



A FAMILY TOOLKIT: PEDIATRIC-TO-ADULT HEALTH CARE TRANSITION

Developed by Got Transition[®] and its
National Health Care Transition
Family Advisory Group

ABOUT GOT TRANSITION®

Got Transition® is a program of The National Alliance to Advance Adolescent Health and is funded through a cooperative agreement from the federal Maternal and Child Health Bureau, Health Resources and Services Administration. Its aim is to improve transition from pediatric to adult health care through the use of innovative strategies for health care professionals and youth, families, and caregivers. For more health care transition resources and information about Got Transition, please visit GotTransition.org. For more information about The National Alliance to Advance Adolescent Health, please visit TheNationalAlliance.org.

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INTRODUCTION

Three major professional organizations – American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians – recommend that all youth receive pediatric-to-adult health care transition (HCT) services. Yet, national data consistently show that the majority of youth with and without special health care needs are not receiving needed HCT support from their health care providers.^{1,2} According to the 2017/2018 National Survey of Children’s Health, 81% of youth with special health care needs and 86% of youth without special health care needs do not receive transition preparation services.² Youth and families report many barriers to transition, which include feeling unprepared to move to a new doctor and manage their own care, anxiety about leaving their current doctor, difficulty finding a new adult doctor, and understanding the adult health care system.¹

This toolkit was developed for families to use during pediatric-to-adult HCT and includes resources for both parents/caregivers and youth/young adults. The next page provides a summary of the tools that are included. These tools can be used to better prepare youth and families for the transition to adult care. This toolkit can be downloaded for free on Got Transition’s website at GotTransition.org.

¹ White PH, Cooley WC, Transitions Clinical Authoring Group, et al. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018;142(5):e20182587.

² Got Transition. *State, Region, and National Health Care Transition Performance for Youth With and Without Special Health Care Needs: The National Survey of Children’s Health 2017-2018*. Washington, DC: Got Transition, 2018.

SUMMARY OF HEALTH CARE TRANSITION TOOLS

This toolkit has a set of resources for you to use as you work with your youth during the transition from pediatric to adult health care.

This toolkit includes two **Health Care Transition (HCT) Timelines** (pages 3-4), one for you and one for your youth. Each one has steps to take, starting at age 12, to prepare your youth to take charge of their own health and health care.

The **Parent Guide** (page 5) is a summary of clinical recommendations from three major professional organizations – American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians – on HCT for youth with and without special health care needs.

The **Questions to Ask Your Doctor** (pages 6-7) are questions for you and your youth to ask while getting ready to move to a new doctor and before making the first visit.

Changing Roles (page 8) shows how the roles of you and your youth change as your youth takes more control of their own health and health care. If you think you need legal decision-making support, the **Charting the Life Course** (page 9) tool – created by the University Center for Excellence in Developmental Disabilities at the University of Missouri-Kansas City Institute for Human Development – can be a useful tool for beginning the conversation with your youth about decision-making support needs in six areas: daily life and employment, healthy living, social and spirituality, safety and security, community living, and citizenship and advocacy.

The **Turning 18** tip sheet (page 11) shares some changes that happen when your youth turns 18 and is a legal adult. Two more tools show the differences between pediatric and adult care. The **Planning to Move from Pediatric to Adult Care** tool (page 12) is for youth. It shows how their care will change once they move to an adult approach to care, shares some thoughts from youth and young adults, and has tips to get ready for the change. **System Differences** (page 14) also has information about the major differences between pediatric and adult care.

To learn about your youth's knowledge about taking care of their own health, have them take the **Transition Readiness Assessment** on page 15. You can also take the readiness assessment on page 16 and compare your answers. Readiness assessments for youth with intellectual/developmental disabilities and their parents/caregivers start on page 17. Your youth can also take an online **Health Care Transition Quiz** (page 21) that was created by Got Transition's National Youth and Young Adult Advisory Group as another test of how ready they are to transition to adult care.

