aspects of health care transition answer the following questions. (The answers and additional information about these issues start on page 17 but, of course, you won't look at the answers first!). And maybe you should also give your parents this quiz - to see what they know and don't know about transition.

True or False??

1. T F You will no longer be eligible for services from a pediatrician when you turn 18.
2. T F Your pediatricians will definitely take care of you until you are 18.
3. T F If you have a health condition that started while you were a child (like cystic fibrosis, asthma, sickle cell disease, congenital heart disease or Type I diabetes) then you will be able to get in-patient care in a children's hospital no matter how old you are.

#2

4. T F If you are age 18 or older, and go to an emergency room, you cannot have your parents in the exam room with you to help answer questions about your medical history.
5. T F It is easy to find adult specialists who know about health conditions that start in childhood (like congenital heart disease, cerebral palsy and juvenile rheumatoid arthritis).
6. T F Your provincial health insurance covers the same services and pays the same amount no matter how old you are.
7. T F Young adults with a chronic health condition or disability do not need to have a family physician because specialists usually provide and coordinate all of the health care that they need.

Answers

1. Usually True. Most pediatricians will not follow you after you turn 18 years old, in fact some may not follow you after you turn 16 or 17 years old. The only way to know is to ask your pediatrician.

2. False. You cannot be sure that the doctors you now see will continue to take care of you until you are 18. Some do take care of older adolescents and young adults but the only way to know is to ask! Write a note to yourself to ask each doctor that you see about their upper age limit. Or you could call your doctors right now to get this question answered.

3. False. Most children's hospitals do have an upper age limit and do not provide in-patient care to individuals over a certain age. This upper age limit varies from hospital to hospital. Ask your doctors about the in-patient policy of the hospitals where you might go. Again, the only way to be sure is to ask.

4. False. If you are age 18 or older, and go to an emergency room, you can ask to have your parents or another person in the exam room with you to help answer questions about your medical history and make decisions about care. Since you are 18, you are in charge of who gets to know about your medical condition, and who gets to help you make medical decisions. If staff in the emergency department say

to Quiz #2

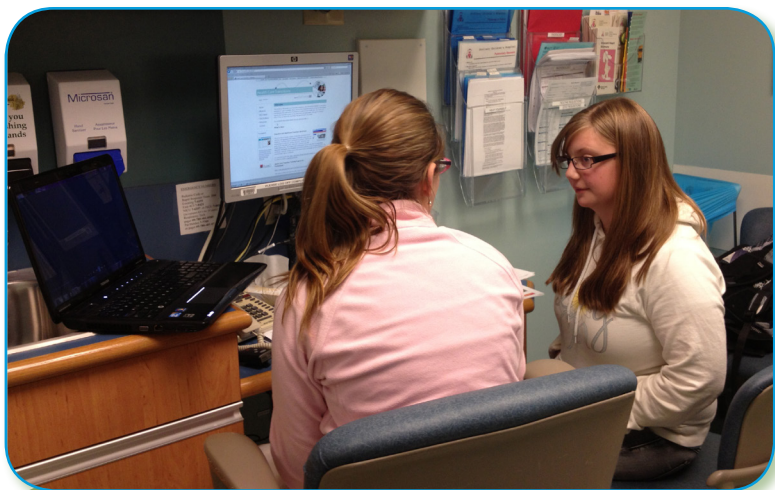
that they prefer to see you alone, you need to speak up and say what you prefer. You may have to sign a release of medical information form, but that's OK.

5. False. Sometimes, it is NOT easy to find doctors who take care of adults and also know about health conditions that start in childhood (like congenital heart disease, cerebral palsy and juvenile rheumatoid arthritis). It may take a year or more to find adult doctors who you are comfortable with and who understand your condition. You can ask your current doctor if there is somewhere or someone that they will refer you to.



