

PLANNING FOR YOUR CHILD'S FUTURE:

A Guide for Transitioning to Adult Health Care



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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 provider? Many parents and youth do not consider this change until it is suddenly upon them. 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 for youth includes the following skills:

- making a doctor's appointment,
- filling a prescription,
- being aware of their personal and family health histories,
- asking questions during their visit,
- assessing your child's skills to help manage their own health,
- developing a medical summary and emergency care plan,
- discussing changes in privacy and consent that occur at age 18,
- discussing their future goals.

The goal is to establish successful transition between the ages of 18 and 20, allowing your youth or young adult to manage their own care. Parents have a key role to play in helping their youth learn to manage their health on their own. Below are a few questions that parents can ask their child's providers:

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 transition to a new doctor for adults?
6. Do you know any adult doctors for my child to transition 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 transition 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:			
• 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.	• 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.	• 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 transition to an adult provider.	• 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:			
• 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 youth to ask their doctor questions about their own health.	• Learn about what your youth knows regarding their own health using the Transition Readiness Assessment. • Talk with the youth's current medical provider about transitioning to adult health care provider (timing, recommendations).	• Encourage your youth to make doctor's appointments, request refills of medications, and see the doctor alone. • Work with the doctor and your youth to develop a medical summary. • Explore the option of legal guardianship or the many alternatives if the youth's special need interferes with their ability to make financial and medical decisions.	• 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)
• 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. • Your parent/caregiver keeps a record of your medical history and vaccines. • Many pediatric specialists provide both specialty and some primary care.	• 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. • 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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Assessing Current Abilities and Needs

Before you and your 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. This assessment will be completed annually with your Care Coordinator to determine your current transition needs. Your youth will also complete an assessment to ensure their current needs are being met.

A Plan of Care will also be completed annually with your Care Coordinator to identify concerns or actions required to ensure a successful transition.

Below are a few initial questions for your consideration:

- Do you understand your youth's diagnosis or medical condition?
- What current medication does your youth take?
- Are there any future medical needs that should be expected?
- How often does your youth see their provider for routine visits?
- Does your youth see any specialists? If so, who does your youth see and how often?
- At what age will your pediatrician transition your youth from their practice?
- Will your youth's provider assist in completing a medical summary which details your youth's medical conditions, treatment, and history (pages 12 and 13 of this workbook)?
- Are you aware of current adult providers who will be able to manage your youth's health care needs?
- Does your youth currently have 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, providing insurance cards, scheduling appointments with providers, and seeing the provider alone.

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

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 youth 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 12 and 13). Remind your young adult to utilize ICE (In Case of Emergency) if they have a cell phone. This is a contact in all cell phones that emergency responders will look for.

Finding an Adult Provider to Treat Your Young Adult

Some providers may transfer patients when they turn a certain age. Don't let this happen to your youth or young adult! Start planning at age 16 for your youth to transition 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, Affordable Care Act (ACA) 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 Healthy Connections is determined by several factors including age, disability, income, and citizenship. To learn more about Healthy 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:

Public Health Region	CYSHCN Office Location	Phone
Upstate	Greenville County Health Department 352 Halton Rd. Greenville, SC 29607	(864) 372-3065 (864) 372-3063
Midlands	Richland County Health Department 2000 Hampton St. Columbia SC 29204	(803) 576-2800
Pee Dee	Florence County Health Department 145 East Cheves St. Florence, SC 29506	(843) 673-6607
	Horry County Health Department 1931 Industrial Park Rd. Conway, SC 29526	(843) 915-8806
Lowcountry	Charleston County Health Department 3685 Rivers Ave. Suite 201 North Charleston, SC 29405	(843) 953-1257 (843) 953-4514

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 youth's 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 check the box that best describes how you feel now.

NO

I WANT TO
LEARN

YES

My child can explain their health needs to others.

☐☐☐

My child knows how to ask questions when they do not understand what their doctor says.

☐☐☐

My child knows their allergies to medicines.

☐☐☐

My child knows our family medical history.

☐☐☐

My child knows to talk to the doctor instead of me talking for them.

