PREPARING YOUR ADOLESCENT FOR THE TRANSITION FROM PEDIATRIC TO ADULT HEALTH CARE

MOVING FROM HEALTH CARE LEADER TO SUPPORTER A WORKBOOK FOR PARENTS AND CAREGIVERS



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 booklet was adapted from the curriculum developed by the Waisman Center, Wisconsin.

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Introduction

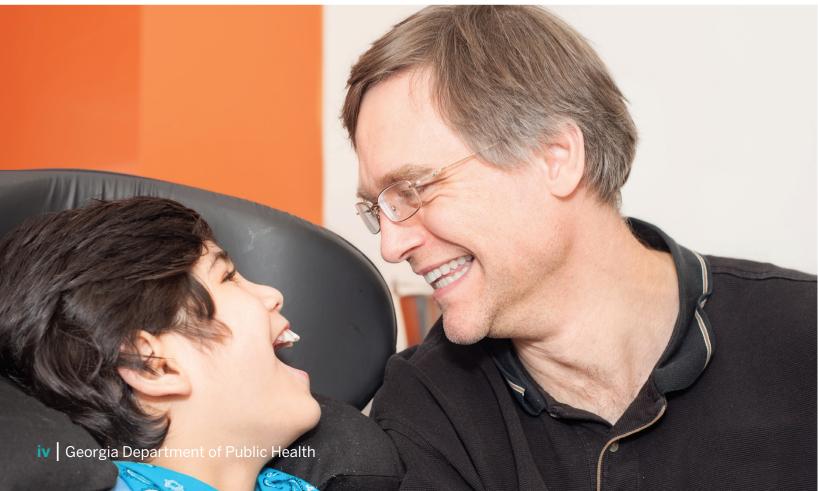
These handouts are intended to serve as a framework for anyone interested in helping young people with special health care needs and their families prepare for the transition to adult health care. It is designed to help prepare parents and families of youth with special health care needs (YSHCN) transition from pediatric to adult health care.

Transitioning from pediatric to adult health care is a process that should involve planning and support from a team (family, pediatrician, and pediatric specialist). The level of support your child will need depends on his/her 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 your child, and they are still available to offer assistance as your child learns to live independently and direct his/her own health care.

Each individual child or youth with special health care needs is unique and has many of the same hopes and dreams. For some youth, health-related issues are more challenging than for others. It is important for your child to be involved in the transitioning process and understanding of his/her own health needs.

It's also important that you and your child understand that transitioning to adult health care is unique to each person and to 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.

These handouts and the training curriculum on this same topic is designed to be a useful tool for planning and practicing for this important transition. This is the beginning, so be patient and know that your child is capable of navigating and making decisions about his/her own health care. Most importantly, remember that there is a team supporting you and your child on this next step to living independently!



<u>CYSHCN</u>



WHO ARE CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS (CYSHCN)?

There are more individuals with special health care needs in our communities than ever before. According to the 2011-2012 National Survey of Children with Special Health Care Needs (http://www.childhealthdata.org/learn/NS-CSHCN):

- ➡ Approximately 14.6 million children ages 0–17 years in the United States (19.8%) have special health care needs
- ➡ Prevalence of CSHCN ranges from 14.4% to 26.4% across the 50 states and the District of Columbia.
- About 65% of CSHCN experience more complex service needs that go beyond a primary need for prescription medications to manage their health condition.
- ➡ Compared to children who do not meet the CSHCN criteria, CSHCN are more likely to be male (58.1% vs. 49.4%) and older 12–17 years (43.2% vs. 31.8%).

These are remarkable statistics and speak to the advancements in medicine, education and community-based services that have evolved over the last fifty years. These statistics also are compelling because they speak to the importance of preparing CYSHCN for adult life.

The federal Maternal and Child Health Bureau defines children with special health care needs as:

Those who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Any discussion among young people with special health care needs must recognize that this includes an impressive number of individuals along a broad continuum. Some young people with special health care needs may become fully independent in managing their own health care. Others may continue to need substantial assistance. The hope is that even those who will require considerable ongoing assistance will be able to engage in meaningful ways in this important aspect of adult life.

