



ages  
13-21



Georgia Department of Public Health

# TAKING CHARGE

MOVING FROM PEDIATRIC TO ADULT HEALTH CARE

# OF MY HEALTH CARE

A WORKBOOK FOR YOUTH AND YOUNG ADULTS  
WITH OR WITHOUT DISABILITIES



## Principles of Transition Services

- Transition is a process, not an event.
- The transition process should begin early to ensure success.
- The adolescent and family should be involved in the decision-making process.
- Providers and parents should prepare to facilitate movement.
- Coordination of services and providers is essential.

*(White 1997)*

## FOR MORE INFORMATION CONTACT:

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**<http://dph.georgia.gov/CMS>**

*This workbook was adapted from the curriculum developed by the Waisman Center, Wisconsin.*

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# Welcome

## **Welcome to the Transition to Adult Health Care Workbook for Youth!**

This workbook is designed to help transition Youth with Special Health Care Needs (YSHCN) from pediatric to adult health care.

Transitioning from pediatric to adult health care is a process that should involve planning and support from your team (family, pediatrician, and pediatric specialist). The level of support you will need depends on your health care condition. Some youth need more assistance than others. Regardless of the level of support needed, the important thing to remember is that you have a team of people who supported you as a child, and they are still available to assist you as you learn to live independently and direct your health care.

We want you to understand that each individual child or youth with special health care needs is unique but have many of the same hopes and dreams. For some youth, health-related issues are more challenging than for others. It is important for you to be involved in your transitioning process and understanding your health needs.

It's also important that you and your family understand that transitioning to adult health care is unique to each person and each family. It is important to respect and appreciate those differences and preferences. In addition, transition is a process; it's not going to happen overnight. You will need to make adjustments as the process will continue to grow and change over time.

This workbook is designed to be a useful tool for planning and practicing for this important transition. This is the beginning, so be patient with yourself and know that you are capable of navigating and making decisions about your health care. Review the workbook and take the information that works for you and your family, and make it your own. Remember to have fun, ask questions, and write things down that your provider shares with you about your health care. Most importantly, remember that you have a team supporting you on this next step to living independently!





# LIFE IS A TEAM SPORT!



Members of a team have a shared goal of winning. Each member plays a role that is very important. Successfully transitioning from pediatric to adult health care is no different. It is a team effort. Your pediatric primary care physician, family, and pediatric specialist are key players on your team. All members of the team must work together to ensure your success. It is important for you to engage your team members in the transition process. Like any sport, life can be a lot of fun and can be challenging. Working as a team can make the transition experience enjoyable!

Nobody is good at everything, but everybody is good at something. That's what makes teamwork so effective.

It takes time to be a part of an effective team, and it does not happen overnight:

- ⇒ Time to learn new information
- ⇒ Time to develop new skills
- ⇒ Time to practice putting the new information and skills into action

This handbook is about getting ready for adult life – especially your health and health care as an adult. It has information and suggestions for you about your health and health care. It also has ideas about how to build a health care team.

This handbook can help you:

- ⇒ Learn about some of the rules you will need to know and what may be expected of you as an adult
- ⇒ Figure out the skills you may already have and the skills you need to work on
- ⇒ Decide who to have on your team and how to work well together

Remember you don't have to do everything at once. The important thing is to get started.

*Start small. Start Slow. Start Now*



### UNDERSTANDING HEALTH-RELATED OUTCOMES

There are many possible goals to work toward as a part of transitioning to the adult-healthcare system. To support those efforts, the Maternal and Child Health Bureau has identified six primary goals for teens and young adults with special health care needs.

#### Teens and young adults should be able to:

- ⇒ Understand their health care condition, including the treatment and/or intervention needed.

*For example:* Jacob has been reading books about seizure disorders from the public library. His parents have helped him select books that are age appropriate and up-to-date. They have engaged him in numerous discussions about his special health care needs over the years and answered his questions as they arise. Jacob has also been included in discussions about treatment options with his parents and doctors. The information was explained in a way that he could understand and ask questions.

- ⇒ Explain their health care condition and needed treatment or intervention to others.

*For example:* Samantha is able to tell people “I have cerebral palsy because I lost oxygen at birth. I use a wheelchair that I am able to operate by controlling a touch pad with my head. I need help with many daily activities such as getting dressed, eating and drinking. I have personal care services through an agency, but I can make my own decisions and direct my care.”

- ⇒ Monitor their health care status on an ongoing basis.

*For example:* Trevor knows the signs and symptoms for when he needs to use his inhaler for his asthma. He also knows what kinds of situation or activities might trigger an asthma attack, and when it is appropriate to use his inhaler as a preventive measure, such as before exercising.

- ⇒ Ask for guidance from their pediatric health care provider on how and when to make the move from pediatrics to adult health care.

*For example:* Marina and her mother have made an appointment for a regular check-up with the pediatrician. Marina is going to ask the pediatrician when she should start seeing a family practice doctor or an internal medicine doctor for her regular care instead of a pediatrician. She will also ask the pediatrician about the differences in how the family practice and internal medicine departments provide care and schedule appointments. This will help her to see if this should be a consideration in selecting a physician since she sometimes needs to get in to see a doctor for same day care.



- ⇒ Learn about systems that will apply to them as adults, such as health care insurance (private or medical assistance) and its importance, social security, and other programs or topics, such as guardianship and power of attorney for health care.

*For example:* Lisa had been getting medical assistance through the Katie Beckett Program based on her disability and she knows that coverage may continue until her 19th birthday. But she is planning to apply for SSI after she turns 18 because she will continue to need medical assistance for her health care. Lisa does not have access to private health insurance through her employer since she works only about 15 hours a week because of health related issues.

- ⇒ Identify both formal and informal advocacy services and supports, which may be needed for a young adult to be as independent as possible, but also utilize trusted advisors/mentors.

*For example:* Jarred ask his parents for advice about his medical care because he says they know about his special health care needs, and he trusts them the most. They are talking about how to make sure he has the help he needs with decision-making after he turns 18, but only in those areas where he really needs it. Jarred is also meeting with a benefits counselor at the local independent living center to make sure he knows about programs and options that are available to him in their community.





## WHAT DOES IT MEAN TO BE AN ADULT?







Technically, as soon as you are 18 years old you are an adult. That sure sounds easy doesn't it? But of course, just having the clock strike midnight at the start of your 18th birthday does not mean you will magically know everything you need to know about being an adult, and being ready to assume the responsibilities of an adult.

Being ready for adult life doesn't happen overnight. As an adult you may be responsible for making a lot of decisions. You may need help with some decisions. Most people have parents, friends, or other individuals they trust to help them think through important questions and concerns.

You may already have people you rely on to help you make decisions. You'll want to think about how to keep some or all of those people involved in the years ahead. There may be others you will add to your team. There's no need to "do it alone." Getting advice or suggestions from those you can trust does not make you any less of an adult. In fact, it is a sign of being a mature responsible adult.

Parents must also understand that they do not continue to be the legal decision-maker for their adult son or daughter, unless they have legal authority, such as a type of guardianship. Even in situations where severe disabilities are involved, adults are presumed to be able to act on their own behalf unless a court of law decides otherwise.

**The following items are things to consider so you can decide the best option for your situation:**

Guardianship vs. Conservatorship	
Guardianship	Conservatorship
• For legally incompetent individuals	• Not considered legally incompetent
• A "guardian" is assigned by the courts to make all decisions for individual	• A "conservator" is assigned by the courts to share or make limited decisions for individual
• The individual under guardianship is called the "ward"	• The individual under conservatorship is called the "conservatee"

Having a legal guardian is the most well-known option for people who need total assistance in making decisions. There are different types of guardianship. Full guardianship may not be needed. Sometimes a limited guardianship can be established so that the individual who has a guardian can still keep some of his/her decision making rights. Maybe a person needs help with legal and financial decisions but he/she is still capable of making decisions, such as who he or she wants for president. In a situation such as that, the person may be able to have a guardian for other decisions, but still keep the right to vote in elections.

