## Your life, your health, your way.





It's time to be more in charge of your health!

This guide is about YOU and YOUT 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

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 Start & d

So what's next for you?

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 middle school.

### 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.

- Tell someone the name of your health condition (your diagnosis).
- Make a list of your medications (with their correct name) when you take your meds and why.
- 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 or guardians to remember all this stuff).

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.

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

- Taking my medications when I am supposed to.
- 2. Order my medications when I need more.
- $\overline{\mathbf{3}}$ . 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:

## Mybife

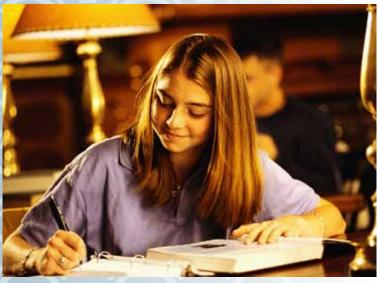
Growing up can be really great: new friends, and more things you can do on your own.

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?

## 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 have been able to meet these challenges and reach their goal of being independent and having a good job. 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 Pafinitions

Chronic is a word that means lasts a long time.

Health condition is another way of saying disease or disability. Some people refer to children and adolescents who have a chronic health condition 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.

Tamilics—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.

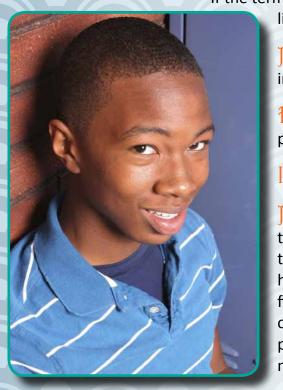
Family Physician—A doctor who is trained to provide primary care to both children and adults.

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

Primary Care Provider (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.

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 specialty.

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 Mealthy

As you have probably heard from your family, having a child with a chronic health condition (like diabetes, asthma, cystic fibrosis, and epilepsy) can take a lot of planning.

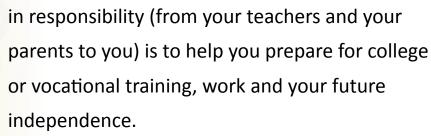
Below are some things that families do for a child who has a chronic health condition. Put a check by the things that your family does to help you be healthy.

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
<ul> <li>Keep a notebook that has information about my health care (for example, my diagnosis, medications I take, names and phone numbers of my doctors)</li> </ul>
List other things your family does to help you be healthy:

## Taking control of Your Future

It's time to be more in charge of your health care.

Where ever you're going from here, you have more responsibilities; things like keeping track of assignments and homework or work hours. This shift





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 the page before this one, 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.

### Responsibility & Fraadom

You can write down some of the things you would like to do for yourself, or learn how to do.

Most 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 and have a job and be on your own.

# Responsibility, Privileges & Consequences

Write down some of the things you are responsible for at home and school. What privileges have you earned by meeting your responsibilities? What consequences have you faced when you didn't? Write down whether or not you think the responsibilities and consequences are fair or not fair.

	At Home	At School
Responsibilities (fair/not fair)		
Driveleges (Stuff I get to do)		
Consequences (fair/not fair)		

Imagine your Life As 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.

School and Work	Where I Will Live Living Independently
I plan to go to high school  Yes Maybe No	In my own house or apartment (with room-mates or by myself)  Be financially independent (support myself)  Yes Maybe No
	Yes Maybe No
I plan to finish high school	
Yes Maybe No	With my parents  Yes Maybe No  Yes Maybe No
I plan to go to college  Yes Maybe No	Get married or have a steady partner
I plan to have a job when I am	family (brother, sister, aunt) Yes Maybe No
an adult Yes Maybe No	Another place (Specify):  Raise a family  Yes Maybe No
What kind of jobs would you like to have?	Have lots of friends
	Yes Maybe No



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. Check the ones you think apply to you or write in your own.

