

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

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



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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.



# 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



**Responsibilities**  
(fair/not fair)

**Privileges**  
(Stuff I get to do)

**Consequences**  
(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 conditions 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 (PCP) – 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 special kinds of medical services. Everyone should have a primary care provider who can help them get the health care that they need.

**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 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 from your family, making sure that teens who have a chronic health condition (like diabetes, asthma, sickle cell disease, and epilepsy) get the care they need takes a lot of planning.



On the next page are some things that families do for a teen who has a chronic health condition.

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 my medications
- Order my 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 condition
- Take notes about what the doctors say
- Remember what the doctors say to do
- Help me learn about and understand my health condition
- Read books to learn more about my condition
- Look things up on the Internet about my condition
- Keep a notebook that has information about my health care (for example, my 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**



# What Teens Ar

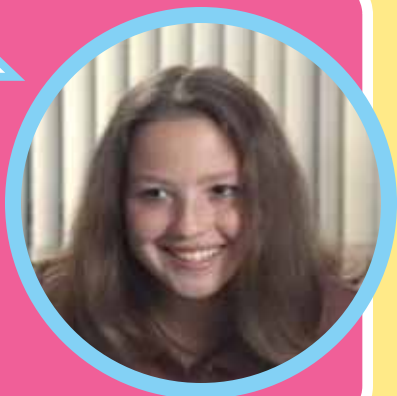


I like the fact that (my health) is my responsibility. I see that as freedom.

**-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**





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**



# Other e Saying

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.

# 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.

# 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 your health condition (your diagnosis).

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. Order my medications when I need more.
3. Call to make an appointment with my doctors.
4. Read books to learn more about my condition.
5. Look things up on the Internet about my condition.
6. 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.

# Talking With Your Doctors

NOW is a good time to get ready to be more in charge of your next visit with a doctor.

Here are some things you should be able to do at a medical visit.



1. Spend some time alone with the doctor (without your mother or father or other adult).
2. Ask your doctors for answers to the questions you have about your health.
3. Let your doctors know when you don't understand.
4. Answer many of the questions that the doctor asks about how you are feeling and how you have been doing.

If you think about it, your doctors probably ask about the same stuff every time you see them.

Write down the questions that your doctors ask at every visit. It's OK to ask your family for help remembering what these questions are.

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From the list on page 21 pick two questions you would like to answer at your next doctor's visit. Let your parents know that you would like to be the one to answer these questions. Try writing down what your answer would be. If you want to take responsibility for answering more questions, use another sheet of paper.

Don't let the space on this page limit you! You can practice saying your answers ahead of time, so you will really be ready. And its OK to write down your answers and take them with you.



Write out the questions and answers.

If the doctor asks:

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I could say:

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If the doctor asks:

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I could say:

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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.

# GETTING ANSWERS TO YOUR QUESTIONS!





Write down one or more questions you have about your condition and how to stay healthy. Next time you see your doctor, take these questions with you and ASK! If you have more questions, use another sheet of paper. Don't let the space on this page limit you!

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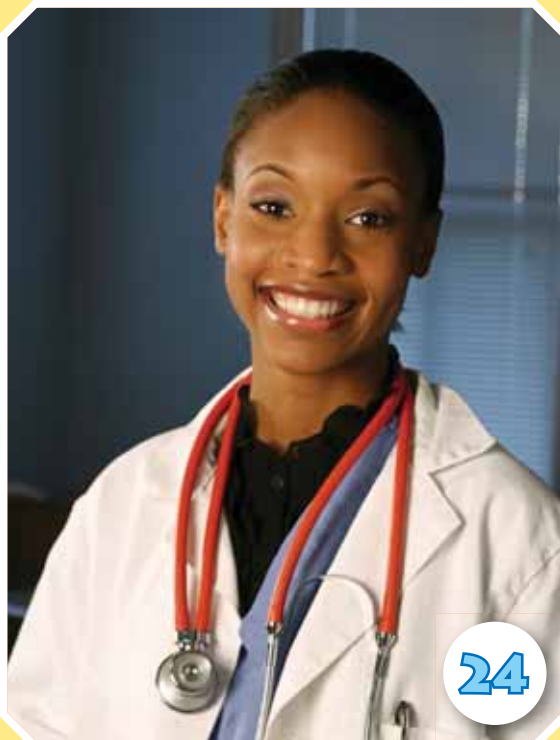
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Doctors want their patients to have the information they need to be healthy. And they are happy when their patients take the time to think about their questions ahead of time, and bring written questions with them to their visits.

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?



