

SINCE YOU'RE

NOT A KID

ANymore



**it's time to be more
IN CHARGE OF YOUR HEALTH**



Health Care Transition Guide for Teens in Middle School

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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 (we hope) will help you be more in charge of your life, be healthy and let you do more of the things you want to do now and in the future.



GETTING STARTED



To get started, you can do some things that will help you see who you are now, how you have changed since you were a kid, and what your life might be like when you get older. If you just started middle school, it's probably easy for you to remember how things were in elementary school and how different things are now...If you are in 8th grade, elementary school may seem like a long time ago...

Either way, you are now old enough to think back and remember how things were and what you were like when you were a kid in elementary school...



Your Life

Elementary School - Middle School

One way of seeing how you have changed is to write down how you spend your time, what you do, and what and who is important to you -

when you were in elementary school and now that you are in middle school. In some ways you are different and in other ways you may be the same.

Fill in
the blanks!

Past -
Elementary School

Now -
Middle 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

Another 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

Careful • Responsible

Organized • Sloppy • 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** • **Flexible** • **Careful**
Sensitive • **Nice** • **Hopeful** • **Easygoing** • **Loyal**
Forgiving • **Imaginative** • **Logical** • **Determined**
Dependable • **Emotional** • **Peaceful**

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 go to high school	Yes	Maybe	No
I plan to finish high school	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 like to have?	_____		

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

Growing up with special health care needs can present many challenges. However, young people with chronic health conditions and disabilities who were able to meet these challenges and reach their goal of being independent and having a good job, 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



Most teens say that they have more responsibilities in middle school.

Most middle schools are a lot bigger - you have several different teachers - and you have to find your way from classroom to classroom.

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

And many teachers and parents say that teens in middle 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 and have a job and be on your own.

Responsibility, Privileges And Consequences

Write down some of the things you are responsible for at home and at school and the privileges you earn if you meet 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** is a word that means lasts a long time.
- 2 **Health condition** is another way of saying **disease or disability**.
Some people refer to children and adolescents who have a chronic health conditions as "children and 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 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.

9 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

As you have probably heard from your family, having a child who has a chronic health condition (like diabetes, asthma, sickle cell disease, and epilepsy) can take a lot of planning.



On the next page are some things that families do for a child 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
- Explain to me about 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:

Since You're not a Kid anymore

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

Now that you are in middle 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 high school, 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.



You know that you need to be as healthy as you can, in order to learn in school, hang out with friends, and do all the other things that you want to do. On page 15, you checked off some of the things that your family does now to help you be healthy.



Take a look at that list again, and think about the things that you can do right now or want to learn how to do this year, so that you can be more in charge.

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 by the time you are ready to start high school.

1

Tell someone the name of your health condition (your diagnosis).

2

Make a list of your medications (with their correct name) when you take your meds and why.

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).

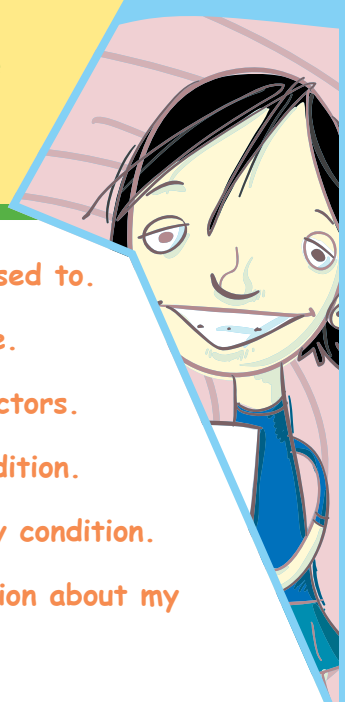


Remember

If you want to be able to do things on your own, like go on a school trip, or go to the mall, or stay overnight with a friend, 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:


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 by the time you are ready to start high school.

