

PLANNING FOR YOUR FUTURE:

A Guide for Transitioning to Adult Health Care



South Carolina Department of Health and Environmental Control



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Introduction

Moving into adulthood is exciting, but you may experience challenges. As you explore and experience new opportunities, changes in your life will be expected. You will need to make decisions about your future, including your health. Because the ability to manage one's health and wellness is critical to your wellbeing, planning your health and future goals goes hand in hand. Decisions about your future can be tough, but this guide will help you plan ahead and overcome challenges that may occur. This checklist provides information and resources about health insurance coverage, self-care, health care transition, and decision-making.

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.

What do I need to know?

- Every young adult transitions to adult care, and most to a new doctor(s), usually between ages 18 and 21.
- Adult-centered care is different from pediatric care. Parents and family are no longer in charge after age 18 - you are. Finding an adult doctor who meets your needs can take some time.
- If you go to a pediatrician, find out when you will have to switch to an adult doctor, and ask if your doctor can help you find a new doctor.
- Talk to your doctor's office staff to make sure your medical information is sent to your new doctor.
- Ask your new adult provider about the services they provide and their costs, as well as the insurance plans they accept.

Decision Making

Decision-making is a skill that requires practice and a variety of experiences. Having this skill will allow you to choose the best course of action to take care of your health and well-being in partnership with your health care providers.

What happens when I turn 18?

When you turn 18, you are in charge of making your own health care decisions and the only one that can access your medical information, unless other plans are made. If you want to have your family or others involved in making your health care decisions or knowing your medical information, you will need to give written permission to your health care providers.

There are a range of options for assistance in decision-making after age 18, ranging from the least restrictive (signed consent form at doctor's office) to the most restrictive (legal guardianship). Another option to consider is supported decision-making, which allows you to direct your own health care with assistance from others whom you trust to help you understand and make decisions for yourself. It is best to consider these options well before age 18.

If you need support with making health care decisions, become familiar with available resources as early as possible. Disability groups in your state can help guide you to free or inexpensive legal resources.

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:

- | | | | |
|---|--|---|--|
| <ul style="list-style-type: none"> • Begin preparing their youth for transition of health care from a pediatric provider to an adult provider. • Keep a health record for their youth. Include all medical paperwork. • Encourage their teen to ask their doctor questions about their own health. | <ul style="list-style-type: none"> • Learn about what their 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 their teen to make doctor's appointments, request refills of medications, and see the doctor alone. • Work with the doctor and their 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 their young adult to keep a copy of their medical summary and insurance information with them. • Encourage their young adult to complete the process in transitioning to an adult provider. • Learn if there are additional changes that occur at age 18 for their 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, you are in charge of your own care and involve your parents/caregivers if you 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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Assessing Current Abilities and Needs

Before you can decide what is needed, you 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 you turn 14 years old. This assessment will be completed annually with your Care Coordinator to determine your current transition needs.

A Plan of Care on will also be completed annually with your Care Coordinator initially when you turn 14 years old to identify concerns or actions required to ensure a successful transition.

Below are a few initial questions for your consideration:

- Do you understand your diagnosis or medical condition?
- What current medical needs do you have?
- Are there any future medical needs that should be expected?
- How often do you see your Primary Health Care Doctor for routine visits?
- Do you see any specialists? If so, how often?
- At what age will your pediatrician discharge you from their practice?
- Will your doctor assist in completing a medical summary which details your medical condition, treatment, and history (pages 12 and 13 of this workbook)?
- Are you aware of current adult providers who will be able to manage your needs?
- Do you currently qualify for Medicaid or Medicare coverage? If so, when will the coverage end?
- Are you currently receiving SSI? If so, how or when should you reapply?

Take Charge of Your Healthcare

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, you must take charge of your care. This can involve you registering with the front desk, presenting insurance cards, scheduling appointments with providers, and seeing the doctor alone.

Ask questions regarding your doctor's visit and communicate openly with the physician.