## RULES OF 18

In Georgia, when a person reaches his or her 18th birthday, he or she becomes a legal adult. Unless a guardian has been appointed through a judge in a court of law, all of the rights and responsibilities that are part of being a legal adult go into effect. Some of these rights include the ability to:

- ⇒ Vote
- ⇒ Get married without parental consent
- ⇒ Make a will (you can legally make a will at age 14 in Georgia)
- ⇒ Make a contract (such as renting an apartment, buying a car, taking out a loan, etc.)
- ⇒ Give or refuse consent for medical treatment
- ⇒ Make independent decisions free from parental control
- ⇒ Apply for credit (including credit cards)

**Remember, in Georgia you are not allowed to drink, purchase or be possession of alcohol until the age of 21.**

At the age of 18, individuals also have certain legal responsibilities, such as:

- ⇒ Self-support (parents are not required to support their adult children unless the youth is enrolled into secondary school, then that age of support ends at 20)
- ⇒ Serving on Jury Duty if called to do so
- ⇒ Being liable for all contracts entered into (such as making loan payments)
- ⇒ Every male citizen and immigrant residing in the United States must register with the selective service within 30 days of his 18th birthday. Even a male with severe disabilities who could not possibly serve in the military must register. Not registering is a federal crime. This does not mean you are joining the military. There is no military draft right now where males of certain ages are required to serve in the military. However, the military still needs to know the name of every male citizen and immigrant living in the United States in case there would be the need for a military draft in the future.







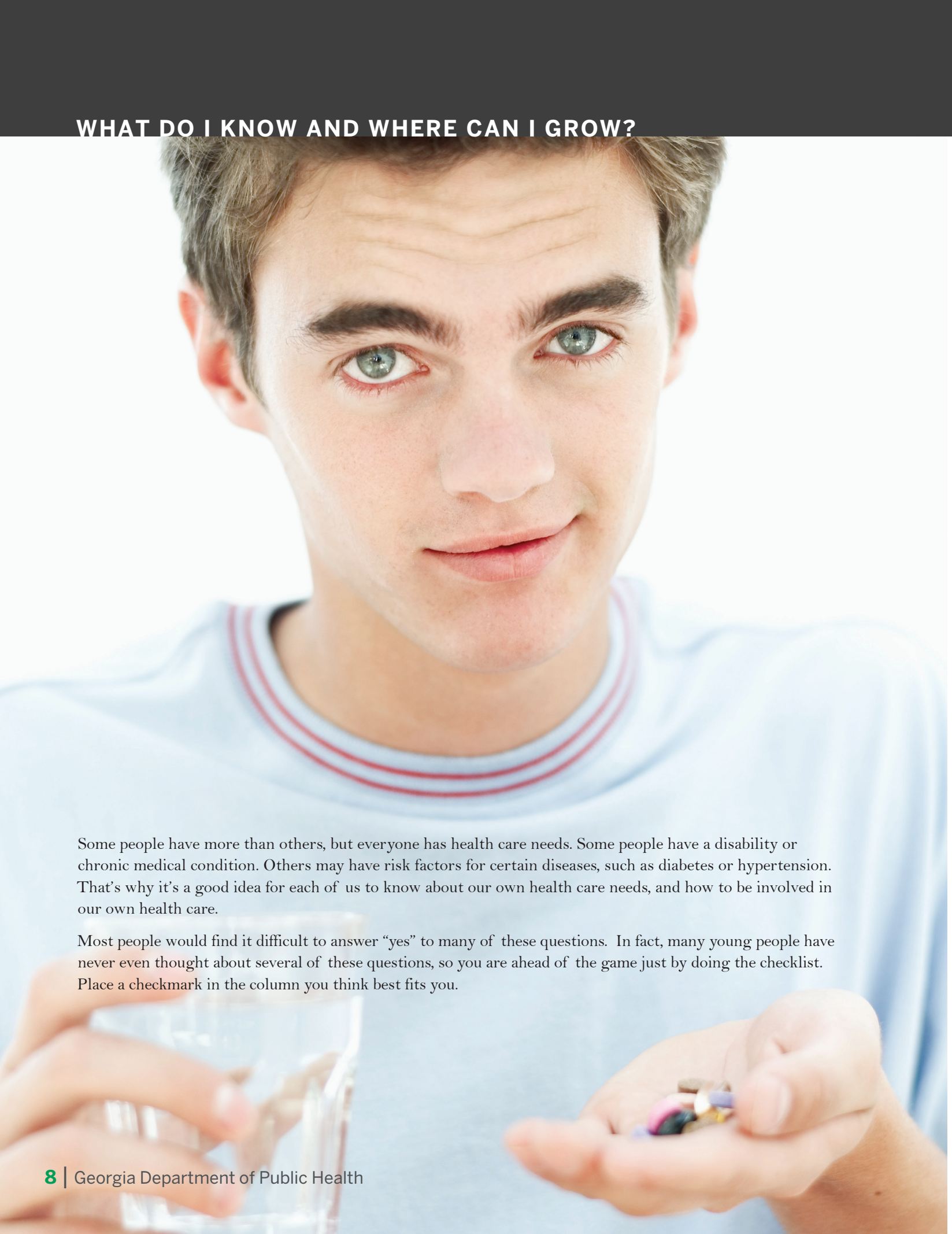
## THINGS TO REMEMBER

- ⇒ Every adult should have someone identified who would make medical decisions in the event of an emergency, and the person is unable to make their own decisions. The name of this person should be in writing, and should clearly name someone to have Power of Attorney for Health Care. This is important because even if an individual makes all of his/her own decisions, if he/she were in an accident or became ill and was unable to make decisions about his/her health care, important medical decisions about care could be affected.
- ⇒ It is extremely important to have discussions with your family members and others you trust to get the best information possible about the legal and decision-making aspects of adult life. Talk with your parents. You can also ask a social worker or care coordinator at your clinic or hospital for information and assistance. If you have a county social worker or case manager, that person can also help you.





## WHAT DO I KNOW AND WHERE CAN I GROW?



Some people have more than others, but everyone has health care needs. Some people have a disability or chronic medical condition. Others may have risk factors for certain diseases, such as diabetes or hypertension. That's why it's a good idea for each of us to know about our own health care needs, and how to be involved in our own health care.

Most people would find it difficult to answer "yes" to many of these questions. In fact, many young people have never even thought about several of these questions, so you are ahead of the game just by doing the checklist. Place a checkmark in the column you think best fits you.



# HEALTH CARE CHECK LIST

HEALTH CARE CHECKLIST	YES	WORKING ON IT
Can I describe my health care needs?		
Are there ways my health care needs affect my day-to-day life? (For example, do I need medication, a special diet, help with personal equipment or supplies, physical therapy...)?		
Do I know what to do when I get sick?		
Do I know what medications I take and why I take them?		
Do I know when to take my medication and possible side effects to report to my doctor?		
Do I know how to get my prescriptions filled and refilled?		
Can I make my own appointments?		
Do I know how to check-in and what to bring to my appointments?		
Am I comfortable providing information and answering questions at my appointments?		
Do I know how to ask questions at my appointments?		
Do I have someone I trust who can go to appointments with me?		
Is there someone to help me make medical decisions?		
Have I talked to my primary care physician about safe sex practices (birth control/family planning information) as needed?		
Do I know about how drugs/alcohol affects my health care condition?		
Do I know health emergency phone numbers and/ or carry emergency contact information in my wallet, purse, or on my cell phone?		
Do I use a calendar/planner to keep track of my appointments/activities?		
Do I have healthy lifestyle habits?		
Do I know what kind of health insurance I will be able to have when I am 18?		
Do I know what kind of help I might need with making decisions after I am 18?		
Do I know about Power of Attorney for Health Care and Advanced Directives?		
When I need to learn something new, do I know how I learn best? (by reading, listening, pictures, watching, one-on-one, in groups)		

## WHERE DO I GO FROM HERE?



### THE NEXT QUESTION IS “WHERE DO I GO FROM HERE?”

Where you are starting from is not as important as where you are going. Now you can make a plan for how to learn more about the items on the checklist and more about yourself.