For more resources, visit GotTransition.org or contact info@gottransition.org.

Health Care Transition Timeline

for Youth and Young Adults

Age 12-13

- Learn about your health condition, medications, and allergies.
- Ask your doctor questions about your health.
- Ask your doctor if and at what age they no longer care for young adults

Age 14-15

- Find out what you know about your health, health care, and family medical history. Both you and your parent/caregiver can take Got Transition's Transition Readiness Assessments* and discuss this together and with the doctor.
- Carry your own health insurance card.
- Learn more about your health and what to do in case of an emergency.
- Practice making a doctor's appointment and ordering prescription refills (either by phone, online, or through an app).
- Begin to see the doctor alone for part of the doctor's visit to help gain independence in managing your health and health care.

Age 16-17

- Make doctor's appointments, see the doctor alone, ask the doctor any questions you have, and refill medications.
- Ask the doctor to talk with you about your privacy rights when you turn 18.
- Work with your doctor to make a medical summary. Keep a copy for yourself.
- Before you turn 18 and become a legal adult, figure out if you will need help making health care decisions. If so, ask your Family Voices chapter for local resources.
- Talk with your parent/caregiver about the age you want to transfer to a new doctor for adult care.

Age 18-21

- You are a legal adult at age 18 and are legally responsible for your care. Parents/caregivers cannot access your medical information or be in the doctor's visit unless you agree.
- Work with your current doctor to find a new adult doctor, if needed. Make sure that the new doctor accepts your health insurance.
- Update your medical summary with your doctor. Have your doctor send this to your new adult doctor. Keep a copy for yourself.
- Call your new adult doctor to schedule the first appointment. Make sure the new office has your medical information, and learn if there are any charges at the visit.
- Learn if there are additional changes at 18 that affect you (e.g., health insurance, Social Security Income).

Age 22-25

- Continue to get care from your adult doctor, learn to manage your health and health care, and update your medical summary.
- Be sure to stay insured. If you change your health insurance, make sure your doctor takes your insurance, and learn if there are any charges at the visit.

*For a Transition Readiness Assessment for youth, visit <https://www.gottransition.org/resourceGet.cfm?id=224> and for a version for parents/caregivers, visit <https://www.gottransition.org/resourceGet.cfm?id=225>.

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Health Care Transition Timeline

for Parents/Caregivers

Age 12-13

- Help your teen learn about their own health condition, medications, and allergies.
- Encourage your teen to ask their doctor questions about their own health.
- Ask your teen's doctor if and at what age they no longer care for young adults.

Age 14-15

- Learn what your teen knows about their own health, health care, and family medical history. Both you and your teen can take Got Transition's Transition Readiness Assessments* and discuss this together and with the doctor.
- Have your teen carry their own health insurance card.
- Help your teen learn more about their own health and what to do in case of an emergency.
- Help your teen practice making a doctor's appointment and ordering prescription refills (either by phone, online, or through an app).
- Encourage your teen to see the doctor alone for part of the doctor's visit to help gain independence in managing their own health and health care.

Age 16-17

- Encourage your teen to make doctor's appointments, see the doctor alone, ask the doctor questions they may have, and refill medications.
- Ask the doctor to talk with your teen about their privacy rights when they turn 18.
- Work with your teen and the doctor to make and share a medical summary.
- Before your teen turns 18 and becomes a legal adult, figure out if they will need help making health care decisions. If so, ask your Family Voices chapter for local resources.
- Talk with your teen about the age they want to transfer to a new doctor for adult care.

Age 18-21

- At age 18, your child is a legal adult and legally responsible for their care. You cannot access their medical information or be in the doctor's visit unless your young adult agrees or certain legal forms have been completed.
- If you need local resources on supported decision-making, ask your Family Voices chapter.
- Learn if there are additional changes at 18 that affect your young adult (e.g., health insurance, Social Security Income).
- Encourage your young adult to ask their current doctor to find a new adult doctor. Make sure that the new doctor accepts your young adult's health insurance, and help them learn if there are any charges at the visit.
- Encourage your young adult to keep a copy of their medical summary and always carry their health insurance information with them.

