When You're 18

YOU ARE IN CHARGE OF YOUR HEALTH

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Children's Medical Services

Health Care Transition Guide for Young Adults

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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 will help you understand what it means to be legally in charge of your health care, and help you be active, healthy and able to do more of the things you want to do now and in the future.

Your New Rights and Responsibilities

Since you are reading this booklet either:

You will turn 18 soon, and want to learn more about what new rights and responsibilities you will have when you are legally an adult

---------- **OR** ----------

You have already had your 18th birthday, and want some more information about what it means to be an adult and in charge of your own health care.

This booklet will help you be prepared to work effectively with your doctor and other health care providers, to understand health insurance, and to have your parents and others as involved in your health care as you want them to be.

On the next page is a short quiz about what rights and responsibilities you have when you turn 18 and are, legally, an adult.

Quiz #1

To test your knowledge about the legal rights of young adults (age 18 -20) in Florida, answer the following questions. (The answers and additional information about your adult rights and responsibilities are on page 5 but don't look yet!).

True or False??

In Florida, individuals age 18 to 20…

1.	T	F	Can vote in State and Local elections
2.	T	F	Cannot vote for president until age 21
3.	T	F	Can sign a contract (like a lease on an apartment) but legally must have a parent co-sign
4.	T	F	Can sign by themselves for a loan (for example to pay for school or a car),
5.	T	F	Have to sign for themselves to give "informed consent" for medical procedures
6.	T	F	Control who can see (and cannot see) their personal medical information
7.	T	F	Cannot get medical treatment unless a parent is informed and also gives consent
8.	T	F	Can live where they want
9.	T	F	Are not responsible for their own debts (like credit card payments) if they do not have enough money to pay them
10.	T	F	Can purchase and drink alcohol
11.	T	F	Can purchase cigarettes
12.	T	F	Can serve on a jury

Your New Rights and Responsibilities

Answers to Quiz #1

1. True. If you are age 18 or older, and register, you can (and should) vote in state and local elections in Florida.

2. False. If you are age 18 or older, and register, you can (and should) vote for President.

3. False. At age 18, you can sign a contract, like a lease, by yourself. You do not need to have your parents co-sign.

4. True. At 18, you can sign a loan agreement (and you are responsible for repaying the loan)

5. True. If you are age 18 or older, health care providers must get informed consent from you in order to carry out a medical procedure. Of course you can ask for advice from you parents, but you are the one who must be informed and give consent. Your parent cannot make medical (or other decisions) for you.

6. True. If you are age 18 or older, doctors, nurses, and other health care providers cannot share any information about you unless you have given written permission (for example, you have signed a release of information form). More about this later…

7. False. Once you turn 18, your parents do not need to be told about or give permission for your medical care.

Your New Rights and Responsibilities

Answers to Quiz #1

8. True.

9. False. At 18, you are financially responsible for yourself. You can live where you want, but you also have to pay your own way. Once you turn 18, your parents no longer have a legally responsibility to support you, financially.

10. False. In Florida, you cannot legally purchase or consume alcohol before your 21st birthday.

11. True. In Florida, you can buy cigarettes when you turn 18, but why would you want to?

12. True. To serve on a jury, you have to be at least 18 years old.

Your Life as an Adult

Having and working toward goals is an import part of being an adult. Below are some questions about what you would like to accomplish by the time you are 25 years old.

Circle or check the answer that is true for you.

By the time I am 25 —

Education and Work

I will finish my vocational training ..... Yes Maybe No
I will complete college..... Yes Maybe No
I will have a job ..... Yes Maybe No

What kind of work would you like to do? _____

_____

_____

Where I Will Live

When I am 25, 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): _____

_____

Your Life as an Adult

Where I Want to Live

When I am 25, I want to live…

- ❑ In Florida
- ❑ In a different state (What state? _____)
- ❑ In a big city. (What city? _____)
- ❑ By the ocean
- ❑ In the country
- ❑ Another place (specify): _____

_____

Living independently

By the time I am 25, I want to

- Be financially independent; support myself ..... Yes Maybe No
- Have a car or van ..... 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
- Communicate well with health care providers ..... Yes Maybe No
- Arrange for and manage my own health care ..... Yes Maybe No
- Pay for my own health insurance .... Yes Maybe No

Being an Adult with a Special Health Care Need

Growing up with a special health care need and becoming an adult can present you with many challenges. However, many young adults with chronic health conditions and disabilities have successfully met these challenges and have reached their goals of being independent and having a good job. They say, that 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 Definitions

1. **Chronic** – A word that means "lasts a long time".