By the time you are 16 or 17, try calling for your own appointments. If you have difficulty speaking on the phone, find 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.

Telehealth provides the opportunity to visit your doctor for routine scheduled visits or if you are sick, virtually, through a phone call or through a computer. The Medical University of South Carolina, PRISMA Midlands and Upstate, and McLeod Health all provide telehealth appointments for their patients. Please note, however, that there are some appointments where you would need to see your Doctor face-to-face for evaluation, but this is another important factor to keep in mind when choosing a provider and taking charge!

Keep track of appointments and refills for prescriptions. This can be done several ways, depending on what suits you (either via calendar, written down, or via apps that are now available on your smart phone).

Be Prepared for Emergencies

Ensure you have your doctor's name, phone number, insurance, and pharmacy information available at all times. Create and update an Emergency Information Form (included on pages 12 and 13). Utilize ICE (In Case of Emergency) if you have a cell phone. This is a contact in all cell phones emergency responders will look for.

Find an Adult Provider to Treat You

Some providers may discharge patients when they turn a certain age. Don't let this happen to you! Start planning at age 14 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 your needs. Ask your current provider, care coordinator, or parent for suggestions or a referral to an adult provider and/or specialists.

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

Transition Readiness Assessment for Youth

Please fill out this form to help us see what you already know about your health, how to use healthcare, and the areas you want to learn more about . If you need help with this form, please ask your parent/caregiver or doctor.

Preferred name_____ Legal Name_____

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 you 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 HEALTH & HEALTH CARE

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

	NO	I WANT TO LEARN	YES
I can explain my health needs to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to ask questions when they do not understand what their doctor says.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my allergies to medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my family medical history.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I talk to the doctor instead of my parent/caregiver talking for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I see the doctor on my own during an appointment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know when and how to get emergency care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know 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
I carry important health information with me every day (e.g., insurance card, emergency contact information).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know that when I turn 18, I have full privacy in my health care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know at least one other person who will support me with my health needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know hot to make and cancel my own doctor appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to get a summary of my medical information (e .g ., online portal).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to fill out medical forms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to get a referral if I need it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what health insurance I have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what I need to do to keep my health \ insurance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I talk with my parent/caregiver about the health care transition process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to find my doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a way to get to my doctor's office.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

MY MEDICINES

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

I know my own medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know when I need to take my medicines without someone telling me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to refill my medicines if and when I need to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Questions To Ask Your Doctor About Transitioning To Adult Health Care

DURING YOUR ADOLESCENT YEARS:

- ☐ When do I start to meet with you on my own for part of the visit to become more independent when it comes to my own health and health care?
- ☐ What do I need to learn to get ready for adult health care? Do you have a checklist of self-care skills that I need to learn?
- ☐ Can I work with you to prepare a medical summary for me and, if needed, a plan for what to do case of an emergency?
- ☐ When I turn 18, what information about privacy and consent do I need to know about? If I need help with making health decisions, where can I get information about this?
- ☐ At what age do I need to change to a new doctor for adult health care?
- ☐ Do you have any suggestions of adult doctors to transfer to?

BEFORE MAKING THE FIRST APPOINTMENT TO A NEW ADULT DOCTOR:

- ☐ Do you take my health insurance? Do you require any payment at the time of the visit?
- ☐ Where is your office located? Is there parking or is it near a metro/ bus stop?
- ☐ What are your office hours, and do you have walk-in times?
- ☐ What is your policy about making and cancelling appointments?
- ☐ How will I be able to communicate directly with the doctor after my visit or in the evenings?
- ☐ If needed, can the new adult doctor help me find adult specialty doctors?

BEFORE THE FIRST VISIT TO THE NEW ADULT DOCTOR:

- ☐ Did you receive my medical summary from my pediatric doctor? (Call your pediatric doctor to remind them to send the medical summary before your first visit to the new adult doctor.)
- ☐ What should I bring to the first visit?
- ☐ Who can help me when you are not available?

Notes:

*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.

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 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