#### How Do You Think Others See You?

My best friend	□Funny □Cool □Sloppy □Artistic □Daring	□Responsible □Thoughtful □Trustworthy □Frustrated □Easygoing	□Happy □Angry □Caring □Weird □Goofy	□Clever □Loving □Smart □Nosy □Loyal	□Shy □Timid □Sad □Kind □Nice	□Athletic □Peaceful □Powerful □Sneaky □Careful	□Confused □Organized □Stubborn □Mixed Up □Persistent	□Careful □Neat □Smart □Sassy □	□Messy □Silly □Fun □Open	□Forgiving □Dependable □Emotional □Flexible
My favorite teacher	□Funny □Cool □Sloppy □Artistic □Daring	□Responsible □Thoughtful □Trustworthy □Frustrated □Easygoing	□Happy □Angry □Caring □Weird □Goofy	□Clever □Loving □Smart □Nosy □Loyal	□Shy □Timid □Sad □Kind □Nice	□Athletic □Peaceful □Powerful □Sneaky □Careful	□Confused □Organized □Stubborn □Mixed Up □Persistent	□Careful □Neat □Smart □Sassy	□Messy □Silly □Fun □Open	□Forgiving □Dependable □Emotional □Flexible
My parents	□Funny □Cool □Sloppy □Artistic □Daring	□ Responsible □ Thoughtful □ Trustworthy □ Frustrated □ Easygoing	□Happy □Angry □Caring □Weird □Goofy	□Clever □Loving □Smart □Nosy □Loyal	□Shy □Timid □Sad □Kind □Nice	□Athletic □Peaceful □Powerful □Sneaky □Careful	□Confused □Organized □Stubborn □Mixed Up □Persistent	□Careful □Neat □Smart □Sassy □	□Messy □Silly □Fun □Open	□Forgiving □Dependable □Emotional □Flexible
Teacher in my worst class	□Funny □Cool □Sloppy □Artistic □Daring	□Responsible □Thoughtful □Trustworthy □Frustrated □Easygoing	□Happy □Angry □Caring □Weird □Goofy	□Clever □Loving □Smart □Nosy □Loyal	□Shy □Timid □Sad □Kind □Nice	□Athletic □Peaceful □Powerful □Sneaky □Careful	□Confused □Organized □Stubborn □Mixed Up □Persistent	□Careful □Neat □Smart □Sassy	□Messy □Silly □Fun □Open	□Forgiving □Dependable □Emotional □Flexible
My brother(s) or sister(s)	□Funny □Cool □Sloppy □Artistic □Daring	□Responsible □Thoughtful □Trustworthy □Frustrated □Easygoing	□Happy □Angry □Caring □Weird □Goofy	□Clever □Loving □Smart □Nosy □Loyal	□Shy □Timid □Sad □Kind □Nice	□Athletic □Peaceful □Powerful □Sneaky □Careful	□Confused □Organized □Stubborn □Mixed Up □Persistent	□Careful □Neat □Smart □Sassy	□Messy □Silly □Fun □Open	□Forgiving □Dependable □Emotional □Flexible
My neighbors	□Funny □Cool □Sloppy □Artistic □Daring	□ Responsible □ Thoughtful □ Trustworthy □ Frustrated □ Easygoing	□Happy □Angry □Caring □Weird □Goofy	□Clever □Loving □Smart □Nosy □Loyal	□Shy □Timid □Sad □Kind □Nice	□Athletic □Peaceful □Powerful □Sneaky □Careful	□Confused □Organized □Stubborn □Mixed Up □Persistent	□Careful □Neat □Smart □Sassy	□Messy □Silly □Fun □Open	□Forgiving □Dependable □Emotional □Flexible
People who don't know me	□Funny □Cool □Sloppy □Artistic □Daring	□Responsible □Thoughtful □Trustworthy □Frustrated □Easygoing	□Happy □Angry □Caring □Weird □Goofy	□Clever □Loving □Smart □Nosy □Loyal	□Shy □Timid □Sad □Kind □Nice	□Athletic □Peaceful □Powerful □Sneaky □Careful	□Confused □Organized □Stubborn □Mixed Up □Persistent	□Careful □Neat □Smart □Sassy □	□Messy □Silly □Fun □Open	□Forgiving □Dependable □Emotional □Flexible
My doctors	□Funny □Cool □Sloppy □Artistic □Daring	□Responsible □Thoughtful □Trustworthy □Frustrated □Easygoing	□Happy □Angry □Caring □Weird □Goofy	□Clever □Loving □Smart □Nosy □Loyal	□Shy □Timid □Sad □Kind □Nice	□Athletic □Peaceful □Powerful □Sneaky □Careful	□Confused □Organized □Stubborn □Mixed Up □Persistent	□Careful □Neat □Smart □Sassy	□Messy □Silly □Fun □Open	□Forgiving □Dependable □Emotional □Flexible