2. **Health condition** – Another way of saying disease or disability.
   Sometime people refer to those who have a chronic health condition as "people with special health care needs". However, most young adults 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. **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.

8. **Primary Care/Medical Home**
   A Primary Care Provider (PCP) is a doctor who takes care of patients for many years, provides screening and preventative services, takes care of routine health problems and makes referrals to needed specialty care providers. Family Practice and Internal Medicine physicians are PCP's for adults. 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 needed care, identify potential state and community resources, and provide young people and their families with educational resources specific to the young person's condition. Every young adult should have a Primary Care/Medical Home.

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. Specialists usually do not deal with health problems that are not in their area of speciality.

Staying Healthy

If you have a chronic health condition (like diabetes, asthma, sickle cell disease, and epilepsy) it takes a lot of planning and work to stay healthy.

On the next page are some things that, as a young adult with a chronic health condition, you need to be able to do. For each task, indicate if you already do this by yourself, or if you need to learn more, in order to do this independently.

Check what is true for you…

Do independently	Need to learn more	
❑	❑	Take all my medications when I need to
❑	❑	Order my medications when I need more
❑	❑	Schedule appointments with my doctors
❑	❑	Go to my medical appointments
❑	❑	Tell the doctors about how I am feeling
❑	❑	Answer all the questions that doctors ask
❑	❑	Ask doctors questions about my condition
❑	❑	Take notes about what the doctors say
❑	❑	Remember what the doctors say to do.
❑	❑	Read books to learn more about my condition
❑	❑	Look things up on the Internet about my condition
❑	❑	Keep a notebook about my condition and health care – (for example my diagnosis, medications I take, name and phone number of my doctors)
❑	❑	Do health insurance paper work
❑	❑	Pay health care bills

Quiz #2

Now that you're 18

…and ARE in charge of your health care, you need to know about your health insurance, Children's Medical Services, and when you will be too old to go to your pediatrician or a children's hospital.

To test your knowledge about these important aspects of health care transition answer the following questions. (The answers and additional information about these issues start on page 17 but, of course, you won't look at the answers first!). And maybe you should also give your parents this quiz - to see what they know and don't know about transition.

True or False??

1. T F You will no longer be eligible for services from Children's Medical Services when you turn 21.

2. T F Your pediatricians will definitely take care of you until you are 21.

3. T F If you have a health condition that started while you were a child (like Cystic Fibrosis, asthma, sickle cell disease, or Type I diabetes) then you will be able to get in-patient care in a children's hospital no matter how old you are.

4. T F If you are age 18 or older, and go to an emergency room, you cannot have your parents in the exam room with you to help answer questions about your medical history.

5. T F It is easy to find adult specialists who know about health conditions that start in childhood (like congenital heart disease, cerebral palsy, and juvenile rheumatoid arthritis).

6. T F If you qualify, financially, for Medicaid when you are 18, then you will definitely qualify for Medicaid when you are 19.

7. T F Medicaid covers and pays for the same amount and type of services, no matter how old you are.

8. T F In Florida, if you qualify for SSI (Social Security's Supplemental Security Income Program) then you automatically qualify for Medicaid.

9. T F If you were not financially eligible for SSI when you were 17, then you need to wait until you are 21 to apply again for SSI.

10. T F Young adults with a chronic health condition or disability do not need to have a medical home because specialists usually provide and coordinate all of the health care that they need.

Answers to Quiz #2

1. True. CMS cannot provide services to individuals who are 21 years old or older. However, while you are still eligible, your CMS care coordinator will work with you and your family and doctors to plan for the time when you graduate from CMS.

2. False. You cannot be sure that the doctors you now see will continue to take care of you until you are 21. Many pediatricians do take care of older adolescents and young adults, but some pediatricians stop seeing teens when they turn 18. The only way to be sure is to ask! Write a note to yourself to ask each doctor that you see about their upper age limit. Or you could call your doctors right now to get this question answered.

3. False. Most children's hospitals do have an upper age limit and do not provide in-patient care to individuals over a certain age. This upper age limit varies from hospital to hospital. Some hospitals take care of both children and adults, but have a part of the hospital that is specially designed for the care of children and teens. In these kinds of hospitals, young adults (age 18 or older), may get a room in the children's section of the hospital, or may get a room on an adult floor. Ask your doctors about the in-patient policy of the hospitals where you might go. Again, the only way to be sure is to ask.