Select three items from the checklist to begin working on right away and how you will go about doing so. If you need help getting started, ask someone you trust to help you.

*Start Small. Start Slow. Start Now.*



### HAVE A GAME PLAN – EVERYONE NEEDS A HEALTH CARE TEAM

Can you name the people on your health care team and what they do? Complete this worksheet to see who you already have on your team. Think about who else you might want to add.



## HAVE A GAME PLAN - EVERYONE NEEDS A HEALTHCARE TEAM

Your Health Care Team	
<b>You</b>	<i>Remember, in addition to being the patient, you are part of the team.</i>
Primary Care Doctor	
Specialty Doctor(s)	
Physician Assistant	
Nurse(s)	
Dentist	
Dental Hygienist	
Therapists (physical, occupational, speech/ language, etc.)	
Dietician/Nutritionist	
Pharmacist	
Mental Health Professional (counselor, psychologist, psychiatrist, etc.)	
Social Worker	
Care Coordinator	
School Nurse	
Home Health Care Workers	
People you trust to help you with medical decisions. These may include:	
Parents or Other Family Members	
Friends	
Others	





## HAVE A GAME PLAN - MEDICAL HOME

You may have heard about Medical Home as a way that some health care teams work together. The title Medical Home can be a little confusing because we usually think of a home as a place.

Medical Home is not a place. It is an approach to how care is delivered that combines where primary care is provided, who provides that care and how they all work together. This includes the patient and family to make sure that quality care is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally appropriate.

To help you understand what a Medical Home means, let's use another example from sports. It might be helpful to think about a baseball game as a way to understand a Medical Home.

In some ways having a Medical Home is like hitting a home run. When you go to a baseball game you have to go to a stadium or some other place where the game is played. The playing field is set up in the shape of a diamond. The diamond has a home plate where the batter stands, three bases, a pitcher's mound, and the field surrounding the diamond. **Your Medical Home is your home base.** This is where you receive guidance and support from your coach. **Your primary health care provider is the coach for your team. It is important that all players on your team communicate with the coach, so the team is working together to win. When you win, the team wins!**

To play the game you have players on the team. Each player has their own special position. They play in those positions when the other team is batting. But they also each take a turn at hitting the ball when their own team is up to bat.

Each player has to be good at what they do and they have to be able to work together. The players need to practice their own skills, but they also have to practice together to get good at working together. They learn how to communicate with each other and how to coordinate their efforts.

When everything comes together at game time, the team may score by hitting the ball and taking bases one at a time, or several at a time. Sometimes a player hits a home run. When that happens we see more than the efforts of just one team member, but the combined effort of all involved.

Another example from sports might be a relay race. In the 2008 Olympics, United States swimmer Michael Phelps won a total of eight gold medals. This was more than any other Olympic athlete had ever won. Michael Phelps competed in individual races, but even then he was part of the USA Olympic Swim Team. The last race for Michael Phelps and the USA Olympic Swim Team was the relay race. During a relay race four team members would each swim part of the race. Each had to do their part so the team could win, and so that Michael Phelps would be able to win his eighth medal. The first thing he did after the race was to thank his teammates. He said, "Without the help of these guys it wouldn't be possible."

The relays and putting the right guys together on the team made it possible for them to win. An interesting fact about Michael Phelps that millions of people learned about through his competition in the Olympics is that he was diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). In an interview after he won, Michael Phelps talked about how a middle school teacher once told him he would never be successful. Michael Phelps was bullied, but worked through his challenges. He and his mom figured out something he was good at and focused his energy on becoming productive and happy in his own life.

## OTHER MEMBERS OF YOUR TEAM

Your team includes others that you may not have considered; the support staff. Within a Medical Home there is a team of health care providers who work together along with you and your family as full partners. The clinic staff knows who you are and remember you from visit to visit. They support you by providing other really important things, like scheduling your appointments, taking your weight and blood pressure, and helping you find resources in the community, such as therapist and other providers. Remember that you have a lot of people supporting you and they want to see you succeed and live independently.



## MY CARE PLAN

Name \_\_\_\_\_

I like to be called \_\_\_\_\_

Date of Birth \_\_\_\_\_

Address \_\_\_\_\_

Phone (Home) \_\_\_\_\_ (Cell) \_\_\_\_\_

(Work) \_\_\_\_\_

Email \_\_\_\_\_

Emergency Contact: \_\_\_\_\_

How I communicate best \_\_\_\_\_

How I like to learn new information or skills \_\_\_\_\_

What I like to do with my time (school, work, hobbies, etc.) \_\_\_\_\_



## THIS IS HOW I USUALLY FEEL:

This is how I usually feel:



Sad or Worried

..... OK .....



Happy



In Pain

..... OK .....



No Pain

This is how I describe my health care needs and concern \_\_\_\_\_

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### My Medications

Name	Amount	Dosage	When Taken

## HEALTH INFORMATION

**My allergies (including latex and/or medication allergies)** \_\_\_\_\_

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**Information on hospitalization and surgeries** \_\_\_\_\_

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**Nutritional Status** \_\_\_\_\_

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**Immunizations (include dates):** \_\_\_\_\_

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**Recent Labs/X-Rays (include date/location):** \_\_\_\_\_

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**Equipment/Supplies/Assistive Technology (include contact information):**

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**Therapy (include frequency/provider contact information):** \_\_\_\_\_

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## MY HEALTH CARE TEAM



Write the names of your doctors, therapist, other health providers,  
(including pharmacy, equipment and supply vendors)

