SINCE YOU’RE NOT A KID ANYMORE

it's time to be more in charge of your health

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Health Care Transition Guide for Teens in Middle School
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 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.
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…

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.

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<tr>
<th>Past - Elementary School</th>
<th>Now - Middle School</th>
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<td>Outside of school my favorite things to do</td>
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<td>At school I’m “into”</td>
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<td>Music I like</td>
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<td>My favorite TV shows</td>
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<td>My favorite book</td>
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<td>Best subject in school</td>
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<td>What I’m really good at</td>
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<td>What I worry about most</td>
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<td>Who I’d like to meet</td>
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<td>My favorite movies</td>
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<td>Career I’d like to have</td>
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<td>Chore I hate most</td>
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<td>What keeps me going</td>
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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

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 |

Fill in the blanks!

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

Daring • Persistent • Inquisitive • Goofy • Flexible • Careful
Sensitive • Nice • Hopeful • Easygoing • Loyal
Forgiving • Imaginative • Logical • Determined
Dependable • Emotional • Peaceful
Growing Up With Special Health Care Needs or a Disability

Growing 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

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 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
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.
**Chronic** – A word that means “lasts a long time”.

**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.

**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.

**Pediatrician** – A doctor who is trained to take care of infants, children and teens.

**Family Physician** – A doctor who is trained to provide primary care to both children and adults.

**Internist** – A doctor who is trained to take care of adults.

**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.

**Pediatric Nurse Practitioner (PNP)** – A nurse who has received special training in the care of infants, children and teens.

**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.

**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.

**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.
As 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).

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
☐ 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, my diagnosis, medications I take, names and phone numbers of my doctors)

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

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

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

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

What Teens Are Saying about growing up with a chronic health condition
Now that you are in middle school, you have more responsibility for keeping track of your assignments and homework. This change 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 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.
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 start high school.

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.

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:

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

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

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.

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 start high school.

1. Spend some time alone with the doctor (without your mother or father or other adult).
2. Answer some 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 these questions.

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.
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 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?

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 or FloridaHATS.org
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. You may be feeling that you are a little different, which 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 can keep you focused and help you see how much progress you are making.

Try it for yourself!
What do you have to lose?
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, 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!

Now that You’re in High School is a booklet that picks up where Since You’re Not A Kid Anymore leaves off. When You’re 18 includes information for young adults (age 18 and over) about being in charge of their 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

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, 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, has lots of information for teens and for parents about staying healthy and preparing for the future.

Healthy Transitions, 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.

Got Transition? web site, 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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