4. False. If you are age 18 or older, and go to an emergency room, you can ask to have your parents or another person in the exam room with you to help answer questions about your medical history and make decisions about care. Since you are 18, you are in charge of who gets to know about your medical condition, and who gets to help you make medical decisions. If staff in the emergency department say that they prefer to see you alone, you need to speak up and say what you prefer. You may have to sign a release of medical information form, but that's OK.

5. False. It is NOT easy to find doctors who take care of adults and also know about health conditions that start in childhood (like congenital heart disease, cerebral palsy, and juvenile rheumatoid arthritis). It may take a year or more to find adult doctors who you are comfortable with and who understands your condition. To find adult doctors, ask your older friends who have a similar condition who they see. Ask your current doctors and, of course, ask your CMS care coordinator.

Answers to Quiz #2

6. False. If you qualify, financially, for Medicaid when you are 18, then you might qualify for Medicaid when you are 19, but you might not. The Medicaid rules and regulations are very complicated, and they change from year to year. Ask your CMS care coordinator for more information.

7. False. Medicaid covers and pays for more services for individuals who are age 20 or younger than they do for people who are 21 or older. Medicaid rules and regulations are very complicated and you might not get the same answer when you ask two different people about Medicaid covered services and supports. So keep asking questions until the answers you get make sense to you and ALWAYS ask for answers in writing. That way you can reread the answers that you might not understand, and you have a record of what you have been told.

8. True. In Florida, if you qualify for SSI (Social Security's Supplemental Security Income Program) then you automatically qualify for Medicaid.

9. False. If you were told that you were not financially eligible for SSI when you were 17 (or younger), then you might qualify, financially for SSI when you turn 18. For individuals, age 18 and older, the SSI Program does not count "family" income, but only the income of the individual applicant. The SSI Program provides cash assistance to individuals who have certain health conditions or disabilities and have a low income. Just like with the Medicaid Program, the SSI Program has complicated rules and you need to talk with people who work for the SSI Program and get the answers in writing.

10. False. Young adults who have a chronic health condition or disability definitely need to have a medical home. An adult cardiologist will provide care related to a heart condition, but will not see you if you have an ear ache. It can take a long time to get an appointment with an adult specialists, and they do not usually help to coordinate your care or link you with community resources. You can usually get an appointment to see an adult primary care provider (PCP) (family practice or internal medicine physician) in a day or two. PCP's who work with care coordinators and other health professionals can be your Medical Home, coordinate all of your health care services and supports, connect you with resources (like support groups) in your community, and teach you how to be more in charge of your health care.

Since YOU are in charge of your health…

Since YOU are in charge of your health here are some things you should be able to do…

- Tell someone the name of your health condition (your diagnosis)
- Tell someone the correct name of all of your medications, when you take your medications and why
- Take your medications when you are supposed to
- Order medications when you need more
- Call to make an appointment with your doctors
- Know what to do in case of an emergency
- Know what you have to do to stay healthy; and DO those things without someone having to reminding you

If you cannot already do all of these things now, you need to learn.

What You Can Do…

If you cannot already do all of the things listed on Page 21, you need to learn. It's OK to ask for help from your parents, your CMS care coordinators, your doctors and nurses. One way to remember some of this information is to write it down (or have someone write it down for you) and carry this important information with you.

If you have a cell phone, one thing you can do right now is to enter in your ICE (In Case of Emergency) contacts. First responders such as paramedics, firefighters, and police officers have been trained to look in cell phone address books under ICE for contacts who can provide important medical information when the person they are helping cannot do so themselves. If there are several people who should be contacted in case of an emergency, make multiple entries like "ICE1", "ICE2", etc.

Talking With Your Doctors and Other Health Care Professionals

Since you are a young adult, you need to be able to communicate effectively with your doctors and other health care professionals.

Many young people have found the **GLADD** approach to talking with health care professionals to be very helpful.

Give Give information about how you are feeling and what you have done to stay healthy. Also give your doctor information about how your condition is affecting your every day life, and what your concerns are.

Listen Listen and Learn. Listen carefully to your health care providers and learn all you can from them about your condition and what you can do to be healthy.

Ask Ask your doctors the questions you have about your health. If you do not understand what you are being told, let the professional know, and ask them to explain it in a different way.

Decide The first D stands for Decide. At every visit with a health care professional, decisions need to be made about what to do next. Make sure that you play an active role in the decision making, since, at 18, you are the one who must agree to the plan of care.