**Name**

**Specialty**

**Phone number**






### WHO HELPS ME WITH MEDICAL DECISIONS AND/OR FOLLOW UP?

Name \_\_\_\_\_

Relationship \_\_\_\_\_

Phone (Home) \_\_\_\_\_ (Cell) \_\_\_\_\_  
(Work) \_\_\_\_\_

Email \_\_\_\_\_

Power of attorney for health care? Yes \_\_\_\_\_ No \_\_\_\_\_

If Yes, Who \_\_\_\_\_

Phone ( ) \_\_\_\_\_

Conservator/Guardian: Self \_\_\_\_\_ Other (name) \_\_\_\_\_

I have a health care plan? Yes \_\_\_\_\_ No \_\_\_\_\_

If Yes, where? \_\_\_\_\_

## EMERGENCY MEDICAL INFORMATION CARD

Name \_\_\_\_\_ Date of Birth \_\_\_\_\_

Address \_\_\_\_\_

Phone (    ) \_\_\_\_\_

Allergies to Latex or Medications \_\_\_\_\_

### Emergency Contacts:

Name \_\_\_\_\_ Relationship \_\_\_\_\_

Phone (    ) \_\_\_\_\_

Name \_\_\_\_\_ Relationship \_\_\_\_\_

Phone (    ) \_\_\_\_\_

### Health care Contacts:

Primary Doctor \_\_\_\_\_ Phone (    ) \_\_\_\_\_

Specialist Doctor \_\_\_\_\_ Phone (    ) \_\_\_\_\_

Hospital/Clinic \_\_\_\_\_ Phone (    ) \_\_\_\_\_

Insurance Card Number \_\_\_\_\_ Phone (    ) \_\_\_\_\_

### Special Health Care Needs Information:

Chronic Illnesses/Diagnoses/Disabilities \_\_\_\_\_

Equipment/Other \_\_\_\_\_

How I Communicate \_\_\_\_\_

Other Important Stuff \_\_\_\_\_

### Medications:

Name \_\_\_\_\_ Dose \_\_\_\_\_

Name \_\_\_\_\_ Dose \_\_\_\_\_

Name \_\_\_\_\_ Dose \_\_\_\_\_

Name \_\_\_\_\_ Dose \_\_\_\_\_

Name \_\_\_\_\_ Dose \_\_\_\_\_

Power of attorney for health care? Yes \_\_\_\_\_ No \_\_\_\_\_

If Yes, Who? \_\_\_\_\_

Phone (    ) \_\_\_\_\_

Conservator/Guardian? If Yes, Who? \_\_\_\_\_

Phone (    ) \_\_\_\_\_



## HOW TO MAKE AN APPOINTMENT



### PRACTICE MAKES PERFECT - HOW TO MAKE AN APPOINTMENT

- ⇒ Be prepared. Fill in as much of this form (on the next page) as you can before you make your phone call. Use it as a guide when you make your call. If you have never done this before, have someone help you. You might even want to practice before you actually make your call.
- ⇒ Have your calendar ready so you can check the date and time. Put your appointment on your calendar right away.
- ⇒ You may need to repeat some of the information if the first person you speak to transfers you to someone else.
- ⇒ You may need to know your date of birth. You may need information from your insurance so have that ready as well.
- ⇒ Know the name of the person you need to see. It may be a doctor, a nurse practitioner or another health care provider.
- ⇒ Know the reason you need the appointment. Is it for a regular check-up or are you having a problem or concern?
- ⇒ If you will need a lift or other assistance to get onto the exam table or some other type of help, such as an interpreter, be sure to mention it when you call.



### Write Down Before You Call

**Physician/Clinic phone number:** \_\_\_\_\_

**Name of Physician You Want to See:** \_\_\_\_\_

**Insurance Information:**

**Name of Insurance Carrier (on card):** \_\_\_\_\_

**Insurance Number (on card):** \_\_\_\_\_

**Name of who has the insurance (you, mom, dad, etc.):** \_\_\_\_\_

## SAMPLE SCRIPT



### SAMPLE SCRIPT - HOW TO MAKE AN APPOINTMENT

⇒ Hello, my name is: \_\_\_\_\_  
(give your first and last name)

⇒ I need an appointment to see (Doctor's name): \_\_\_\_\_  
because \_\_\_\_\_  
(example: I need a check-up, I'm having headaches, I'm having back pain...)

⇒ How soon can I get in?  
Write the date and time here \_\_\_\_\_  
If this date and time are ok, just say: **Thank you that will be fine.**  
If not, just say: **That won't work for me. Can you look for something else?**

⇒ How long is the appointment?  
Write amount of time here \_\_\_\_\_  
If you think you will need more time, just say: **I think I will need more time.**  
If you will need some equipment like a lift or extra help just say:  
**I will need** \_\_\_\_\_  
(example: a lift to get onto the exam table)  
Before you end the phone call, repeat the date and time of your appointment

⇒ OK, I will be there on \_\_\_\_\_ at \_\_\_\_\_  
(Date) (Time)

**Thank you. Good-bye.**

Follow-up step: \_\_\_\_\_  
(example: I will write this appointment on the family calendar right now so I won't forget about it)



# SAMPLE CARE PLAN

## UPCOMING APPOINTMENT WITH MY REGULAR DOCTOR

Doctor's Name: \_\_\_\_\_

Appointment Date: \_\_\_\_\_

Why am I going to see the doctor: \_\_\_\_\_

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How have I been feeling lately: \_\_\_\_\_

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### Information from the Appointment:

Weight \_\_\_\_\_ Height \_\_\_\_\_ Blood Presser \_\_\_\_\_

Other \_\_\_\_\_

Follow-up \_\_\_\_\_

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## UPCOMING APPOINTMENT WITH A NEW DOCTOR

Why I am here: \_\_\_\_\_

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Important information you should know about my medical history: \_\_\_\_\_

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Medications and allergies: \_\_\_\_\_

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Past surgeries and hospitalizations: \_\_\_\_\_

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Other doctors I have seen: \_\_\_\_\_

How I communicate best: \_\_\_\_\_

Other things I want you to know about me: \_\_\_\_\_

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What should I know about you? \_\_\_\_\_

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# HOW TO ARRANGE TRANSPORTATION



## HOW TO ARRANGE TRANSPORTATION FOR YOUR APPOINTMENTS?

START MAKING PLANS FOR TRANSPORTATION AS SOON AS YOU MAKE YOUR APPOINTMENT.

YOU MAY BE ASKING A FRIEND OR RELATIVE TO DRIVE YOU OR YOU MAY BE USING A TRANSPORTATION SERVICE. YOUR CHANCES OF BEING ABLE TO GET A RIDE ARE BETTER IF YOU PLAN AHEAD. REMEMBER TO CHECK ON A RIDE BACK HOME AFTER YOUR APPOINTMENT IF YOU WILL NEED ONE.

IF YOU ARE TAKING A CITY BUS YOU WILL WANT TO MAKE SURE YOU KNOW WHICH BUS TO TAKE AND HOW LONG IT WILL TAKE SO YOU ARE NOT LATE. YOU MAY EVEN WANT TO TAKE A PRACTICE RIDE ON THE BUS IF YOU HAVE NOT DONE THIS BEFORE JUST TO MAKE SURE YOU KNOW WHERE AND WHEN TO GET ON THE BUS.

IF YOU ARE USING A REGULAR TAXI CAB YOU PROBABLY WON'T NEED TO CALL UNTIL THE DAY BEFORE OR THE DAY OF THE APPOINTMENT BUT YOU WILL WANT TO CHECK WITH THE COMPANY AHEAD OF TIME.

IF YOU ARE NOT SURE WHO TO CALL OR WHAT TO DO, ASK YOUR PARENTS, YOUR COUNTY CASE MANAGER OR SOCIAL WORKER AT THE CLINIC OR HOSPITAL.

YOU CAN FILL IN THE BLANKS ON THE FORM ON THE NEXT PAGE AND THEN USE IT AS AN OUTLINE WHEN YOU MAKE YOUR CALL. IF YOU ARE USING A TRANSPORTATION SERVICE YOU MAY ALSO NEED TO HAVE YOUR MEDICAID NUMBER READY WHEN YOU CALL.

## SAMPLE SCRIPT - HOW TO ARRANGE TRANSPORTATION



⇒ **Name of Driver or Service:** \_\_\_\_\_

⇒ **Phone Number:** \_\_\_\_\_

⇒ **Hello, my name is:** \_\_\_\_\_  
(give your first and last name)

⇒ **I need to arrange a ride to a medical appointment.**  
The date and time are \_\_\_\_\_  
I am going to \_\_\_\_\_  
(say the clinic or hospital name and the address)

⇒ **You will need to pick me up from** \_\_\_\_\_  
(say your address)

⇒ **Can you do this? Yes** \_\_\_\_\_ **No** \_\_\_\_\_  
**If the answer is Yes, ask: What time will you pick me up?** \_\_\_\_\_  
(write the time here)

**If the answer is No, you can ask:**  
**Is there someone else you can recommend?** \_\_\_\_\_  
(write the name here)

⇒ **I will also need a ride home from the appointment.**  
It should last \_\_\_\_\_  
(say how long the appointment should take)

⇒ **Who do I call if there is a problem?** \_\_\_\_\_  
(write the name and phone number here)

⇒ **Will I need any paperwork or money?** \_\_\_\_\_  
(write the answer here)

⇒ **Thank you. Goodbye.**

⇒ **Follow-up Step:** \_\_\_\_\_

## PRACTICE MAKES PERFECT



When your doctor wants you to take medication, a prescription may be called in by telephone to a pharmacy. You will need to go to the pharmacy to pick up your medicine. If the doctor gives you a written prescription you will need to take it to the pharmacy to get it filled. Be sure to take your Medicaid and/or insurance card with you. There may be a co-pay charge so you will want to have some money too.

