

PLANNING FOR YOUR CHILD'S FUTURE:

A Guide for Transitioning to Adult Health Care



South Carolina Department of Health and Environmental Control



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Introduction

Parents are familiar with the many changes their children experience as they grow – their first steps, first words, first day of school, and last day of high school. But what about the last visit to the pediatrician or the first visit to an adult doctor? Many parents and youth do not consider this change until it is suddenly upon them. And this may be even more true for youth and young adults with special health care needs who use the health care system more often.

What is Health Care Transition

Health care transition is the purposeful, planned movement of adolescents and young adults from child-centered to adult-centered medical care. Health Care Transition includes the following skills: your child or young adult making a doctor's appointment, filling a prescription, being aware of their personal and family health histories, and asking questions during an office visit. Transition planning could include asking your child questions about their skills to help manage their own health and assist with developing a medical summary and emergency care plan. The planning should also include discussing changes in privacy and consent that occur at age 18, and discussing your child's or adolescent's future goals. The goal is to establish successful transition between the ages of 18 and 20, allowing your child or adolescent to manage their own care. Parents have a key role to play in helping their youth to learn to manage their health on their own. Below are a few questions that parents can ask their child's doctors:

1. When does my child start to meet with you alone for part of the visit to become more independent in their health care?
2. What does my child need to learn to get ready for adult health care? Do you have a checklist of self-care skills that my child needs to learn?
3. Can I work with you to prepare a medical summary and emergency care plan for my child?
4. Before my child turns 18, what information about privacy and consent do we need to learn about? If my child needs help making health decisions, where can I get information about this?
5. At what age does my child need to change to a new doctor for adults?
6. Do you know any adult doctors for my child to transfer to?

The American Academy of Pediatrics (AAP), advises that parents and their doctors begin to plan for transition as early as age 12. They also advise parents to plan for the move to an adult doctor between ages 14 and 18. Doctors and parents can assist their youth and young adults to manage their own health and health care. Additional questions and resources available on page 10 of this workbook.

Health Care Transition Timeline

Age 12-15

Age 15-16

Age 16-17

Age 18 & Up

According to developmental ability youth can:

- | | | | |
|--|--|--|--|
| <ul style="list-style-type: none"> • Learn about their health condition, medications, and allergies. • Ask their Doctor questions about their health, and at what age their current doctor will no longer care for young adults. | <ul style="list-style-type: none"> • Find out what they know about their health, health care, and family medical history. • Take the Transition Readiness Assessment. • Carry insurance card. • Learn what to do in the event of an emergency. • Begin making appointments. | <ul style="list-style-type: none"> • Make doctor's appointments and see the doctor alone. • Request refill of Medications. • Ask the doctor to talk with them about privacy rights when they turn 18. • Work with their doctor to complete a medical summary (example included in this workbook). • Talk with their parent/ caregiver about the age they wish to transfer to an adult provider. | <ul style="list-style-type: none"> • Explore community resources: ABLE, Vocational Rehabilitation, Legal services, Independent living. • Check eligibility for insurance, SSI, etc. and apply as needed. • Transfer care from pediatric provider to adult provider. • Update their medical summary. • Complete a release of information signed by them if they would like parent/ caregiver to participate in care. |
|--|--|--|--|

According to your child's needs, parents can begin to:

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| <ul style="list-style-type: none"> • Begin preparing your youth for transition of health care from a pediatric provider to an adult provider. • Keep a health record for your youth. Include all medical paperwork. • Encourage your teen to ask their doctor questions about their own health. | <ul style="list-style-type: none"> • Learn about what your teen knows regarding their own health using the Transition Readiness Assessment. • Talk with medical provider about transitioning to adult health care provider (timing, recommendations). | <ul style="list-style-type: none"> • Encourage your teen to make doctor's appointments, request refills of medications, and see the doctor alone. • Work with the doctor and your teen to develop a medical summary. • Explore the option of legal guardianship or the many alternatives if the youth's special need interfere with the ability to make financial and medical decisions. | <ul style="list-style-type: none"> • Encourage your young adult to keep a copy of their medical summary and insurance information with them. • Encourage your young adult to complete the process in transitioning to an adult provider. • Learn if there are additional changes that occur at age 18 for your young adult (health insurance, SSI, etc.) |
|--|---|---|---|

Differences in Adult and Pediatric Providers

Health care for youth is different than health care for adults. In adult care, your youth is in charge of their own care and involve parents/caregivers if they choose. These are some of the changes that happen when you move to adult care.

