

# Now that you're in High School...

**IT'S TIME TO BE MORE  
IN CHARGE OF YOUR HEALTH**

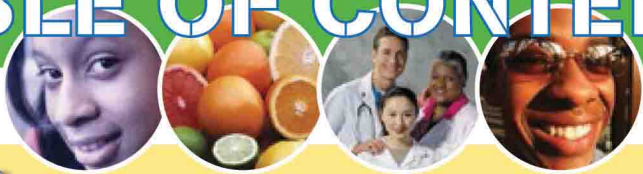


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**Health Care Transition Guide for Teens in High School**

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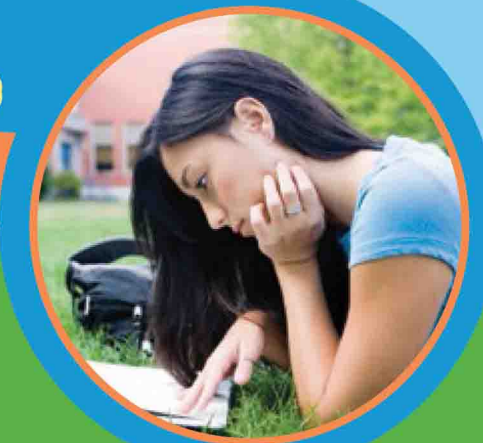
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# THIS BOOK



**T**his 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 be more in charge of your life, be active and healthy and be able to do more of the things you want to do now and in the future.



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# GETTING STARTED !

**S**o here you are in high school and you are probably thinking more about what you want to do with your friends this weekend, than about the home work that is due tomorrow. Since you have some special medical needs, those are also on your mind. Sometimes you may feel your parents are still treating you like you were a little kid; and at other times you may feel like all the things you have to do and think about are just too much. It's easy to forget how much you have learned and how much you have changed over the last few years.

The first step in being more in charge of your health, is to take a look at who you are now, and how much you have changed since you were a kid in elementary school.



# ME

Now and Then

To see how you have changed, think about how things were when you were in elementary school. Below, write down how you spend your time, what you do and what and who is important to you now - and how things were back then. In some ways you are different and in other ways you may be the same.

Fill in the blanks!

	Now - High School	Then - Elementary School
Outside of school my favorite things to do are		
At school I'm "into"		
Music I like		
My favorite TV shows		
My favorite book		
Best subject in school		
What I'm really good at		
What I worry about most		
Who I'd like to meet		
My favorite movies		
Career I'd like to have		
Chore I hate most		
What keeps me going		

# What Others Think

**A**nother way of looking at yourself is to think about what other people think you are like - your classmates and friends, the people in your family, your teachers, and others. Below are some words people might use to describe you. Use these words or other ones that you think of to fill in the blanks.



*What do others think about me*

**Funny** • **Sad** • **Happy** • **Clever** • **Sneaky** • **Athletic** • **Shy**  
**Confused** • **Cool** • **Smart** • **Angry** • **Loving** • **Sloppy**  
**Careful** • **Responsible** • **Organized** • **Caring** • **Artistic**



**Frustrated** • **Weird** • **Trustworthy** • **Thoughtful**  
**Nosy** • **Kind** • **Timid** • **Stubborn** • **Silly** • **Smart** • **Sassy**  
**Powerful** • **Peaceful** • **Mixed Up** • **Messy** • **Neat**

Fill in the blanks!

## What Others Think About Me

My best friend	
My favorite teacher	
My parents	
Teacher in my worst class	
My brother(s) or sister(s)	
My neighbors	
People who do not know me	
My doctors	



**Daring** • **Persistent** • **Inquisitive** • **Goofy** • **Careful**  
**Sensitive** • **Nice** • **Hopeful** • **Easygoing** • **Loyal**  
**Forgiving** • **Imaginative** • **Logical** • **Determined**  
**Dependable** • **Emotional** • **Flexible**

# YOUR LIFE WHEN YOU ARE AN ADULT

Another way of looking at yourself is to think about some things in your future - like how long you want to go to school, what kind of job you want, and where you want to live. Below are some questions to ask yourself.

Circle, check, and fill in the answers below that are true for you.

## School and Work

- I plan to finish high school ..... Yes Maybe No
- I plan to get vocational training ..... Yes Maybe No
- I plan to go to college ..... Yes Maybe No
- I plan to have a job when I am an adult ... Yes Maybe No
- What kind of jobs would you enjoy doing to earn money?  
\_\_\_\_\_

## Where I Will Live

When I am an adult, 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): \_\_\_\_\_

## Living Independently

When I am an adult, I want to...