Sometimes there is a pharmacy located right in the clinic where you see your doctor. You may have a neighborhood drug store or another pharmacy you can use. If you will be taking the medication for a while, the doctor may write on the prescription that you may have refills.

You will want to make sure you order your refill before your medication is gone so you don't miss any doses. Mark your calendar to remind you of when to call in your prescription refill. Call to order your medication when you have one week of medicine left, so you don't run out on a weekend, holiday or while on a trip.

There are some special rules about certain drugs. These are also known as controlled substances. These prescriptions cannot be ordered too far ahead, the prescription cannot be faxed and the use of these medications are carefully monitored.

To order a refill on a medication, you will use the information on the medication label. There are other options of prescription refills. You can request home delivery, re-occurring pick up at your local pharmacy and mail order. You can also take your medication bottle to the pharmacy or you can call ahead and order the refill by telephone.

When you call the pharmacy, a person may answer and take all the information. Sometimes you may get an answering machine telling you how to give the information the pharmacy needs to refill your prescription. If this is too hard or confusing, you can usually stay on the phone or push a number to get help from a person. Some pharmacies have apps for your phone or electronic device that can be used to refill prescriptions.

Make sure you understand how and when to take your medication. Make sure you understand any possible side effects to be aware of and what to do if you experience them. You will get written information along with your medication but be sure to ask the pharmacist any questions you may have.

If you get home and have a question or concern about your medication, call your pharmacist (number is on your prescription bottle). You can also contact your doctor's office and ask to speak to your doctor's nurse. Nurses can also answer a lot of questions and can check with your doctor, if needed.

If you are taking a prescription that makes you feel different or bad, let someone know. Some medications have side effects that can change how you feel.



## HOW TO GET PRESCRIPTION MEDICATIONS AND REFILL



⇒ Hello, my name is: \_\_\_\_\_  
(give your first and last name)

⇒ I need to pick up a new prescription. Can you tell me about the dosage?

⇒ How often should I take this? Are there directions for how to take it?

⇒ What should I do if I miss a dose?

⇒ Here is a list of my other medications: \_\_\_\_\_  
\_\_\_\_\_

⇒ Will this one interfere with any of them? If yes, what should I do? \_\_\_\_\_  
\_\_\_\_\_

What are the side effects of this new medication? \_\_\_\_\_  
\_\_\_\_\_

What should I do if I experience any of these? \_\_\_\_\_  
\_\_\_\_\_

⇒ Is there anything else about this medication I should know about? \_\_\_\_\_  
\_\_\_\_\_

⇒ When can I pick it up? \_\_\_\_\_  
(Can you deliver it? If yes, when?) \_\_\_\_\_  
(Can someone else pick it up for me?) \_\_\_\_\_

⇒ Is there a co-pay charge? \_\_\_\_\_ How much? \_\_\_\_\_

You have been really helpful. Thank you.

## SAMPLE SCRIPT - HOW TO GET PRESCRIPTION MEDICATION REFILLS

⇒ Hello, my name is: \_\_\_\_\_  
(give your first and last name)

⇒ I need to get a refill on a prescription.

⇒ The prescription number is \_\_\_\_\_

⇒ The name of the medication is \_\_\_\_\_

⇒ When can I pick it up? \_\_\_\_\_  
(Can you deliver it? If yes, when?) \_\_\_\_\_  
(Can someone else pick it up for me?) \_\_\_\_\_

⇒ Is there a co-pay charge? \_\_\_\_\_ How much? \_\_\_\_\_

Thank you. Good-bye.



## COMMUNICATION TIPS



People sometimes say that communication is a two-way street. But when it comes to effective communication and medical appointments for youth it is usually a three-way street:

### PARENT(S) + HEALTH CARE PROVIDER + YOUTH

Transition is a time of changing roles and expectations. It is a time for youth to actively assume more responsibility and for parents as well as health care providers to encourage this change to the greatest extent possible even when they have special health care needs. Open communication is essential to this process so that the three-way street becomes:

### YOUTH + HEALTH CARE PROVIDER + [PARENT(S) AS NEEDED]

#### KEY QUESTIONS FOR YOUTH, HEALTH CARE PROVIDER AND PARENT(S)

- ⇒ Do I show others the respect that I want to receive?
- ⇒ Do I listen carefully and completely to questions or comments before responding?
- ⇒ Do I participate in discussions willingly and with an open mind?
- ⇒ Do I accept responsibility for my actions and opinions?
- ⇒ Do I ask for further explanation when I don't understand something?
- ⇒ Do I actively participate in planning and problem solving?

#### KEY QUESTIONS FOR YOUTH

- ⇒ Do I participate in my appointments by offering information, answering questions, expressing my concerns and asking questions?
- ⇒ Do I express my own thoughts and feelings even when they differ from my parent(s) or health care provider?
- ⇒ Do I ask for some time alone with my health care provider at my appointments for private discussion and am I able to ask questions without feeling embarrassed?

#### KEY QUESTIONS FOR PROVIDERS

- ⇒ Do I focus my attention primarily on the youth rather than the parent?
- ⇒ Do I discuss topics that are age and developmentally appropriate and include but are not limited to the youth's special health care needs?
- ⇒ Do I offer time alone with the youth for private discussion?
- ⇒ Do I respect confidentiality as much as possible?
- ⇒ Do I create a comfortable environment that encourages collaboration?

#### KEY QUESTIONS FOR PARENTS

- ⇒ Do I actively encourage my son or daughter to participate as fully as possible?
- ⇒ Do I actively encourage the health care provider to do the same?
- ⇒ Do I facilitate confidential communication between my son or daughter and his or her health care provider to the greatest extent possible?
- ⇒ Do I recognize my own legitimate needs as a parent during the transition process and seek appropriate supports and resources to meet these needs?



## GETTING READY FOR YOUR MEDICAL APPOINTMENTS



Use a notebook or folder to get ready for your appointment. You will want to use the notebook to have some of your health information available and also as a place to write notes while you are at your appointment. This could include basic or new information, follow-up needed or care instructions.

- ⇒ Put the name of the health care provider you are seeing and the appointment date at the top of any notes you make during your appointment.
- ⇒ Write down how you have been feeling lately and any special concerns you have so you will not forget to mention anything in your appointment.
- ⇒ Think about your body starting at the top of your head and all the way down to your toes. Think about any aches or pains or anything you have a question or concern about. If you are not sure how to describe your symptoms you can point to the area and your doctor can ask you questions to help you identify what is concerning you. You can also use a drawing like the one on the next page of this workbook.