It is important to acknowledge the uniqueness of the transition process for each young person and every individual family. Appreciating and respecting individual differences and preferences is important to all people, including those with special health care needs. In addition, transition is a developmental process that cannot be accomplished in a single effort, but must evolve over time.

UNDERSTANDING



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.

 \Rightarrow 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."

 \Rightarrow 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.

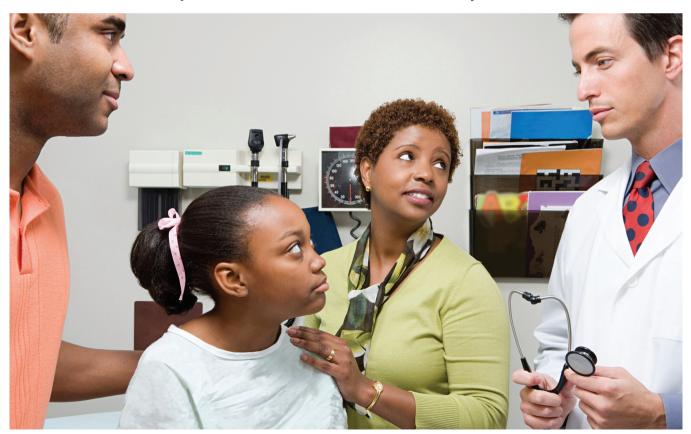
Ask for guidance from their pediatric health care provider on how and when to make the move from pediatrics to adult health care.

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.



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HANDOUTS FOR PARENT WORKSHOP

INTERVIEW FORMAT



PLAYER PROFILE INTERVIEW FORMAT

Write a one- or two-sentence description of your player:

Briefly describe your player's special health care needs:

Briefly describe any of your player's special talents or abilities:

Briefly describe how your player learns best:

Describe how this player contributes to your family team:

Describe your goals for this player's involvement or independence in his/her life:

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
- A Make a will (you can legally make at will at age 14 in Georgia)
- \Rightarrow Make a contract (such as renting an apartment, buying a car, taking out a loan, etc.)
- \Rightarrow Give or refuse consent for medical treatment
- A 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.
- ➡ Parents must understand that they do not continue to have decision-making authority for their adult child after that child turns 18. Even in cases of severe disability, adults are presumed 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. Types of guardians include: guardian of the person, guardian of the estate, temporary guardian, limited guardian, standby guardian and successor guardian. Parents do not necessarily need to serve as their adult child's guardian. A friend, another family member or a volunteer appointed by the judge can also assume this role.

Another option to consider may include utilizing power of attorney. Having a representative payee for financial matters may be sufficient. Parents must get good information to make informed decisions in this area and discuss these issues with their teen to the greatest extent possible. As in other areas of life, the least restrictive option possible should be seriously considered.

A PARENT'S HEALTH CARE CHECKLIST

QUESTION	YES	NOT YET	FIRST STEPS
Do I know how my teen learns best?			
Can my teen describe his/her special health care needs?			
Do we discuss and demonstrate healthy lifestyle habits as a family?			
Can my teen name his/her doctor?			
Can my teen communicate that he/she is feeling ill?			
Can my teen describe symptoms when feeling ill?			
Do we use a family calendar for tracking appointments, activities, etc.?			
Is my teen involved when I schedule appointments?			
Can my teen schedule appointments on his/her own?			
Do I encourage my teen to give information and answer questions at appointments?			
Have I discussed transitioning to adult care providers with my teen's present providers?			
Do I involve my teen in registering or checking in for appointments (showing insurance/Medicaid card, etc.)?			
Do I involve my teen in filling and refilling prescriptions?			
Is my teen involved in maintaining/ordering monthly supplies, equip- ment or scheduling home care?			
Do I know what insurance or health care coverage will be available to my teen when he/she turns 18?			
If my teen is on my insurance, do I know how long that can continue?			
Have we talked about and made plans for guardianship (none, full, limited)?			
Have we discussed and planned for Power of Attorney for Health Care?			
Do I use formal and/or informal advocacy or supports and is my teen aware of this?			