Please circle any items in the Adult Approach to Care column that you have questions about. Bring this to your next doctor visit to start a conversation about any questions you may have.

Pediatric Care (Where you are now)	Adult Approach to Care (Where you will be)
<ul style="list-style-type: none"> • Your parent/caregiver is with you for most or all of your visit. • Your parent/caregiver helps answer questions and explain your medical conditions, any medicines, and medical history. • Your parent/caregiver is involved in making choices about your care. • Your parent/caregiver helps make appointments and get your medicines. • Your parent/caregiver helps with your care and reminds you to take your medicines. • Your parent/caregiver can see your health information, including test results. • Your parent/caregiver knows your health insurance and pays any charges at the visit. • Your parent/caregiver keeps a record of your medical history and vaccines. • Many pediatric specialists provide both specialty and some primary care. 	<ul style="list-style-type: none"> • You see the doctor alone unless you agree for others to be present. • You answer questions and explain your medical conditions, medicines, and medical history. • You make your own choices about your care, asking your parents/ caregivers as needed. • You make your own appointments and get your medicines. • You take control of your care and take medicines on your own. • Health information is private unless you agree to let others see it. • You keep your health insurance card with you and pay any charges at the visit. • You keep a record of your medical history and vaccines. • Adult specialists often do not provide primary care, so you need to have a primary care doctor along with a specialist.

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Got Transition (GotTransition.org) is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) (U1TMC31756). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government.

Assessing Current Abilities and Needs

Before you and your child/youth can decide what is needed, you both must first determine where you are. What do you have now, what will you need, and who can get it for you? Please take a few minutes to complete the Transition Readiness Assessment on page 8 initially when your child/youth turns 12. This assessment will be completed annually with your Care Coordinator to determine your current transition needs. Your child/youth will also complete an assessment to ensure current needs are being met.

A Plan of Care on will also be completed annually with your Care Coordinator beginning when your child/youth turns 12 to identify concerns or actions required to ensure a successful transition.

Below are a few initial questions for your consideration:

- Do you understand your child's/youth's diagnosis or medical condition?
- What current medical needs does your child/youth have?
- Are there any future medical needs that should be expected?
- How often does your child/youth see the Primary Health Care Doctor for routine visits?
- Does your child/youth see any specialists? If so, how often?
- At what age will your pediatrician discharge your child/youth from their practice?
- Will your child's/youth's doctor assist in completing a medical summary which details your child's/youth's medical conditions, treatment, and history (pages 11 and 12 of this workbook)?
- Are you aware of current adult providers who will be able to manage your child's/youth's needs?
- Does your child currently qualify for Medicaid or Medicare coverage? If so, when will the coverage end?
- Is your child/youth currently receiving SSI? If so, how or when should they reapply?

Let Your Young Adult Take Charge

Let Your Young Adult Take Charge

One of the main differences between pediatric and adult health care services is that pediatric services are focused on the family, while adult services are patient specific.

To begin the transition process, allow your young adult to take charge of their care. This can involve allowing them to register with the front desk, provide insurance cards, schedule appointments with providers, and provide the opportunity for your young adult to be evaluated alone.

Encourage your young adult to ask questions regarding their doctor's visit and to communicate with the physician.

Maximum independence for your young adult should be the goal. By the time your child is 16 or 17 years old, encourage them to call for their own appointments. If they have difficulty speaking on the phone, assist them in finding an alternative way to schedule appointments. Many physicians in South Carolina will now allow you to schedule appointments online, and offer a variety of telehealth options.

Encourage your child to keep track of appointments and refills for prescriptions. This can be done several ways, depending on what suits your young adult's current situation (either via calendar, written down, or via apps that are now available on your smart phone).

Encourage Your Young Adult to be Prepared for Emergencies

Ensure your young adult has their doctor's name, phone number, insurance, and pharmacy information available at all times. Assist them in creating an Emergency Information Form (included on page 11 and 12). Remind your young adult to utilize ICE (In Case of Emergency) if they utilize a cell phone. This is a contact in all cell phones emergency responders will look for.