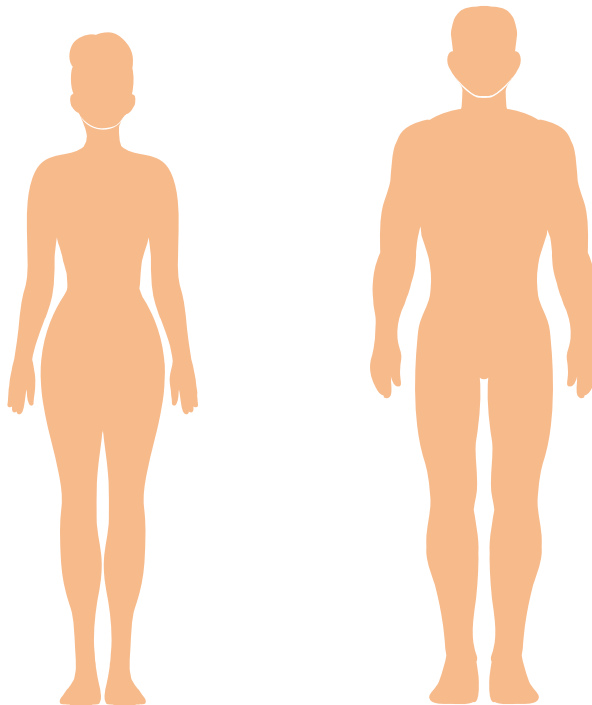


- ⇒ If you are not feeling well, write down your symptoms so you can share them with your health care provider and not worry about forgetting anything.
- ⇒ You may want to have someone you trust go to the appointment with you. That person can be with you throughout the appointment or just at the beginning or end of the appointment so you can still have some time alone with your health care provider.
- ⇒ Write down information and instructions at your appointment so you don't have to try to remember everything. If you need help doing this just ask your provider or the person you brought with you to help.

- ⇒ Remember: You should be able to talk with your doctor about any of your health concerns or questions. Your doctor needs to know your true feelings and concerns in order to help you. If you are sad, worried or afraid of something or someone it is important for you to tell your doctor so you can talk about options that might be available to help you. The doctor may want to make a referral to a specialist or a community resource for additional follow-up. It is okay to ask for information to be repeated or explained again if you do not understand it the first time.
- ⇒ Be sure to take your medications in the original containers along with you so you can review all the medications you are taking, how much and how often with your doctor. Or you can take a complete listing of your medications, how much you take and when. If you have a care plan it should include this information. Remember to keep this kind of information up to date.
- ⇒ Pharmacy Information

**THINK ABOUT YOUR BODY STARTING AT THE TOP OF YOUR HEAD AND ALL THE WAY DOWN TO YOUR TOES. NOTICE ANY ACHES OR PAINS OR ANYTHING YOU HAVE A QUESTION OR CONCERN ABOUT.**

**IF YOU ARE NOT SURE HOW TO DESCRIBE YOUR SYMPTOMS YOU CAN POINT TO THE AREA AND YOUR DOCTOR CAN ASK QUESTIONS TO HELP YOU IDENTIFY WHAT IS BOTHERING YOU.**



# QUESTIONS TO ASK AT YOUR APPOINTMENT



## QUESTIONS TO ASK AT YOUR REGULAR APPOINTMENT

- ⇒ How do you think I am doing?
- ⇒ Are there any problems I should know about?
  - If yes, please explain any problem(s) and what I need to do.
- ⇒ Will the problem(s) get better?
  - Why or why not?
- ⇒ Do I need any medical tests?
  - If yes, what kind?
- ⇒ Do I need new medication or changes in my medication?
  - If yes, what kind?
  - Are there any side effects of the new medication(s)?
- ⇒ Are there any changes in what I should do day-to-day to take care of myself?
  - If yes, what kind of changes?
- ⇒ Are there any changes in what I can or cannot do?
  - If yes, what kind? (especially at work or in school)
- ⇒ Do I need another appointment?
  - If yes, when?
- ⇒ Is there other information I should remember?
- ⇒ Is there any follow-up? What is my next step?



## QUESTIONS TO ASK AT AN APPOINTMENT WHEN YOU ARE SICK

- ⇒ What is wrong or why am I feeling bad?
- ⇒ What caused this?
- ⇒ What should I do about it?
- ⇒ How long will it last?
- ⇒ Can I go to work/school?
- ⇒ Do I need medicine?
  - If yes, are there any side effects to this medicine?
- ⇒ Are any of the medications I take already affected by this new medicine?
- ⇒ What should I do if I don't start feeling better or if I start feeling worse?
- ⇒ Are there any changes in what I'm supposed to do to take care of myself?
- ⇒ Do I need another appointment?
- ⇒ Are there any other instructions or information I need to know?





### QUESTIONS TO ASK ABOUT HOSPITALIZATION OR SURGERY

- ⇒ Why do I need surgery or to go in the hospital?
- ⇒ Are there any alternatives or treatments?
- ⇒ What will need to be done?
- ⇒ What are the risks or possible complications?
- ⇒ How long will I be in the hospital?
- ⇒ What will happen when I am there?
- ⇒ How will I be different after the surgery?
- ⇒ How will I be the same?
- ⇒ Do I need to do anything different to prepare for the surgery and/or hospitalization?
- ⇒ Are there any special written instructions I need to have before, during or after?
- ⇒ Where do I go when I get to the hospital?
- ⇒ What do I need to bring with me?
- ⇒ Should I bring someone with me?
- ⇒ If I want you to share information about my condition, what do I need to do before going to the hospital or having surgery?



## GETTING READY FOR A DENTAL APPOINTMENT



- ⇒ You will want to do the same things you do for any medical appointment. This includes preparing ahead of time and using your notebook or folder to write down questions and concerns to discuss with your dentist and to write notes during your appointment about follow-up needed or care instructions.
- ⇒ You will want to let your dentist know if you are taking medications.
- ⇒ You will want to let the dentist know if you ate before your appointment.
- ⇒ You will want to let your dentist know if you are having pain in your mouth or teeth, pain with cold or hot food or drinks or pain that wakes you up at night.
- ⇒ You will also want your dentist to know if you are afraid of dental appointments and what helps you to calm down. Sometimes listening to music or having something calming to look at or hold can help.
- ⇒ You will want to mention if you gag easily or have trouble holding your mouth open. Your dentist and dental hygienist can work with you to help with these concerns.

### SOMETHING TO THINK ABOUT

⇒ **CAN YOU SHOW WHERE ON YOUR MOUTH OR FACE YOU HAVE PAIN?**

⇒ **CAN YOU SHOW WHICH TEETH HURT OR ARE SENSITIVE TO HOT OR COLD?**

**IF NOT, YOU MAY WANT TO BRING SOMEONE WITH YOU TO HELP DESCRIBE WHAT IS BOTHERING YOU.**

- ⇒ Your dentist may want to know your daily care routine:
  - How often you brush your teeth
  - The type of toothbrush and toothpaste you use
  - If you floss between your teeth and how often
  - If you use mouthwash, how often and what kind