- Be financially independent (support myself) .. Yes Maybe No
- Drive a car ..... 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

# Growing Up With Special Health Care Needs or a Disability

**G**rowing up with special health care needs or a disability can present many challenges. However, young people with chronic health conditions and disabilities who were able to meet these challenges and reach their goals, say that they had to do several things to be successful. They had to:

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



# Responsibility And Freedom



**M**ost teens say that they have more responsibilities in high school...

Most high schools are big and busy. You have a different teacher for every class - and you have to find your way from classroom to classroom.

You have more responsibility for keeping track of your assignments and homework...

You probably use a notebook to write down and keep track of your assignments and other things you need to remember.

And many teachers and parents say that teens in high school get to make more decisions for themselves and have a lot more freedom...maybe too much freedom.

And most teens have heard:

**“With privileges come responsibilities and consequences.”**



They say these responsibilities and consequences get you ready to be an adult, have a job, and be on your own.

# Responsibility, Privileges And Consequences

**W**rite down some of the things you are responsible for at home and at school and the privileges you earn if you fulfill your responsibilities and the consequences that you face if you do not...and if you think the responsibilities and consequences are fair or are not fair.



Fill in the blanks!

	At Home 	At School 
<b>Responsibilities</b> (fair/not fair)		
<b>Privileges</b> (Stuff I get to do)		
<b>Consequences</b> (fair/not fair)		



- 1 **Chronic** – A word that means “lasts a long time”.
- 2 **Health condition** – Another way of saying **disease or disability**. Some people refer to adolescents who have a chronic health condition as “youth with special health care needs”. However, most teens 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 **Internist** – A doctor who is trained to take care of adults.
- 7 **Primary Care Provider / Medical Home** – A **Primary Care Provider (PCP)** is a doctor who takes care of patients for many years and knows about all of their health care needs. A PCP can take care of many of the health care problems that people have and help patients find a “specialist” if they need special tests or other kinds of medical services. A PCP along with nurses, a care coordinator, social workers, and

other health professionals, becomes an individual's “Medical Home.” A Medical Home works with patients and families to schedule and follow-up on the care they need. Everyone should have a Primary Care/Medical Home, no matter how old they are.

- 8 **Pediatric Nurse Practitioner (PNP)** – A nurse who has received special training in the care of infants, children and teens.
- 9 **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. A psychiatrist helps people when they have problems with how they think, feel or behave. Specialists usually do not deal with health problems that are not in their area of specialty.
- 10 **Care Coordinator** – A nurse or other professional who helps you, your family and your doctors coordinate your health care. That may include developing a care plan, identifying new doctors, scheduling appointments, or finding community services that you need. This person is sometimes called a case manager or patient navigator.
- 11 **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.



# STAYING HEALTHY

**A**s you have probably heard others say, it is important to stay healthy in order to participate in all the activities you enjoy. But it takes some work and planning, especially for teens who have a chronic condition (like diabetes, asthma, sickle cell disease, or epilepsy).



On the next page are some things that families do to help teens stay healthy.

Put a check by the things that your family does to help you be healthy.

My parents or another member of my family:

- Tell me when to take medications that I need
- Order medications when I need more
- Schedule appointments with my doctors
- Take me to my medical appointments
- Come into the examination room with me
- Tell the doctors about how I am feeling
- Answer the questions that the doctors ask
- Ask the doctors questions about my health
- Take notes about what the doctors say
- Remember what the doctors say to do
- Explain to me about my health condition or allergies
- Read books or use the internet to learn more about my health condition
- Keep a notebook that has information about my health care (for example, diagnosis, medications I take, names and phone numbers of my doctors)

List other things your family does to help you be healthy:



Prior to age 16 my parents were very involved and my doctors talked to my parents about my surgeries and I kind of went along with that. But at 16 doctors started to talk to me...and by the time I was 18, I was making the decisions.

**-Jeff**



I think you should be thinking about your future, no matter how old you are, so you can make that transition (to being an adult) more easily. Good health to me means I can live a long and happy life and fulfill all my dreams...and maybe a few more...

**-Loretta**



# What other Teens Are Saying

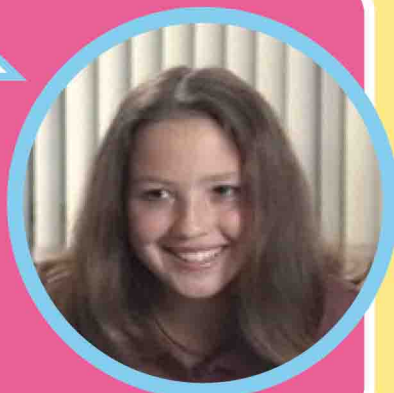


I like the fact that (my health) is my responsibility. I see that as freedom.