Answers

6. False. Your provincial health insurance may change when you turn 18 depending on the province that you live in. Some things like eye exams may be covered before you are 18. After you turn 18 you may have to pay for the exam or have third-party insurance (through your parents or your own insurance) to cover these costs. The best way to check is to talk to your doctors or the Provincial Health Insurance office for the province you live in.



to Quiz #2

7. False. Young adults who have a chronic health condition or disability definitely need to have a family physician. An adult cardiologist will provide care related to a heart condition, but will not see you if you have an ear ache. It can take a long time to get an appointment with adult specialists and they do not usually help to coordinate your care or link you with community resources. You can usually get an appointment with your family doctor in a day or two and they will be able to help you find out whom to talk to about accessing community resources you might need for your condition.



Since YOU are in charge of your health...

Since YOU are in charge of your health here are some things you should be able to do...

- Tell someone the name of your health condition (your diagnosis)
- Tell someone the correct name of all of your medications, the doses, when you take your medications and why
- Take your medications when you are supposed to
- Order medications when you need more
- Call to make an appointment with your doctors
- Know what to do in case of an emergency
- Know what you have to do to stay healthy; and DO those things without someone reminding you



If you cannot already do all of these things now, you need to learn.

What You Can Do...

If you cannot already do all of the things listed on page 21, you need to learn. It's OK to ask for help from your parents, your doctors and nurses. One way to remember some of this information is to write it down and carry this important information with you.



If you have a cell phone, one thing you can do right now is to enter in your ICE (In Case of Emergency) contacts. First responders such as paramedics, firefighters and police officers have been trained to look in cell phone address books under ICE for contacts who can provide important medical information when the person they are helping cannot do so themselves. If there are several people who should be contacted in case of an emergency, make multiple entries like "ICE1", "ICE2", etc.

Talking With Your Other Health Care

Since you are a young adult, you need to be able to communicate effectively with your doctors and other health care professionals.

Many young people have found the **GLADD** approach to talking with health care professionals to be very helpful.



Give

Give information about how you are feeling and what you have done to stay healthy. Also give your doctor information about how your condition is affecting your every day life and what your concerns are.



Listen

Listen and Learn. Listen carefully to your health care providers and learn all you can from them about your condition and what you can do to be healthy.



Ask

Ask your doctors the questions you have about your health. If you do not understand what you are being told, let the professional know, and ask them to explain it in a different way.



Decide

The first D stands for Decide. At every visit with a health care professional, decisions need to be made about what to do next. Make sure that you play an active role in the decision making, since, at 18, you are the one who must agree to the plan of care.



Do

The second D stands for Do. Do your part in following the plan!

ur Doctors and e Professionals

Using the GLADD approach.

G – Giving Information. As a young adult, you are responsible for giving your health care providers complete and detailed information. Be honest! If you have not taken your medications when you were supposed to, or have done some things that you were told not to do, let your doctor know.

In order to give your doctors the complete and detailed information that they need, you need to keep a medical diary and write down information about when, for example, you experience symptoms (like headaches), how severe your symptoms are and how long they last, and what, if anything, helps. Ask your doctors what information they want you to give to them, so you can keep a record and refer to it when they ask their questions.

Also it is important for you to give your doctors an understanding of how your condition is affecting your every day life. Sometimes health care professionals focus on your symptoms and medications, and do not see the “big picture” of your life as a whole.

L – Listening and Learning. As a young adult, you are responsible for listening to and remembering what health care professionals tell you. Most people can recall only 2 or 3 things that doctors tell them, unless they write the information or the instructions down. So take your medical diary with you when you visit the doctor, and write down the information that you need to remember.

Getting Answers To Your Questions

A – **Ask.** Ask the questions you have about your health and keep asking until you understand.

It's a good idea to write down and take your questions with you to help you remember ALL of the them.

Right Now! Get your health diary or a notebook and write down some of the questions that you have about your condition and about how to stay healthy. Keep this notebook with you and add questions as they occur to you. And the next time you see your doctor, take these questions with you and ASK!



Doctors want their patients to have the information they need to be healthy. And they are happy when their patients take the time to think about their questions ahead of time, and bring written questions with them to their visits.

Some doctors let their patients send questions to them in an email and respond the same way. Do any of your doctors use email?