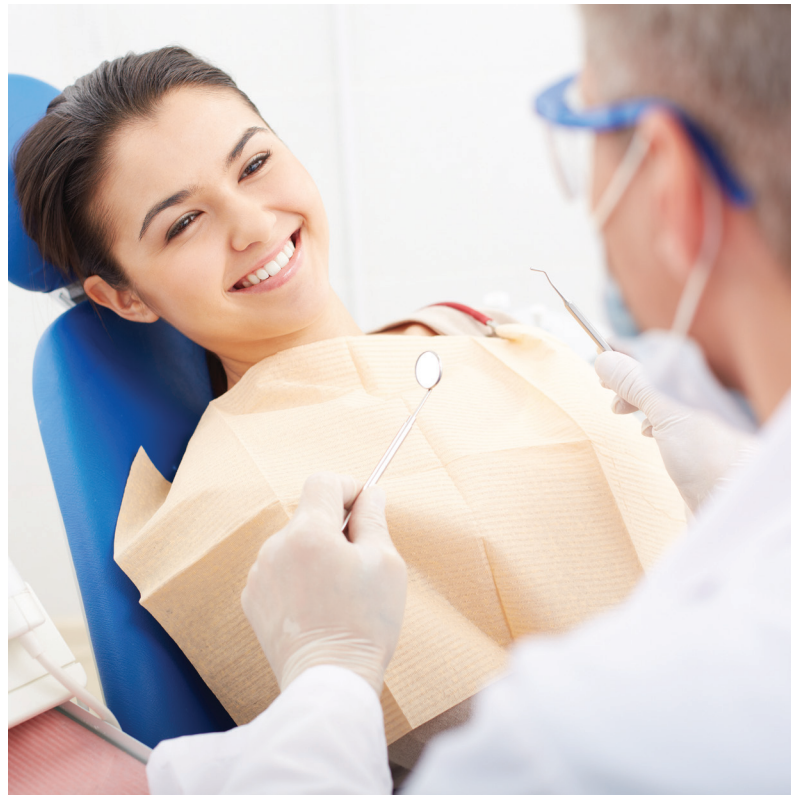
## QUESTIONS TO ASK YOUR DENTIST



**MAKE SURE TO TELL THE DENTIST IF YOU ARE AFRAID, IF YOU GAG EASILY, OR IF YOU HAVE TROUBLE KEEPING YOUR MOUTH OPEN.**

- ⇒ What kinds of dental problems do I have?
- ⇒ What causes these problems?
- ⇒ What can I do to make these problems better or not get any worse?
- ⇒ Is there a special toothbrush I should use?
- ⇒ Is there a special type of toothpaste I should use?
- ⇒ How often and when should I be brushing my teeth?
- ⇒ Is there a special mouthwash I should use?
- ⇒ How often should I use mouthwash?
- ⇒ Can you please show me ways to make flossing easier?
- ⇒ When should I floss?
- ⇒ Are there any changes in my diet you recommend?
- ⇒ When do I need another appointment?

**(THE DENTIST MAY HAVE THE DENTAL HYGIENIST SHOW YOU HOW TO BRUSH AND FLOSS. THE DENTAL HYGIENIST USUALLY CLEANS TEETH AND DOES PATIENT EDUCATION AS WELL AS PART OF THE DENTAL APPOINTMENT. YOU CAN FEEL FREE TO ASK THE DENTAL HYGIENIST QUESTIONS AS WELL.)**





## EVALUATING CHOICES



# HEALTHY LIFESTYLE HABITS



## LIFESTYLE HABITS ARE THE THINGS WE DO EVERY DAY SUCH AS:

- ⇒ what we eat and drink
- ⇒ how much we exercise
- ⇒ how much we sleep
- ⇒ our personal cares and grooming
- ⇒ leisure and relaxation activities (hobbies and other interests)
- ⇒ relationships and social network
- ⇒ family traditions
- ⇒ spiritual practices
- ⇒ work and/or school
- ⇒ safety and security practices

## WHAT WE DO CAN AFFECT HOW WE FEEL? HOW WE FEEL CAN AFFECT WHAT WE DO?

It's important for each person to develop a regular routine that works best for that person.

It's also important to figure out what to include in a daily routine and what to include on a weekly, monthly or some other schedule. For example:

- ⇒ Combing my hair is something I will do every day and even several times a day. But I may wash my hair every other day. And I may get a haircut every six weeks.
- ⇒ Going out with friends several evenings a week may be fun, but I may also spend several evenings at home by myself just to relax.
- ⇒ I brush my teeth and use mouthwash at least twice a day (every morning and before bedtime) and I floss my teeth at least once a day. But I also have a regular cleaning and check-up with my dentist every six months.
- ⇒ I need to take care of my personal hygiene.
- ⇒ I need to keep a record of my menstrual cycle, which includes writing down the day it starts and ends each month (Girls Only)
- ⇒ I know how to use and read thermometer and when my temperature is elevated.

# DAILY LOG

IT'S EASY TO LOSE TRACK OF HOW WE USE OUR TIME. SOMETIMES IT IS A GOOD IDEA TO WRITE DOWN EVERYTHING WE DO FOR A DAY. THEN WE CAN MAKE CHANGES IN OUR ROUTINES.

WHAT DO YOU INCLUDE IN YOUR DAILY ROUTINE? HOW ABOUT YOUR WEEKLY OR MONTHLY ROUTINE? THIS DAILY LOG IS TO HELP TRACK YOUR DAILY AND MONTHLY ROUTINES.

Time	Activity	Special Reminders or Notes
6:00 am		
7:00 am		
8:00 am		
9:00 am		
10:00 am		
11:00 am		
12 Noon		
1:00 pm		
2:00 pm		
3:00 pm		
4:00 pm		
5:00 pm		
6:00 pm		
7:00 pm		
8:00 pm		
9:00 pm		
10:00 pm		
11:00 pm		



## SAMPLE DAILY LOG

Time	Activity	Special Reminders or Notes
6:00 am	Get up by 6:15 Take a shower/wash hair	Do some stretching exercised before breakfast
7:00 am	Eat breakfast Take medication Brush teeth Use mouthwash	Hot or cold cereal during the week Pack lunch for work and put it in carry case near the front door
8:00 am	Leave for bus stop by 8:15	Be sure to check the weather before leaving
9:00 am	Punch in at work	Put lunch in refrigerator
10:00 am	Break time – eat fruit and something to drink	Milk or water – not soda
11:00 am		
12 Noon	Eat lunch Take medication	No orange juice with this medication
1:00 pm	Talk to supervisor about time off for doctor appointment	Write down best dates and times to take off work
2:00 pm	Break time – Check on plans for bowling after work Call to make doctor's appointment	Try to get dates/times my supervisor said would work best for time off
3:00 pm	Meet group for bowling at the bus stop by 3:15	Make sure to have bus pass and some money for bowling
4:00 pm	Leave for bus stop by 4:45	
5:00 pm	Eat supper	Make sure to eat salad and vegetables. Not too much bread!
6:00 pm	Call Mom or Dad about ride to doctor appointment	Also check on grocery shopping this weekend
7:00 pm	Favorite TV show on tonight!	
8:00 pm	Work on puzzle	
9:00 pm	Get ready for bed – brush teeth and floss	Set alarm clock for 6:00 am Lay out clothes for tomorrow Make sure door is locked
10:00 pm		Listen to some relaxing music before going to sleep
11:00 pm		

## ROOM FOR IMPROVEMENT



**SOMETIMES WHAT WE WANT IS DIFFERENT FROM WHAT WE NEED OR WHAT MAY BE GOOD OR BAD FOR US IN TERMS OF HEALTHY LIFESTYLE HABITS. FOR EXAMPLE,**

- ⇒ I may want to maintain a healthy weight or even lose some weight, but I may also want to eat a hot fudge sundae every night.
- ⇒ I may want to exercise for 30 minutes every day, but I find that I am watching TV after I get home from work and after supper.
- ⇒ I may want to make more friends, but I usually stay home every weekend.

These are the kinds of things that may be revealed when I fill out my own daily log and then look at how I use my time. This gives me an opportunity to plan some of the things I want to do into my day. For example, I may schedule a 30 minute walk after work and before I eat supper on Monday, Wednesday and Friday. I may volunteer at the local library every other Saturday afternoon. By scheduling these activities into my day, I am showing that they are important to me. I also have a better chance of doing them when I schedule them into my time instead of just hoping that I will do them.

Getting to know ourselves and our priorities is an important aspect of becoming a mature adult. We can do this by thinking about:

- ⇒ Our strengths
- ⇒ Our challenges
- ⇒ What we want
- ⇒ What we need
- ⇒ What we think is important
- ⇒ Our responsibilities

Our strengths include our natural abilities, the way we affect the world around us just by existing, talents we have developed and personality traits that are helpful to us.