#### Talking with The Doc



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.

- Spend some time alone with the 3 Let your doctor know when you doctor (without your mother or father or other adult).
  - don't understand.
- 2 Ask your doctor for answers to the questions you have about your health.
- 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 okay to ask your family for help remembering what these questions are.

#### Second

Now pick one or 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.

Write out the questions and answers. If the doctor asks: I could say: If the doctor asks: I could say: \_\_\_\_\_

#### **Getting answers to**

### Your Questions

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 patients to have the information they need to be healthy. And they appreciate it when patients take the time to think about their questions, and bring them to their visit. Some doctors are happy to have patients e-mail questions to them.

## What to say when You Don't Undgrstand



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?

What else could you say when you don't understand?

- Where can I find more information about this?
- Is there something you can give me to read?



### Me Now & Then

To see how you have changed, think about how things were when you were in middle 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.

		•
	Now	Then 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 am 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		

## Now that You're Fifteen Youth Transition plan worksheet

Health		Things I need to know or do	Will someone else have to do this for me?	I will finish by (date)	Done
1. I understand my healthcare needs.	YN		ΥN		
2. I explain my special needs to others.	YN		Y N		
3. I tell the doctor(s) how I am doing and can answer their questions.	YN		Y N		
4. I know the name of my doctor(s).	YN		ΥN		
5. I take my medicine with supervision.	YN		Y N		
6. I know the name(s) of the medicine I take and possible side effects.	YN		Y N		
7. I know when I am sick.	YN		ΥN		
8. I carry a copy of my insurance card.	YN		ΥN		
9. I carry a summary of my medical information with me.	YN		Y N		
10. I am learning to schedule my own appointments.	YN		Y N		

Independent Living		Things I need to know or do	Will someone else have to do this for me?	I will finish by (date)	Done
1. I care for my own personal needs or know how to ask for them	Y N		Y N		
2. I know my phone number and address.	YN		ΥN		
3. I know how to get help in an emergency, including calling 911.	YN		ΥN		
4. I am responsible for doing my homework.	YN		ΥN		
5. I think about what I want to do when I grow up.	YN		Y N		
6. I am learning to make choices.	ΥN		Y N		
7. I spend time with my friends.	YN		Y N		
8. I do chores at home.	YN		Y N		

#### More stuff about Transition

This guide 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.

For people with disabilities, this document is available on request in other formats. To submit a request, please call 1-800-525-0127 (TDD/TTY 1-800-833-6388). Para personas discapacitadas, este documento está disponible a su pedido en otros formatos. Para hacer su pedido, llame al 1-800-525-0127 (TDD/TTY 1-800-833-6388).

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#### Children With Special Health Care Needs Program Web Site

http://www.doh.wa.gov/cfh/mch/cshcnhome2.htm
This web site has information about the Children With
Special Health Care Needs Program.

#### 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!

#### Healthy 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!