Ask and Keep on Asking

It can be hard to understand what a doctor tells you. Sometimes they use words you don't really understand OR talk too fast OR give you too much information at one time. Sometimes they don't really answer the question you asked. And you might want them to give you something to read, rather than give you a lecture.

Doctors really do want their young adult patients to have the information they need to be healthy. Therefore, you need to let them know when you don't really understand what they are talking about...

If you don't understand, you might say:

- Please tell me more about that.
- Could you explain that to me again?
- Could you write that down for me?
- Is there something you can give me to read?

Remember –
there's no such thing as a "dumb question".

D – **Decide.** Play an active role in deciding what needs to be done next and who is going to do what. Don't agree to a plan that you are not willing and able to follow. BECAUSE...

D – **The second D stands for Do.** Do your part in following the plan!!



What's

As you look ahead, it is important to keep in mind that living with a health condition means that you will need to do more planning and preparation than other people your age. This takes time and effort – but it definitely pays off.

If you are planning to get more education and training after high school, be prepared to explain to others how your health condition affects you and what accommodations you need in order to succeed.

In the past, you may have had an individualized school program to help you in school. The high school counselors and teachers were responsible for helping to develop and implement this plan.

In college or other post secondary educational programs, it is up to YOU, the student, to request “reasonable accommodations”. Ask for the office that works with “students with disabilities”. You may not think of yourself as having a disability, or may not like the term disability. But if you do have a health condition, you need to take advantage of the guidance and assistance that the school’s “disability services program” can provide. This program is usually part of the Dean of Students Office.

Contact this office before classes begin. If you wait until your health condition begins to affect your ability to get

Next???

your school work done, it's too late. You will need to explain how your health condition may affect you during the semester; and they will let you know how they can help. They will help you determine what accommodations might be helpful, and help to get you these accommodations when you need them.



It's also important to have a doctor who works on campus or near your college. Your current doctors probably can help you find this doctor, who you can see right away if you get sick while at college. Make an appointment with this doctor before classes begin, so you can get to know each other before there is an emergency.

With this extra planning and preparation with your doctors and school staff, you will be better prepared to successfully deal with any problems that may arise.

More About Transition

By reading this booklet and completing the activities, you have started to be more in charge of your life and your health and are better prepared to do more of the things you want to do now and in the future.

Now that you have gotten started, here are some other things you can look at that will help you keep moving in the right direction.

The Good 2 Go Transition Program has been created by a team at the Hospital for Sick Children in Toronto, ON. This website contains a mix of resources for patients, parents and health care providers dealing with transition.

A great resource for teens is the MyHealth Passport, a customized, wallet-size card that gives you instant access to your important medical information. It can be used when you go to a new doctor, visit an emergency room or are writing your first novel and want the names of your medications for your hero.

www.sickkids.ca/myhealthpassport

 **Good 2 Go**
Transition Program



www.sickkids.ca/good2go

On The Web

Canadian Congenital Heart Network

www.cachnet.org

Patient and provider information on Adult Congenital Heart Clinics in Canada.

Canadian Congenital Heart Alliance

www.cchaforlife.org

Good general congenital heart disease information. Also has a link to life, medical and travel insurance information.

Health Care Transitions Website

<http://hctransitions.ichp.ufl.edu/>

Multi-media resources for teens to help them become better users of the adult health care system.

Service Canada

www.servicecanada.gc.ca

Government of Canada resources for all life stages including information about government programs.

Young and Healthy

<http://www.youngandhealthy.ca/caah/>

Information for teens about adolescent health issues like sexually transmitted infections, drug and alcohol use.

Healthy Alberta

www.healthyalberta.com

Helpful resources for living a healthy lifestyle and eating a healthy diet.

Healthy Ontario

<http://www.mhp.gov.on.ca/en/healthy-ontario.asp>

More helpful resources for living a healthy lifestyle and eating a healthy diet.

Health Canada

www.hc-sc.gc.ca/

A resource for all Canadians about health related issues.



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