# 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.

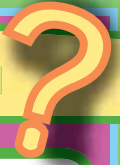
Since doctors really do want teens to have the information they need to be healthy, you need to let them know when you don't really understand what they are talking about...

## 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



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

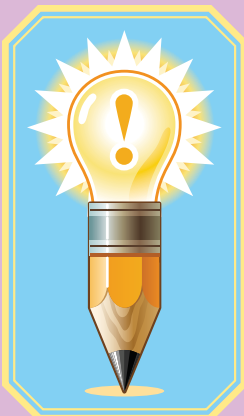


# MY LIFE

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 you and your life. And having a chronic health condition and maybe feeling that you are a little different 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?

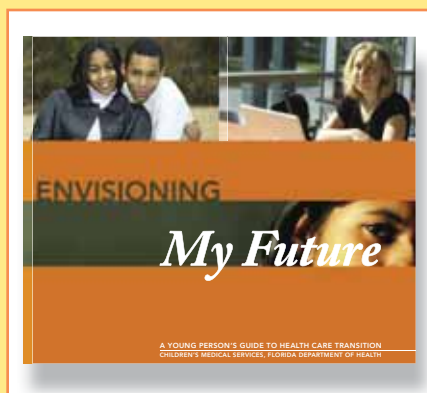


# More About Transition

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.

"Envisioning My Future" is a booklet that picks up where "Now That You're In High School" leaves off. This booklet includes information for youth in high school and for young adults (age 18 and over) about health care transition. Ask your CMS Care Coordinator or your Doctor for a copy of this book.



**CMS Health Care Transition Planning Guides.** These 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.

Ask your CMS Care Coordinator for a copy of a planning guide. Then talk to your Coordinator about the goals and plans you and your family develop using the workbook, and find out how she/he can help you achieve your goals. These guides are also available on the CMS Web site: [www.cms-kids.com](http://www.cms-kids.com).

# On The Web:



## Children's Medical Services Web Site

[www.cms-kids.com](http://www.cms-kids.com)

This web site has lots of information for teens and for parents about staying healthy and preparing for the future.

## Health Care Transition Training Web Site

[hctransitions.ichp.ufl.edu](http://hctransitions.ichp.ufl.edu)

This web site was developed by the University of Florida for teens, parents and professionals. It has lots of information about transition and some videos about teens who have taken charge of their health.

## Emergency Information Form for Children with Special Needs

[tinyurl.com/eifcsn](http://tinyurl.com/eifcsn)

## Jim's Story

[www.ichp.ufl.edu/videos/hctjs](http://www.ichp.ufl.edu/videos/hctjs)

This 10-minute on-line video is about a young man with Cystic Fibrosis.

## College and Beyond

[www.ichp.ufl.edu/videos/hctcb](http://www.ichp.ufl.edu/videos/hctcb)

This 20-minute on-line video is about Jeff, a young man who has a severe physical disability. As he grew up, Jeff learned how to be in charge of his health and make medical decisions with his doctors. This helped him be able to be independent and successful at college. Now he is about to graduate and get a job!

## This Is Health Care Transition

[www.ichp.ufl.edu/videos/tihct](http://www.ichp.ufl.edu/videos/tihct)

This 30-minute on-line video gives you lots of information about getting ready to receive health care from doctors who take care of adults.

## Florida Health and Transition Services (FloridaHATS)

[www.floridahats.org](http://www.floridahats.org)

This site includes a Health Services Directory which young adults can use to find health care providers in their area and a health care transition Tool Box that is filled with helpful documents and links to local, state and national resources.

## Health and Ready To Work Web Site

[www.syntiro.org/hrtw/](http://www.syntiro.org/hrtw/)

This web site has lots of information about being healthy and getting ready for the future!

## UC and Crohn's Web Site

[www.ucandcrohns.org](http://www.ucandcrohns.org)

This site features teens talking about living with colitis and Crohn's. They share their stories and tips. Even if you don't have colitis or Crohn's, you will learn a lot, directly from other teens, about how they have taken charge of their health and are working toward realizing their dreams.



“Now That You’re in High School,” a health care transition guide, is a product of the Health Care Transition Initiative of the Institute for Child Health Policy (ICHP) at the University of Florida and was developed under a contract (COQMQ) from Florida Children’s Medical Services Program (Florida Department of Health) to ICHP.

**Production Team Members**

**John G. Reiss, Ph.D. – Author (ICHP/UF)**

**Randal Miller – Project Coordinator (ICHP/UF)**

**Robert Peck – Designer (ICHP/UF)**

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**Florida Department of Health, Children’s Medical Services**

**Susan J. Redmon, R.N., M.P.H. – Contract Manager**



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