Finding an Adult Provider to Treat Your Young Adult

Some providers may discharge patients when they turn a certain age. Don't let this happen to your young adult! Start planning at age 16 for your young adult to be transferred to a physician who treats the adult population. Actual transition usually occurs between the ages of **18 and 21**.

You may need assistance in finding a provider who can care for the needs of your young adult. Ask your child's/youth's current provider for suggestions or a referral to an adult provider and/or specialists, and follow up with your care coordinator for assistance.

Insurance Overview

One of the main concerns for children and youth as they transition to adulthood revolves around health insurance.

Currently, under the Affordable Care Act, a youth or adult can remain covered under the parent's insurance up to age 26.

Health Benefits can be obtained through any of the following:

- Employer based coverage
- A plan purchased directly from an insurance agency (not through work)
- A government-sponsored health plan (discussed over the next page): Medicaid, Medicare, TRICARE, or Partners for Healthy Children (PHC).
- Children and Youth with Special Health Care Needs (CYSHCN) Program through age 18 for certain qualifying conditions.

Medicaid

Medicaid is a government program that assists in paying for some or all medical charges for individuals with disabilities or those who may not be able to afford medical care. South Carolina's Medicaid program is Healthy Connections. Eligibility for Health Connections is determined by several factors including age, disability, income, and citizenship. To learn more about Health Connections, please visit scdhhs.gov

Supplemental Security Income (SSI)

SSI is a program run by the Social Security Administration that provides monthly income to individuals who meet the eligibility requirements. Eligibility for SSI is determined if the individual is blind or suffers from a disability affecting everyday life, meets income requirements, is a resident of one of the 50 states, the District of Columbia, or Northern Mariana Islands, is a US Citizen, and meets the additional requirements for the program. For more information, please visit ssa.gov

Special Medicaid Waivers

Special Medicaid Waivers are waivers which provide Medicaid coverage for disabled persons who require intensive support to live at home. South Carolina offers a number of waivers through either the Department of Health and Human Services (DHHS) or the Department of Disabilities and Special Needs (DDSN). If your child/youth requires intensive support to live at home, please visit scdhhs.gov

If you need assistance in applying for a Medicaid Waiver, TEFRA, or other assistance, please contact our partner Family Connection of South Carolina at 1-800-578-8750, or visit their website at familyconnections.org



Partners for Healthy Children (PHC)

Partners for Healthy Children (PHC) provides health insurance plans for children who live in families with income at or below 208% of the Federal Poverty Level. Your child/youth must be under 19 years of age to qualify, a resident of South Carolina, and United States Citizen, and have a Social Security number. For more information, please visit scdhhs.gov

South Carolina's Children and Youth with Special Health Care Needs (CYSHCN)

South Carolina's Children and Youth with Special Health Care Needs (CYSHCN) is a federally and state funded Title V program whose mission is to provide support to assure optimal functioning of children and youth with special health care needs in their homes, schools, and communities. CYSHCN payment program assists with medical needs through the 18th birthday. Care Coordination services can be provided through the 21st birthday. Transition services are available up to age 26. Eligibility requirements for the CYSHCN program include South Carolina residency, US Citizenship, qualifying medical diagnosis, and specific income requirements.

For more information please contact the regions listed below:

Charleston: 843-953-1264

Columbia, SC: 803-576-2800

Florence, SC: 843-661-4835

Greenville, SC: 864-372-3064

Parent's Transition Readiness Assessment

Please fill out this form to help us see what your child already knows about their health and the areas you think they want to learn more about. After you complete the form, you can ask your child to share their answers from their completed form, and you can compare them. Your answers may be different. Your child's doctor will help you work on steps to increase your child's health care skills.

Youth name _____ Parent/Caregiver Name _____

Youth Date of birth _____ Today's date _____

TRANSITION IMPORTANCE & CONFIDENCE

Please circle the number that best describes how you feel now.

The transfer to adult health care usually takes place between the ages of 18 and 22. How important is it to your child to move to a doctor who cares for adults before age 22?