Age 22-25

- Encourage your young adult to get care from their adult doctor, learn to manage their own health and health care, and update their medical summary.
- Encourage your young adult to stay insured. If they change health insurance, encourage them to make sure their doctor takes their insurance and learn if there are any charges at the visit.

*For a Transition Readiness Assessment for youth, visit <https://www.gottransition.org/resourceGet.cfm?id=224> and for a version for parents/caregivers, visit <https://www.gottransition.org/resourceGet.cfm?id=225>.

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PREPARING FOR THE TRANSITION FROM PEDIATRIC TO ADULT HEALTH CARE: PARENT GUIDE

Parents are familiar with the many transitions 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? What about the planning that might make that transition less stressful and more successful? Many parents and youth do not consider this transition 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.

The American Academy of Pediatrics (AAP), along with the American Academy of Family Physicians (AAFP) and the American College of Physicians (ACP) recently updated their recommendations for this important transition. In 2018 they published “[Supporting the Transition of Health Care from Adolescence to Adulthood in the Medical Home](#).” This clinical report offers guidance for pediatric and adult providers to help youth and parents gain skills to manage their own health as youth move to adult care.

The 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. These skills include making an appointment and filling a prescription. It also includes knowing their personal and family health histories and asking questions during an office visit. During these years, transition planning could include asking the youth questions about their skills to manage their own health and making and sharing a medical summary and emergency care plan. The planning should include discussing changes in privacy and consent that happen at age 18 and preparing a plan of care with youth on their transition goals. The goal is to have this transition happen sometime between age 18 and the early 20s.

Health care transition may be different for youth and young adults with special needs. That includes those with serious chronic medical or behavioral needs and those with developmental or intellectual disabilities. These young adults may require more in-depth planning and on-going support because a variety of specialists can be involved. If the young adult will require help with health care decisions, legal plans for this must be in place by age 18.

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?

More information about transition to adult health care for youth, parents and guardians, and health care clinicians can be found at GotTransition.org.

The AAP, AAFP, and ACP would like all youth to be as ready and able as possible to manage their own health care needs and to navigate health care services throughout their lives. To build self-care skills, a structured process of planning achieved through a partnership between doctors, youth, and parents is key.

FOR YOUTH AND YOUNG ADULTS: 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/youthfamilies.



FOR PARENTS/CAREGIVERS:

QUESTIONS TO ASK YOUR CHILD'S 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?