- 
1. Spend some time alone with the doctor (without your mother or father or other adult).
 2. 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 okay to ask your family for help remembering what these questions are.

Now pick one or two questions you would like to answer at your next doctors 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.



Write out the questions and answers.

If the doctor asks:

I could say:

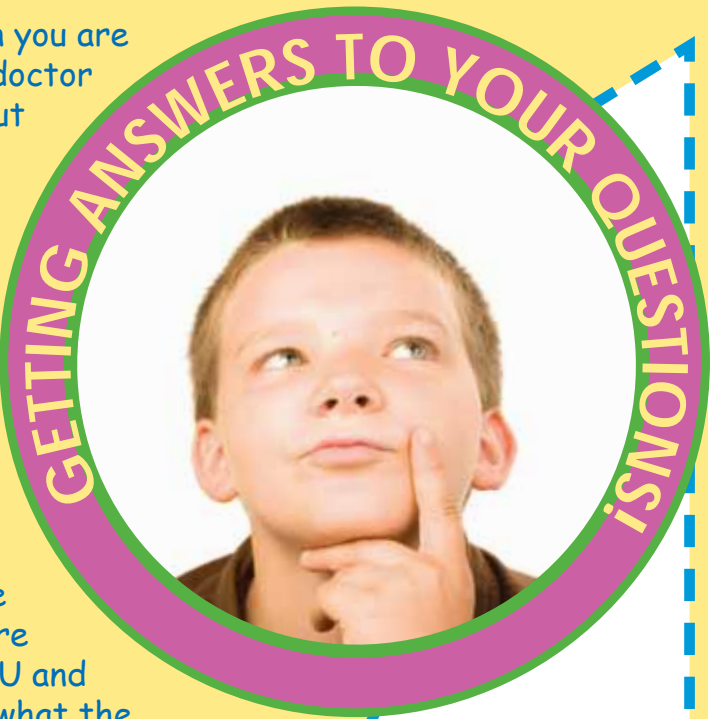
If the doctor asks:

I could say:

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.

So 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.



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!

Doctors want their patients to have the information they need to be healthy. And they appreciate it when their patients take the time to think about their questions ahead of time, and bring their questions with them to their visit.

Some doctors are happy to have their patients e-mail questions to them.



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. Sometimes it's easier to remember if you can read something, rather than having them give you a lecture.

Since doctors really do want their patients to have the information they need to be healthy, you need to let them know when you really don't 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?



A large rectangular area with a green border, containing ten horizontal green lines for writing.



Your Life 2

Being a teen in middle school can be really great: new friends, and more things you can do 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 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.

But they all find that spending the time to put 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.

Writing down your goals for school or for taking more responsibility for your own health care can keep you focused and help you see how much progress you are making.

Try it for yourself!

What do you have to lose?





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

-Amy

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 other teens are saying

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

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

More Stuff About Transition

This book introduced you to the topic of health care transition and provided information about ways that 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, here are some other things you can look at that will help you keep going.

"Envisioning My Future" is a booklet that picks up where "Since You're Not A Kid Anymore" leaves off. This booklet includes information for youth in high school and for young adults (age 18 and over) about being in charge of your health care. Ask your CMS Care Coordinator or your doctor for a copy of this book.



CMS Health Care Transition Workbooks. These workbooks 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 workbooks 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 workbook. 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 workbooks are also available on the CMS Web Site: www.cms-kids.com/CMSNTransition.htm

On The Web:



Children's Medical Services Web Site

www.cms-kids.com/CMSNTransition.htm

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

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.

Jim's Story

video.ichp.ufl.edu/JimStory2.htm

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

College and Beyond

video.ichp.ufl.edu/collegeandbeyond.htm

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!

Health and Ready To Work Web Site

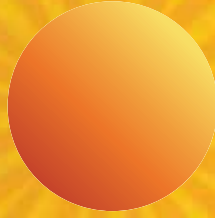
www.hrtw.org

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

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.



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