DAILY LOG

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		

ers or Notes
ed before breakfast
e week t it in carry case near
er before leaving
edication
times to take off
supervisor said f
s and some money
vegetables. Not too
ping this weekend
ı w
sic before going

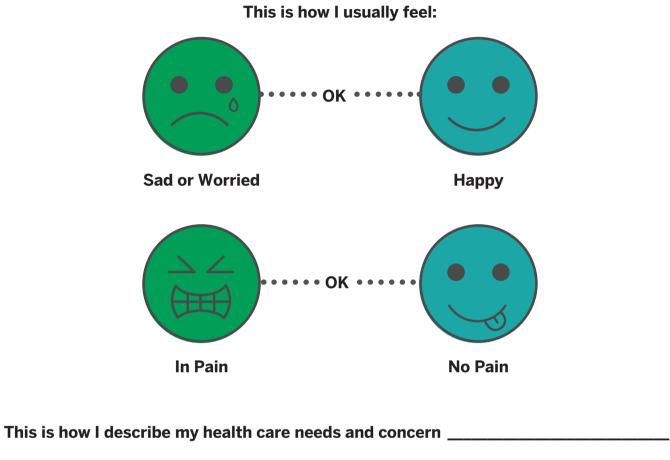
HAVE A GAME PLAN - EVERYONE NEEDS A HEALTHCARE TEAM

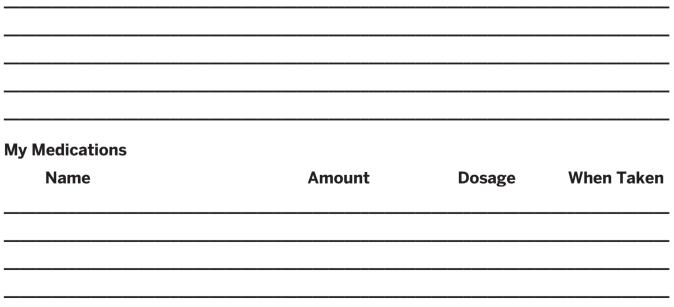
Your Health Care Team			
Transitioning Youth/Young Adult	Remember, in addition to being the patient, your youth/adult child is part of the team.		
Primary Care Doctor			
Specialty Doctor(s)			
Physician Assistant			
Nurse (s)			
Dentist			
Dental Hygienist			
Therapists (physical, occupational, speech/ 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			

SAMPLE CARE PLAN

Name		
I like to be called		
Date of Birth		
Address		
Phone (Home)	(Cell)	
(Work)		
Email		
How I communicate best		
	tion or skills	
What I like to do with my time ((school, work, hobbies, etc.)	

THIS IS HOW I USUALLY FEEL:





HEALTH INFORMATION

My allergies (including latex and/or medication allergies)			
Information on hospitalization and surgeries			
Nutritional Status			
Immunizations (include dates):			
Recent Labs/X-Rays (include date/location):			
Equipment/Supplies/Assistive Technology (include contact information):			
Therapy (include frequency/provider contact information):			

MY HEALTHCARE TEAM





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

Name

Specialty

Phone number

MAKING DECISIONS



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

Name		
Relationship		
Phone (Home)		
(Work)		
Email		
Power of attorney for health care?		
If Yes, Who		and the second
Phone ()		
Conservator/Guardian: Self	Other (nam	ne)
I have a health care plan? Yes	No	and and
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	
Special Health Care Needs Information:	
Chronic Illnesses/Diagnoses/Disabilities	
Equipment/Other	
How I Communicate	
Other Important Stuff	
Medications:	
Name	Dose
Power of attorney for health care? Yes	No
If Yes, Who?	
Phone ()	
Conservator/Guardian? If Yes, Who?	
Phone ()	

<u>HOW TO MAKE AN APPOINTMENT</u>



When you call to make an appointment, you need to have some basic information ready. You should also have your calendar. Fill in as many of the blanks on this form as you can before you make your call. Then you can use it as an outline when you do call. The person answering the phone may be able to help you or may need to transfer your call to someone else. If that happens, you may have to repeat some of the same information.