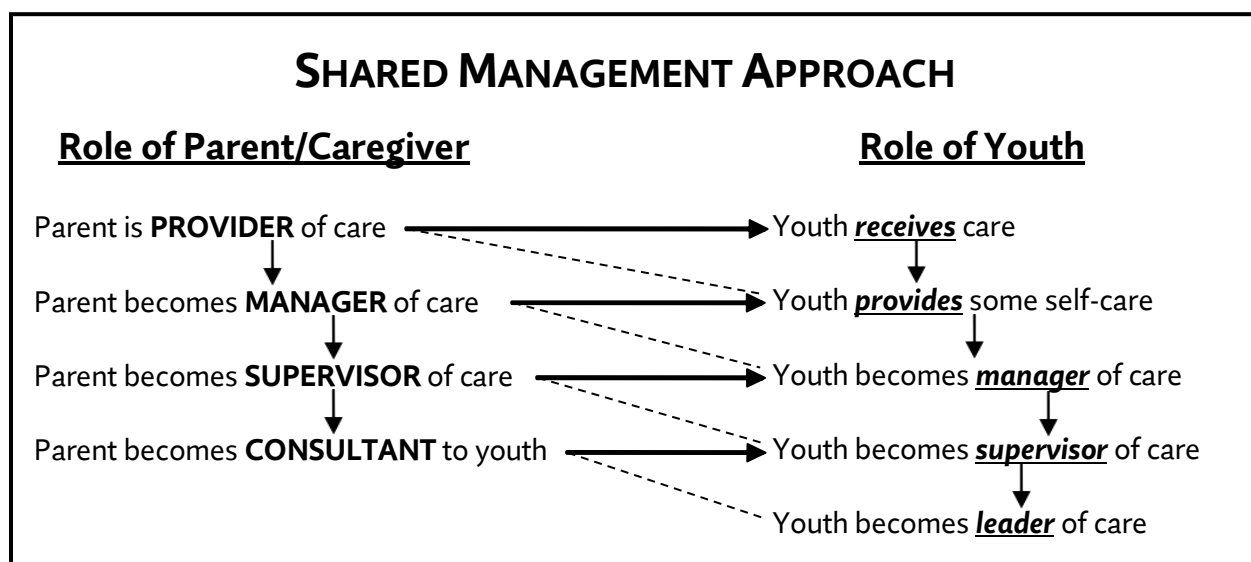
NOTES: _____

*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/youthfamilies.



WHAT ARE THE CHANGING ROLES OF PARENTS/CAREGIVERS AND YOUTH IN THE TRANSITION PROCESS?

The goal of pediatric-to-adult health care transition (HCT) is to improve the ability of youth and young adults to manage their own health and effectively use health services, and the role of parents/caregivers is to support this gradual movement from overseeing care for the youth to becoming a consultant (answering questions when asked) to the young adult around their health and health care. This is called a shared management approach and is shown below, displaying these changing roles. Each youth and parent/caregiver will travel through this process at their own pace. While moving through this process, it will be necessary to talk to your youth’s doctor about necessary legal decision support documentation and other paperwork to support this approach.



Adapted from: University of WA Adolescent Health Transition Project. *Parent-Child Shared Management: Path to Independence*. Seattle, WA: 2010. Available at <https://depts.washington.edu/healthtr/documents/sharedmanage.pdf>.

Is your youth ready to become the **leader** of their care? Take Got Transition’s transition readiness assessment to find out! For a youth version, visit <https://www.gottransition.org/resourceGet.cfm?id=224>. For a parent/caregiver version, visit <https://www.gottransition.org/resourceGet.cfm?id=225>. For additional HCT information and resources, visit GotTransition.org.



Tool for Exploring Decision Making Supports

This tool was designed to assist individuals and supporters with exploring decision making support needs for each life domain.

Name of Individual: _____

Name of person completing this form: _____

Relationship to individual (*circle one*): Self Family Friend Guardian Other: _____

How long have you known the individual? _____

For each question below, mark the level of support you need when making and communicating decisions and choices in the Charting the LifeCourse life domains.



I can decide with no extra support



I need support with my decision



I need someone to decide for me

DAILY LIFE & EMPLOYMENT

| | | | |
|--|--|--|--|
| Can I decide if or where I want to work? | | | |
| Can I look for and find a job (<i>read ads, apply, use personal contacts</i>)? | | | |
| Do I plan what my day will look like? | | | |
| Do I decide if I want to learn something new and how to best go about that? | | | |
| Can I make big decisions about money? (<i>open bank account, make big purchases</i>) | | | |
| Do I make everyday purchases? (<i>food, personal items, recreation</i>) | | | |
| Do I pay my bills on time (<i>rent, cell, electric, internet</i>) | | | |
| Do I keep a budget so I know how much money I have to spend? | | | |
| Am I able to manage the eligibility benefits I receive? | | | |
| Do I make sure no one is taking my money or using it for themselves? | | | |