**-Amy**

My mom taught me how to interact with health professionals and to tell them what I need and what I want, because I know me the best and how my body works...and how they can help me.

**-Laura**



## about growing up with a chronic health condition



A lot of times when you are in the room with your parents and the doctor, there are things you want to ask the doctor but you don't want to ask the doctor stuff in front of your parents and it creates stress because you are afraid of your parents' reaction.

**-Andrea**

# NOW THAT YOU'RE IN HIGH SCHOOL

... IT'S TIME TO BE MORE IN CHARGE OF YOUR HEALTH CARE

**N**ow that you are in high school, you have more responsibility for keeping track of your assignments and homework. This shift in responsibility (from your teachers and your parents to you) is to help you prepare for college or vocational training, work and your future independence.



Since you have learned how to be more responsible and do more things for yourself in school, it's a good time to start taking more responsibility for your own health.

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**Y**ou know that you need to be as healthy as you can, in order to learn in school, hang out with friends, drive a car, date, and do all the other things that you want to do. On page 14, you checked off some of the things that your family does to help you be healthy.



Take a look at that list again, and think about things that you can do right now or want to learn how to do this year, so that you can be more in charge. On page 20, write down some of the things you can do for yourself, or can learn how to do.

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# What You Can Do

NOW is a good time to learn as much as you can about your health care needs. Here are some things you should be able to do now that you are in high school.

1

Tell someone the name of any chronic medical conditions or allergies you have.

2

Make a list of your medications (with their correct names), when you should take your meds, and why you take them.

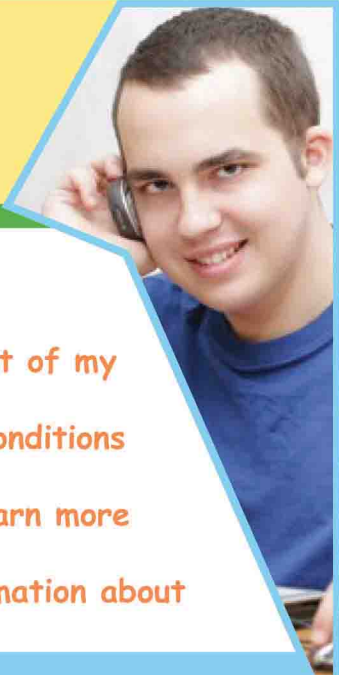
3

Tell someone what you have to do to stay healthy. (You probably have heard your doctor tell you these things, but most teens expect their parents to remember all this stuff.)

## Remember

If you want to be able to do things on your own, like drive a car, go to the mall, or spend the weekend at a friend's house, you need to be more in charge of your health. Also, you need to know what to do in case of an emergency and your family is not around.

Look at the list below and circle the things you could take more responsibility for.



1. Taking my medications when I am supposed to.
2. Tell my parents when I am almost out of my medications.
3. Ask questions about chronic health conditions or allergies I have
4. Read books or use the internet to learn more about my health condition.
5. Help keep a notebook that has information about my health care.

Now write down some other things that you could take more responsibility for or learn how to do:

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Maybe today is a good time to talk to your family about taking more responsibility for your own health care.

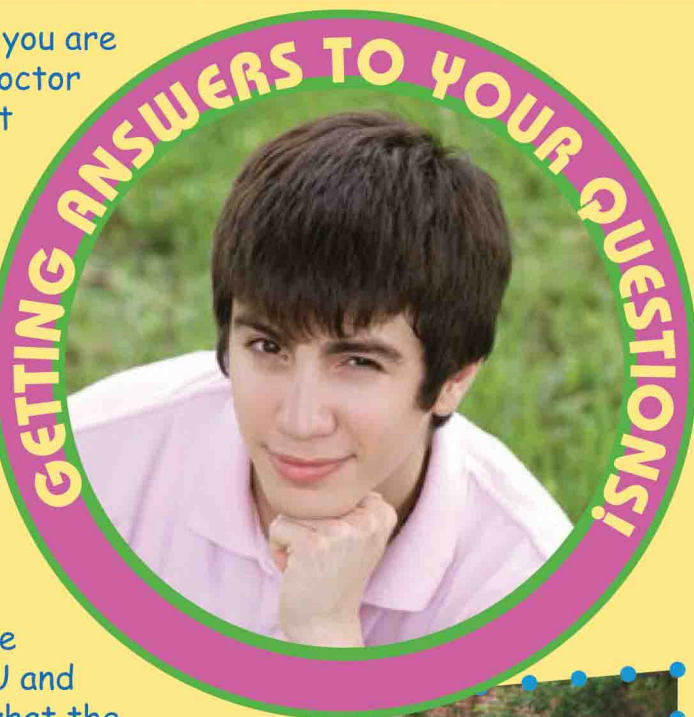
Remember, parents are more likely to give you more privileges when you show them that you are more responsible.