→ Make your call using this phone number: ______

→ Hello, my name is: ____

(give your first and last name)

 \Rightarrow 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

Follow-up step:

(Date)

(Time)

(example: I will write this appointment on the family calendar right now so I won't forget about it)

_at__

- ⇒ Just in Case: You might need some additional information
 - Your Date of Birth: _____
 - Your Phone Number: _____
 - Name of Insurance Carrier (on card):

Insurance Number (on card): _

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

UPCOMING APPOINTMENT

UPCOMING APPOINTMENT WITH A NEW DOCTOR

Why I am here:		
Important information you should know about my medical history:		
Medications and allergies:		
Past surgeries and hospitalizations:		
Other doctors I have seen:		
How I communicate best:		
Other things I want you to know about me:		
What should I know about you?		
UPCOMING APPOINTMENT WITH MY REGULAR DOCTOR (This is a form to use while you are at an appointment)		
Doctor's Name: Date:		
Why I am here:		
Information that is important for me to remember:		
14		
Do I need any medical tests? (write them here)		
Do I need any new medications or any changes in my medication?(write them here)		
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?		

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HOW TO ARRANGE TRANSPORTATION



HOW TO ARRANGE TRANSPORTATION FOR YOUR APPOINTMENTS?

IF YOU NEED TO SET UP TRANSPORTATION FOR YOUR APPOINTMENTS, YOU MAY BE CALLING A FRIEND OR SOMEONE ELSE WHO DRIVES YOU PLACES. YOU MAY BE CALLING A TRANSPORTATION SERVICE. BE SURE YOU CALL RIGHT AFTER YOU MAKE YOUR APPOINTMENT TO AVOID PROBLEMS. YOU CAN FILL IN THE BLANKS ON THIS FORM AND USE IT AS AN OUTLINE WHEN YOU MAKE YOUR CALL. IF YOU NEED A RIDE AFTER THE APPOINTMENT, SAY SO IN THE SAME CALL.



⇒ Name of Driver or Service:		
Phone Number:		
➡ Hello, my name is:		
→ I need to arrange a ride to a medical app The date and time are	•	
I am going to		
→ 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 with		(write the time here)
If the answer is No, you can ask: Is there someone else you can recomme		· · · ·
✓ I will also need a ride home from the ap It should last	pointment.	the name here)
\Rightarrow Who do I call if there is a problem?		phone number here)
 ⇒ Will I need any paperwork or money? _ ⇒ Thank you. Goodbye. 		e answer here)

HOW TO GET NEW PRESCRIPTION MEDICATIONS



When your doctor wants you to take medication, the prescription may be called in to a pharmacy and you will pick it up. If the doctor gives you a written prescription, you will take it to your pharmacy to get it filled. Take your insurance or Medicaid card when you go to get your medicine. When you call the pharmacy, a person may answer and take the information. Sometimes you may get an answering system that tells you how to give the information the pharmacy needs by pushing certain numbers on the phone. If this is too hard or too confusing, you can usually stay on the phone or push a number given to get help from a person who will take the information from you.

Make sure you understand how to take your medication and any side effects that might happen. You will get written information when you pick up your medication, but ask the pharmacist any questions you may have. If you get home and have a question or concern, call and ask the pharmacist for information over the phone. You can also call your doctor's office and ask to speak to your doctor's nurse. Nurses can also answer a lot of your questions and can check with your doctor if needed.

- ➡ 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?
- \Rightarrow 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:______
- \Rightarrow 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? _____

- \Rightarrow Is there anything else about this medication I should know about?_____

HOW TO GET PRESCRIPTION MEDICATION REFILLS



If there are refills ordered so that you will continue to take the medication, you will need to order refills so you don't run out of the medication. To order a refill on a medication you already have, use the information on your medication bottle. Have the bottle with you or write the information in the blanks on this form before you make your phone call. You can then use this form as an outline for your call. The phone number of the pharmacy is usually on the label on the medication bottle.

When you call the pharmacy, a person may answer and take the information. Sometimes you may get an answering system that tells you how to give the information the pharmacy needs by pushing certain numbers on the phone. If this is too hard or too confusing, you can usually stay on the phone or push a number given to get help from a person who will take the information from you. The number of refills is usually on the lower left part of the label on the medication bottle. If you don't have any more refills left, but still need the medication, the pharmacy will usually call your doctor to get a new prescription. Call to order refills on 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. Mark your calendar to remind yourself of when to re-order.