Challenges may include visible and invisible disabilities, chronic illness, undeveloped or underdeveloped skills and personality traits that are not helpful to us.

Sometimes what we want is not the same as what we need. If we think about what we want and what we need, we can make choices about how to spend our time and energy.

We also need to think about our responsibilities to ourselves and others, and see how they are affected by the things we want and need. We want to have fun and yet meet our responsibilities.







## PAYING FOR HEALTH CARE



Health care is expensive. Teens and young adults need to know how they will meet the cost of their health care as adults. Families need to think about family insurance limits, types of health insurance coverage that might be available and the ways eligibility is determined.

In Georgia, if you receive Supplemental Security Income (SSI) from the Social Security Administration, you are automatically eligible for Medicaid. Some will allow indefinite continued coverage if the adult child is disabled and the disability occurred before age 18 and the parent continues to provide 50% or more of the adult child's support or maintenance. This must be carefully considered if the adult child will be receiving Supplemental Security Income (SSI) because some aspects of SSI payments are based on the adult child no longer being claimed as a dependent by the parents, while others allow the parents to continue to provide support to the adult child but then SSI payments are at a reduced rate. For children on the Katie Beckett program, at age 18 they may be eligible for SSI even if they had not been previously because of parent income. You can apply for SSI Disability Benefits online at: <http://www.ssa.gov/disabilityssi/>

A young adult may continue COBRA coverage for up to 36 months after leaving the parent's family insurance plan due to losing their status as a dependent. The individual is responsible for paying the individual premiums for the COBRA coverage and, while this can be quite expensive, it may still be worthwhile. If health and dental plans are offered separately, each plan should be considered based on its own cost and potential value. For example, given some of the access problems with dental care for Medicaid patients, it may be worthwhile to continue dental insurance under COBRA if the cost is affordable.

This law requires plans and issuers that offer dependent coverage to make the coverage available until a child reaches the age of 26. Both married and unmarried children qualify for this coverage. This rule applies to all plans in the individual market and to new employer plans. Beginning in 2014, children up to age 26 can stay on their parent's employer plan even if they have another offer of coverage through an employer.

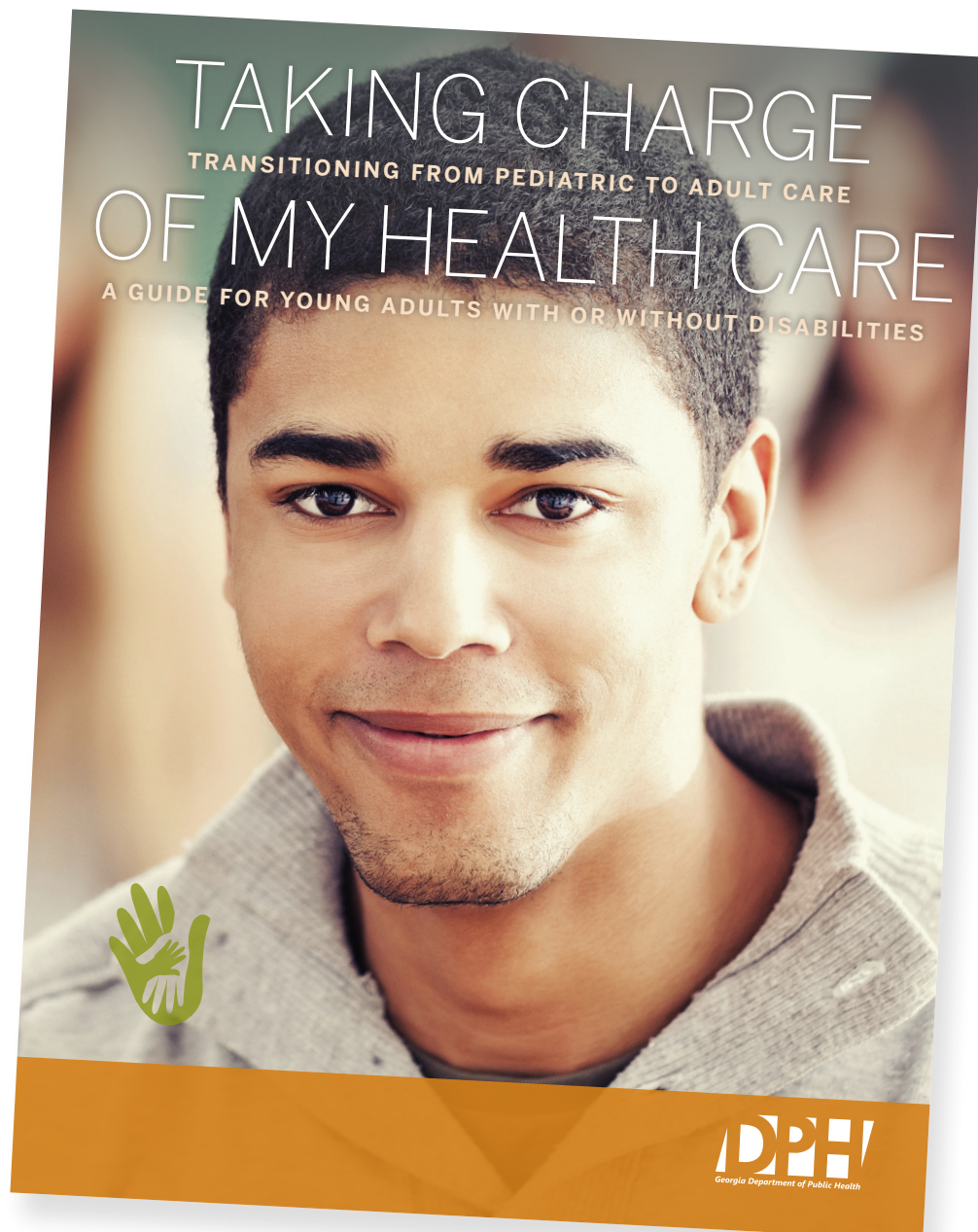
Parents need to read their policies carefully before their young adult reaches 26. Some will allow indefinite continued coverage if the adult child is disabled and the disability occurred before age 18 and the parent continues to provide 50% or more of the adult child's support or maintenance. This must be carefully considered if the adult child will be receiving Supplemental Security Income (SSI) because some aspects of SSI payments are based on the adult child no longer being claimed as a dependent by the parents, while others allow the parents to continue to provide support to the adult child but then SSI payments are at a reduced rate. In Georgia, if you receive Supplemental Security Income (SSI) from the Social Security Administration, you are automatically eligible for Medicaid. For children on the Katie Beckett program, at age 18 they may be eligible for SSI even if they had not been previously because of parent income. You can apply for SSI Disability Benefits online at: <http://www.ssa.gov/disabilityssi/>

## RESOURCES



➡ **GEORGIA DEPARTMENT OF PUBLIC HEALTH,  
TRANSITIONING YOUTH TO ADULT CARE**  
<http://dph.georgia.gov/transitioning-youth-adult-care>

➡ **TAKING CHARGE OF MY HEALTH CARE BOOKLET**  
[https://issuu.com/georgiamaternalandchildhealth/docs/taking\\_charge\\_of\\_my\\_health\\_care\\_fin](https://issuu.com/georgiamaternalandchildhealth/docs/taking_charge_of_my_health_care_fin)



# NOTES

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# TAKING CHARGE OF MY HEALTH CARE

MOVING FROM PEDIATRIC TO ADULT HEALTH CARE

A WORKBOOK FOR YOUTH AND YOUNG ADULTS  
WITH OR WITHOUT DISABILITIES



*Georgia Department of Public Health*

**GEORGIA DEPARTMENT OF PUBLIC HEALTH**  
CHILDREN'S MEDICAL SERVICES

<http://dph.georgia.gov/cms>