Do The second D stands for Do. Do your part in following the plan!

Using the GLADD approach.

G – Giving Information. As a young adult, you are responsible for giving your health care providers complete and detailed information. Be honest! If you have not taken your medications when you were supposed to, or have done some things that you were told not to do, let your doctor know.

In order to give your doctors the complete and detailed information that they need, you need to keep a medical diary and write down information about when, for example, you experience symptoms (like headaches), how severe your symptoms are and how long they last, and what, if anything, helps. Ask your doctors what information they want you to give to them, so you can keep a record and refer to it when they ask their questions.

Also it is important for you to give your doctors an understanding of how your condition is affecting your every day life. Sometimes health care professionals focus on your symptoms and medications, and do not see the "big picture" of your life as a whole.

L – Listening and Learning. As a young adult, you are responsible for listening to and remembering what health care professionals tell you. Most people can recall only 2 or 3 things that doctors tell them, unless they write the information or the instructions down. So take your medical diary with you when you visit the doctor, and write down the information that you need to remember.

Getting Answers To Your Questions

A – Ask. Ask the questions you have about your health and keep asking until you understand.

It's a good idea to write down and take your questions with you to help you remember ALL of the them.

Right Now! Get your health diary or a notebook and write down some of the questions that you have about your condition and about how to stay healthy. Keep this notebook with you and add questions as they occur to you. And the 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 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?

Ask and Keep on Asking

It can be hard to understand what a doctor tells you. Sometimes they use words you don't really understand OR talk too fast OR give you too much information at one time. Sometimes they don't really answer the question you asked. And you might want them to give you something to read, rather than give you a lecture.

Doctors really do want their young adult patients to have the information they need to be healthy. Therefore, 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.
- Could you explain that to me again?
- Could you write that down for me?
- Is there something you can give me to read?

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

D – Decide. Play an active role in deciding what needs to be done next and who is going to do what. Don't agree to a plan that you are not willing and able to follow. BECAUSE…

D – The second D stands for Do. Do your part in following the plan!!

What's Next???

As you look ahead, it is important to keep in mind that living with a health condition means that you will need to do more planning and preparation than other people your age. This takes time and effort – but it definitely pays off.

If you are planning to get more education and training after high school, be prepared to explain to others how your health condition affects you and what accommodations you need in order to succeed.

In the past, you may have had an IEP (Individualized Education Plan) or a 504 Plan. The high school counselors and teachers were responsible for helping to develop and implement this plan.

In college or other post secondary educational programs, it up to YOU, the student, to request "reasonable accommodations". Ask for the office that works with "students with disabilities". You may not think of yourself as having a disability, or may not like the term disability. But if you do have a health condition, you need to take advantage of the guidance and assistance that the school's "disability services program" can provide. This program is usually part of the Dean of Students Office.

Contact this office before classes begin. If you wait until your health condition begins to affect your ability to get your school work done, it's too late. You will need to explain how your health condition may affect you during the semester; and they will let you know how they can help. They will help you determine what accommodations might be helpful, and help to get your these accommodations when you need them.

It's also important to have a doctor who works near your college. Your current doctors probably can help you find this doctor, who you can see right away if you get sick while at college. Make an appointment with this doctor before classes begin, so you can get to know each other before there is an emergency.

With this extra planning and preparation with your doctors and school staff, you will be better prepared to successfully deal with any problems that may arise.

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 "When You're 18" 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 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 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 the 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**.

On The Web

Children's Medical Services Web Site
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 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.

This Is Health Care Transition
video.ichp.ufl.edu/tihct.php
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.

Jim's Story
video.ichp.ufl.edu/JimStory2.php
This 10-minute on-line video is about a young man with Cystic Fibrosis.

College and Beyond
video.ichp.ufl.edu/cab.php
This 20-minute video is about Jeff, who has a severe physical disability. Jeff learned how to be in charge of his health, make medical decisions and be successful at college.

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!

UC and Crohn's Web Site
www.ucandcrohns.org
This site features young adults sharing tips about living with a chronic health condition.. You will learn about how they have taken charge of their health and are working to realizing their dreams.

Talking with Your Doctor
video.ichp.ufl.edu/twyd.php
This 18-minute video provides training in the GLADD approach to communicating effectively with health care professionals.

"When You're 18 — A Health Care Transition Guide for Young Adults" 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's Children's Medical Services Program (Florida Department of Health) to ICHP.

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JUNE, 2009 EDITION