	Hello, my name is:
	(give your first and last name)
Ę	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?)
4	Is there a co-pay charge? How much? Thank you.

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.

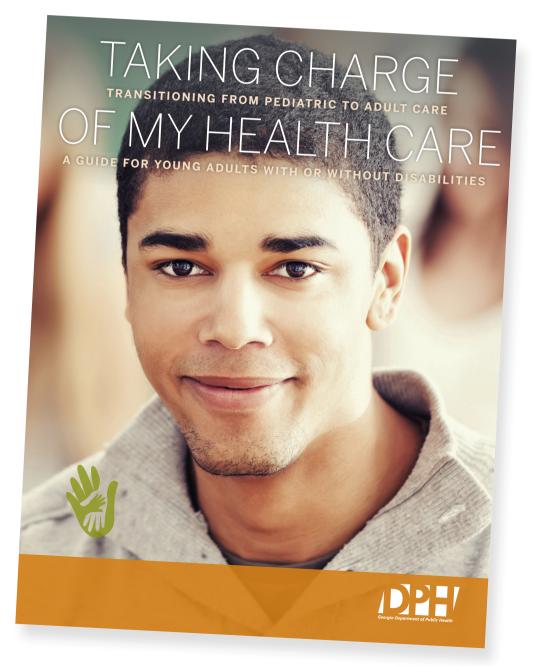
Parents need to read their policies carefully before their young adult reaches 26. Some will allow indefinite continued coverage if the adult child is disabled and the disability occurred before age 18 and the parent continues to provide 50% or more of the adult child's support or maintenance.