Remember, when you are alone with your doctor you can talk about some things you may not want to discuss when your parents are in the room.

Therefore, it is important that you learn how to speak up for yourself, ask the questions that are important to YOU and then remember what the doctor says.

It's OK to write down and take your questions with you, to help you remember. Or you can give the written questions to your doctors, and let them read them themselves.



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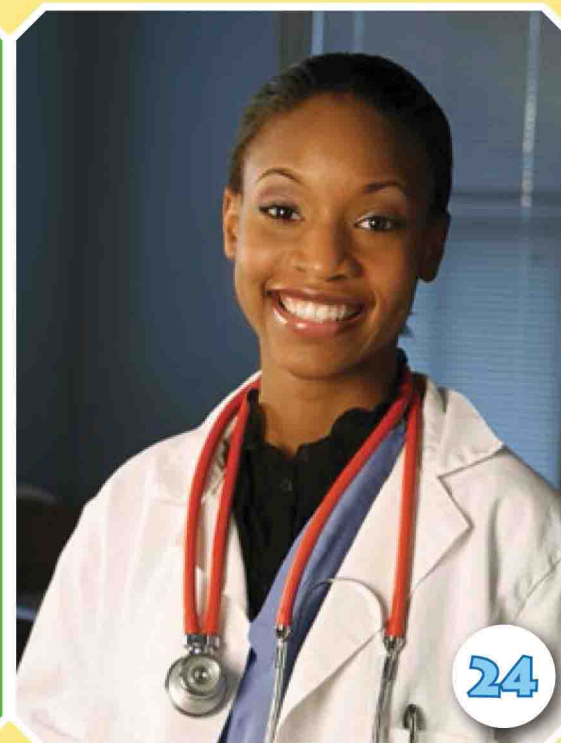
If you still see pediatric doctors, you'll need to start thinking soon about transferring to adult doctors. Here are 3 questions you should definitely ask:

1. When should I transfer to adult primary and specialty care physicians?
2. Who should I go to for adult primary and specialty care?
3. Will you help with the transfer of care by communicating my needs and providing a transfer summary?

Write down these and other questions you have about your health and how to stay healthy. Next time you see your doctor, take the 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 e-mail and respond the same way. Do any of your doctors use e-mail?



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# WHAT TO SAY WHEN YOU DON'T UNDERSTAND

Sometimes it's hard to understand and remember what the doctor tells you. Sometimes they use words you don't really understand. Sometimes they talk too fast. Sometimes they give you way too much information. Sometimes they don't really answer the question you ask. It might be better if they gave you something to read, rather than giving you a lecture.

Since doctors really do want teens to have the information they need to be healthy, 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.
- What does that mean in simple English?
- Could you explain that to me again?
- Could you write that down for me?
- Where can I find more information about this?
- Is there something you can give me to read?