☐☐☐

My child sees the doctor on their own during an appointment.

☐☐☐

My child knows when and how to get emergency care.

☐☐☐

My child knows where to get medical care when the doctor's office is closed.

☐☐☐

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

MY CHILD'S MEDICINES

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

	NO	I WANT TO LEARN	YES
My child knows their own medicines.	☐	☐	☐
My child knows when they need to take their medicines without someone telling them.	☐	☐	☐
My child knows how to refill their medicines if and when they need to.	☐	☐	☐

Questions To Ask Your Doctor About Transitioning To Adult Health Care

DURING YOUR CHILD'S ADOLESCENT YEARS:

- ☐ How do I best prepare my child to meet with you alone for part of their visit to become more independent when it comes to their own health and health care? When will they start to have time alone with you?
- ☐ 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?
- ☐ Can I work with you to prepare a medical summary for my child and, if needed, a plan for what to do in case of an emergency?
- ☐ Before my child turns 18 and becomes a legal adult, what information about privacy and consent do we need to learn about? If my child needs help with making health decisions, where can I get information about this?
- ☐ At what age does my child need to change to a new doctor for adult health care?

BEFORE TRANSFERRING TO A NEW ADULT DOCTOR:

- ☐ Do you have any suggestions of adult doctors for my child to transfer to?
- ☐ What kinds of doctors in adult care does my child need (e.g., a primary care doctor, a specialist, a behavioral health provider)?
- ☐ Will you send my child's medical summary to the new adult doctor?
- ☐ If needed, will you communicate with the new adult doctor about my child's care?
- ☐ Before the initial visit is made to the new adult doctor, will you still refill their medicines and treat them for acute care needs?

*The American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians recommend that all youth and young adults work with their doctor or other health care provider to build independence and prepare for the transition to adult care. For more information about transition, please visit gottransition.org/youth-and-young-adults and gottransition.org/parents-caregivers.

[illegible]

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

- | | |
|---|--|
| ☐ Primary Diagnosis _____ | |
| ☐ Secondary Diagnosis _____ | |
| ☐ Behavioral _____ | |
| ☐ Communication _____ | |
| ☐ Feeding & Swallowing _____ | |
| ☐ Hearing/Vision _____ | |
| ☐ Learning _____ | |
| ☐ Orthopedic/Musculoskeletal _____ | |
| ☐ Physical Anomalies _____ | |
| ☐ Respiratory _____ | |
| ☐ Sensory _____ | |
| ☐ Stamina/Fatigue _____ | |
| ☐ Other _____ | |

Medications:

Medication	Dose	Frequency	Medication	Dose	Frequency

Prior Surgeries, Procedures, And Hospitalizations

Date: _____ Surgery/Procedure/Hospitalization _____

Date: _____ Surgery/Procedure/Hospitalization _____

Date: _____ Surgery/Procedure/Hospitalization _____

Baseline

Vital Signs:

Height

Weight

RR

HR

BP

Neurological status: _____

Most Recent Labs And Radiology

Test	Result	Date	Test	Result	Date
------	--------	------	------	--------	------

Equipment, Appliances, And Assistive Technology

☐ Gastrostomy

☐ Tracheostomy

☐ Suctions

☐ Nebulizer

☐ Communication Device

☐ Adaptive Seating

☐ Wheelchair

☐ Orthotics

☐ Crutches

☐ Walker

Monitors:

☐ Apnea

☐ O2

☐ Cardiac

☐ Glucose

Youth signature

Date

Print name

Phone

Parent/Caregiver signature

Date

Print name

Phone

Clinician/Care staff signature

Date

Print name

Phone

Resources

- South Carolina Department of Public Health, Children and Youth with Special Health Care Needs (CYSHCN), dph.sc.gov/health-wellness/child-teen-health/children-and-youth-special-health-care-needs-cyshcn
- Got Transition, The National Alliance to Advance Adolescent Health, gottransition.org
- Family Connection of South Carolina, SC Parent-to-Parent Organization, familyconnections.sc.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/Acknowledgments

- 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/special-needs/adolescent-health-transition-program
- 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



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