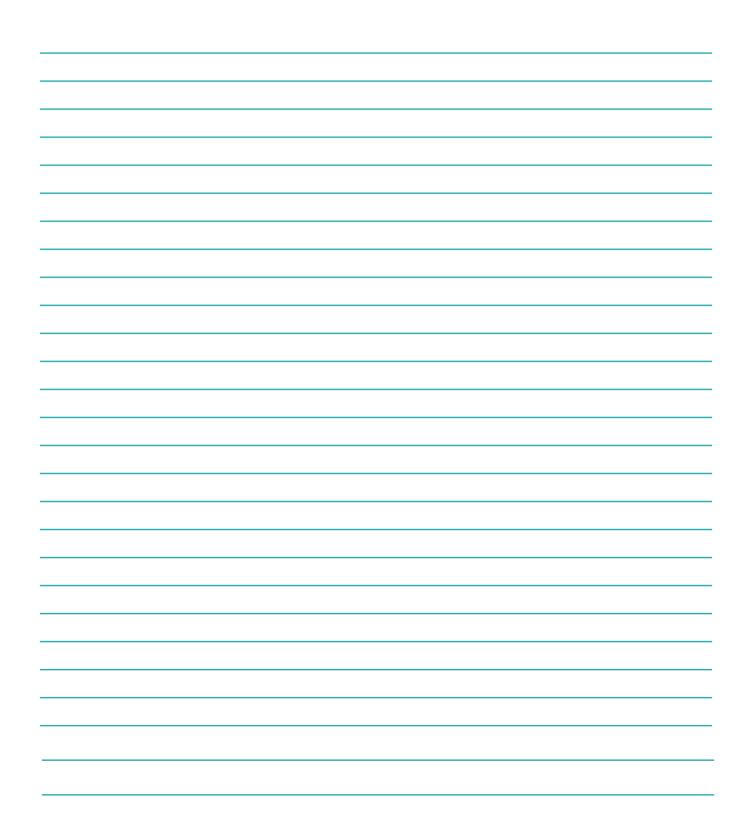
RESOURCES

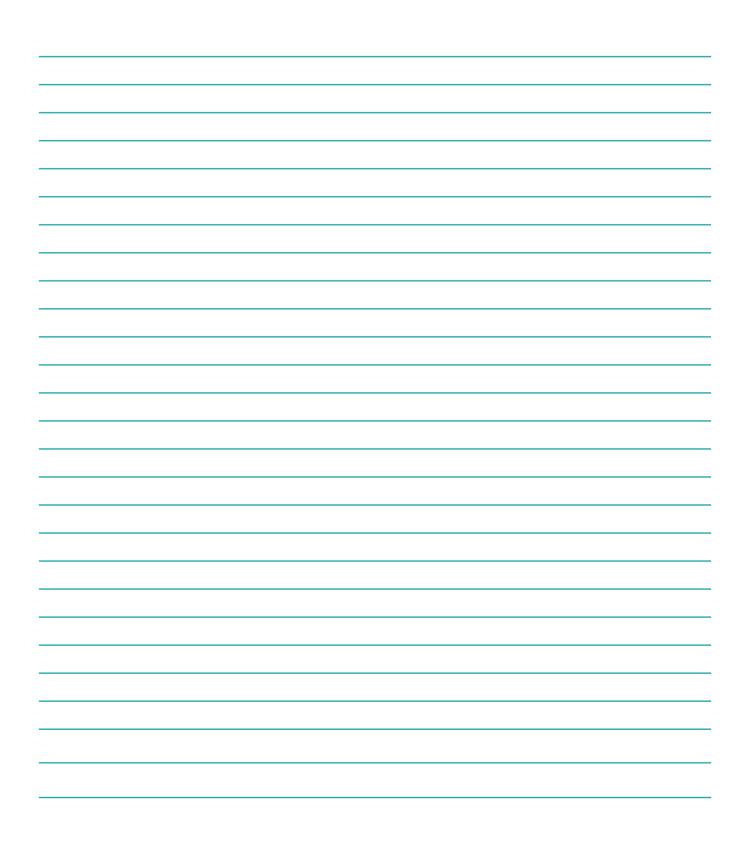


- GEORGIA DEPARTMENT OF PUBLIC HEALTH, TRANSITIONING YOUTH TO ADULT CARE http://dph.georgia.gov/transitioning-youth-adult-care
- TAKING CHARGE OF MY HEALTH CARE BOOKLET https://issuu.com/georgiamaternalandchildhealth/docs/taking_charge_of_my_ health_care_fin

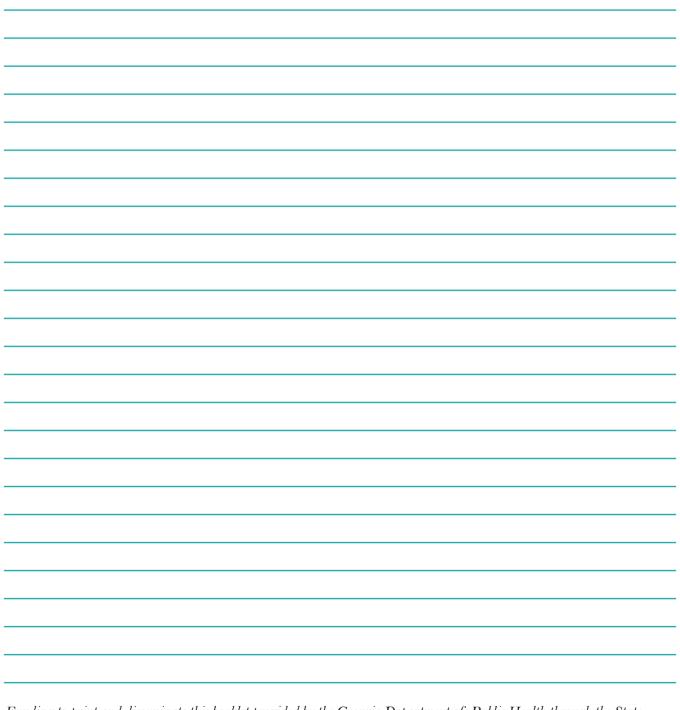


NOTES





NOTES



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PREPARING YOUR ADOLESCENT FOR THE TRANSITION FROM PEDIATRIC TO ADULT HEALTH CARE MOVING FROM HEALTH CARE LEADER TO SUPPORTER

A WORKBOOK FOR PARENTS AND CAREGIVERS



GEORGIA DEPARTMENT OF PUBLIC HEALTH CHILDREN'S MEDICAL SERVICES

http://dph.georgia.gov/cms