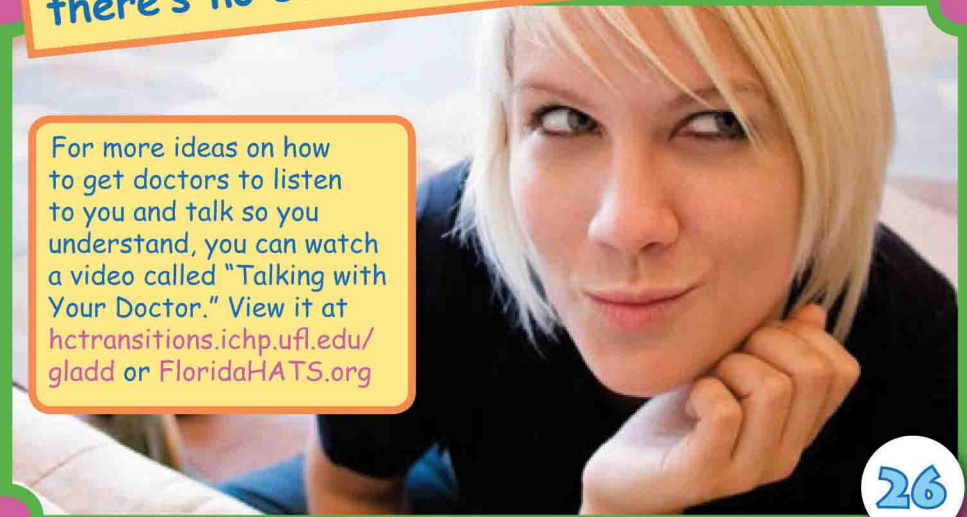


What else could you say when you don't understand



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

For more ideas on how to get doctors to listen to you and talk so you understand, you can watch a video called "Talking with Your Doctor." View it at [hctransitions.ichp.ufl.edu/gladd](http://hctransitions.ichp.ufl.edu/gladd) or [FloridaHATS.org](http://FloridaHATS.org)

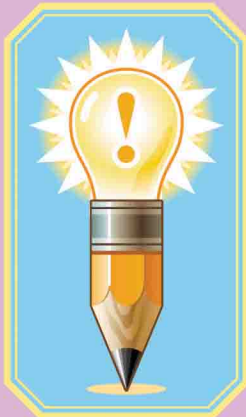


# MY LIFE

Being in high school can be really great: new friends and being old enough to do more things on your own. And it can be really hard: more responsibilities; finding friends who are really friends; dealing with lots of changes in your life. You may be feeling that you are a little different, which can make it even harder.



One thing that many high school aged teens do to deal with all the changes, and keep in touch with who they are and what they are feeling is to keep a journal.



Some write in a spiral notebook and some type into a computer. Taking time to put your thoughts and feelings into words and onto paper can really help make sense of what is going on.

Expressing your feelings in writing can help to keep things that bother you from going around and around in your head.

You can also write down your goals - for school - or for taking responsibility of your own health - Writing down these goals can help you focus on what is really important to you and will help you see how much progress you are making.

Try it for yourself and see.

What do you have to lose?



# More About Transition On The Web:

This book introduced you to the topic of health care transition and provided information about ways you can be more in charge of your life, be healthy and be able to do more of the things you want to do now and in the future.

Now that you have gotten started, there are some other things you can look at that will help you keep moving in the right direction. The **Florida Health and Transition Services (HATS)** web site, [FloridaHATS.org](http://FloridaHATS.org), has lots of information about transition for teens, young adults, families and professionals. You'll find links to many resources and other web sites, including the University of Florida's Health Care Transition Initiative. In addition, talk to your family, doctors, and care coordinator about your goals and find out how they can help you achieve them!

**When You're 18** is a booklet that picks up where *Now that You're in High School* leaves off. It includes information for young adults (age 18 and over) about being in charge of their own health care. **Envisioning My Future** is another guide that has transition information for youth in high school and young adults.

**Health Care Transition Planning Guides** will help you and your family think about future goals and identify the things that you are doing now to be more in charge of your health. These guides will also help you to figure out what else you and your family need to do now and over the next few years so that, when you are a young adult, you are prepared for the transition from pediatric to adult-oriented health care; and that you are ready for work and living more independently

**Advocating for Yourself in School** is a tip sheet that helps middle and high school students identify and take steps to get the accommodations and support they need in school.



**Talking With Your Doctor And Other Health Care Professionals** is a video that shows the GLADD approach to talking with providers, which many have found to be very helpful. Other videos include **College and Beyond** and **Jim's Story**, and can be viewed directly from [hctransitions.ichp.ufl.edu](http://hctransitions.ichp.ufl.edu)

**MyMedSchedule.com** offers medication schedules and email or text reminders to help you manage your medications and communicate with your doctors.

**My Health Passport**, designed by the Florida Center for Inclusive Communities, [flfcic.fmhi.usf.edu](http://flfcic.fmhi.usf.edu), is a fun, easy way to organize your health care information and provide it to all your doctors.

**Children's Medical Services** web site, [cms-kids.com](http://cms-kids.com), has lots of information for teens and for parents about staying healthy and preparing for the future.

**Healthy Transitions**, [healthytransitionsny.org](http://healthytransitionsny.org), is a fun interactive website with lots of great tools and videos developed by the New York State Institute for Health Transition Training.

**Florida Youth Council** is a group of youth (ages 15-17) and emerging leaders (ages 18-30) with disabilities who are involved in self-advocacy, peer mentoring and lots of other activities. You can find more about the FYC by visiting the Family Cafe web site, [familycafe.net](http://familycafe.net)

**Got Transition?** web site, [gottransition.org](http://gottransition.org), also has lots of information about being healthy and getting ready for the future, including monthly radio broadcasts about topics important to you!





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