0 1 2 3 4 5 6 7 8 9 10

How confident do you feel about your ability to move to a doctor who cares for adults before age 22?

0 1 2 3 4 5 6 7 8 9 10

MY CHILD'S HEALTH & HEALTH CARE

Please circle the number that best describes how you feel now.

	NO	I WANT TO LEARN	YES
My child can explain my health needs to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to ask questions when they do not understand what their doctor says.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows their allergies to medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows our family medical history.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows to talk to the doctor instead of me talking for them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child sees the doctor on their own during an appointment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows and how to get emergency care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows where to get medical care when the doctor's office is closed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	NO	I WANT TO LEARN	YES
My child carries important health information with them every day (e.g., insurance card, emergency contact information).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows that when they turn 18, they have full privacy in their health care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows at least one other person who will support them with their health needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to make and cancel their own doctor appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to get a summary of their medical information (e.g., online portal).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to fill out medical forms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to get a referral if they need it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows what health insurance they have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows what they need to do to keep their health insurance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child talks with their parent/caregiver about the health care transition process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to find their doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows a way to get to their doctor's office.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

MY CHILD'S MEDICINES

If they do not take any medicines, please skip this section.

My child knows their own medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows when they need to take their medicines without someone telling them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to refill their medicines if and when they need to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Medical Summary and Emergency Care Plan

Contact Information:

Preferred name _____ Legal name _____
Date of birth _____
Preferred language _____
Address _____
Cell phone/ Home phone _____ Best time to reach _____
Email _____ Best way to reach text phone email
Health insurance and/or plan _____ Group and ID numbers _____
Parent/Caregiver name _____ Relationship _____ Phone _____

Emergency Care Plan:

- Limited decision-making legal documents available, if needed
- Disaster preparedness plan completed

Emergency Contact _____ Relationship _____ Phone _____
Preferred emergency care location _____

Allergies:

Allergies _____ Reaction _____
Allergies _____ Reaction _____
Allergies _____ Reaction _____

Health Care Clinicians:

Name/Specialty _____
Clinic or Facility Name/Phone Number _____

Diagnoses and Current Problems:

Problem	Details and Recommendations
<input type="checkbox"/> Primary Diagnosis _____	
<input type="checkbox"/> Secondary Diagnosis _____	
<input type="checkbox"/> Behavioral _____	
<input type="checkbox"/> Communication _____	
<input type="checkbox"/> Feeding & Swallowing _____	
<input type="checkbox"/> Hearing/Vision _____	
<input type="checkbox"/> Learning _____	
<input type="checkbox"/> Orthopedic/Musculoskeletal _____	
<input type="checkbox"/> Physical Anomalies _____	
<input type="checkbox"/> Respiratory _____	
<input type="checkbox"/> Sensory _____	
<input type="checkbox"/> Stamina/Fatigue _____	
<input type="checkbox"/> Other _____	

Resources

- South Carolina Department of Health and Environmental Control, Children and Youth with Special Health Care Needs (CYSHCN), scdhec.gov/health/child-teen-health/services-children-special-health-care-needs
- Got Transition, The National Alliance to Advance Adolescent Health, gottransition.org/about/index.cfm
- Family Connections of South Carolina, SC Parent-to-Parent Organization, familyconnectionsc.org
- South Carolina Department of Health and Human Services, scdhhs.gov
- Government Benefits, a cross-governmental collaboration between multiple Federal agencies, benefits.gov
- Georgia Department of Public Health, Children's Medical Services, Transitioning Youth to Adult Care, dph.georgia.gov/transitioning-youth-adult-care

Credits/Acknowledgements

- Georgia Department of Public Health, Children's Medical Services, Transitioning Youth to Adult Care, dph.georgia.gov/transitioning-youth-adult-care
- Rhode Island Department of Health, Graduate to Adulthood, health.ri.gov/specialneeds/about/adolescenttransition
- Ministry of Children and Family Development, British Columbia, chs.ca/sites/default/files/uploads/your_future_now.pdf
- Health Transition Wisconsin, healthtransitionwi.org/youth-families
- North Carolina Department of Health and Human Services, A Youth Guide to Transition from Pediatric to Adult Health Care, sys.mahec.net/media/brochures/youth_guide.pdf