HEALTHY LIVING

| | | | |
|---|--|--|--|
| Do I choose when to go to the doctor or dentist? | | | |
| Do I decide/direct what doctors, medical/health clinics, hospitals, specialists or other health care providers I use? | | | |
| Can I make health/medical choices for my day-to-day well-being? (<i>check-ups, routine screening, working out, vitamins</i>) | | | |
| Can I make medical choices in serious situations? (<i>surgery, big injury</i>) | | | |
| Can I make medical choices in an emergency? | | | |
| Can I take medications as directed or follow a prescribed diet? | | | |
| Do I know the reasons why I take my medication? | | | |
| Do I understand the consequences if I refuse medical treatment? | | | |
| Can I alert others and seek medical help for serious health problems? | | | |
| Do I make choices about birth control or pregnancy? | | | |
| Do I make choices about drugs or alcohol? | | | |
| Do I understand health consequences associated with choosing high risk behaviors (<i>substance abuse, overeating, high-risk sexual activities, etc.</i>)? | | | |
| Do I decide where, when, and what to eat? | | | |
| Do I understand the need for personal hygiene and dental care? | | | |

CHARTING the LifeCourse



For each question below, mark the level of support you need when making and communicating decisions and choices in the Charting the LifeCourse life domains.



I can decide with no extra support



I need support with my decision



I need someone to decide for me



SOCIAL & SPIRITUALITY

| | | | |
|---|--|--|--|
| Do I choose where and when (and if) I want to practice my faith? | | | |
| Do I make choices about what to do and who to spend time with? | | | |
| Do I decide if I want to date, and choose who I want to date? | | | |
| Can I make decisions about marriage (<i>If I want to marry, and who</i>)? | | | |
| Can I make choices about sex, and do I understand consent and permission in regard to sexual relationships? | | | |



SAFETY & SECURITY

| | | | |
|--|--|--|--|
| Do I make choices that help me avoid common environmental dangers (<i>traffic, sharp objects, hot stove, poisonous products, etc.</i>)? | | | |
| Do I make plans in case of emergencies? | | | |
| Do I know and understand my rights? | | | |
| Do I recognize and get help if I am being treated badly (<i>physically, emotionally or sexually abused, or neglected</i>)? | | | |
| Do I know who to contact if I feel like I'm in danger, being exploited, or being treated unfairly (<i>police, attorney, trusted friend</i>)? | | | |



COMMUNITY LIVING

| | | | |
|---|--|--|--|
| Do I decide where I live and who I live with? | | | |
| Do I make safe choices around my home (<i>turning off stove, having fire alarms, locking doors</i>)? | | | |
| Do I decide about how I keep my home or room clean and livable? | | | |
| Do I make choices about going places I travel to often (<i>work, bank, stores, church, friends' home</i>)? | | | |
| Do I make choices about going places I don't travel to often (<i>doctor appointments, special events</i>)? | | | |
| Do I decide how to get to the places I want or need to go? (<i>walk, ask a friend for a ride, bus, cab, car service</i>)? | | | |
| Do I decide and direct what kinds of support I need or want and choose who provides those supports? | | | |



CITIZENSHIP & ADVOCACY

| | | | |
|--|--|--|--|
| Do I decide who I want to represent my interests and support me? | | | |
| Do I choose whether to vote and who I vote for? | | | |
| Do I understand consequences of making decisions that will result in me committing a crime? | | | |
| Do I tell people what I want and don't want (verbally, by sign, device), and tell people how I make choices? | | | |
| Do I agree to and sign contracts and other formal agreements, such as powers of attorney? | | | |
| Do I decide who I want information shared with (family, friends etc.)? | | | |



Turning 18: What it Means for Your Health

Turning 18 may not make you feel any different, but legally, this means you are an adult.

What does this mean?

- After you turn 18, your doctor talks to **you**, not your parents, about your health.
- Your health information and medical records are private (or confidential) and can't be shared unless you give the OK.
- It is up to you to make decisions for your own health care, although you can always ask others for help.

Things to know

- The confidentiality between you and your doctor is legally known as the Health Insurance Portability and Accessibility Act, or HIPAA.
- This law gives privacy rights to minors (people who are under age 18) for reproductive and sexual health, mental health, and substance abuse services. Check your state's minor consent laws for more information.

What needs to be done?

- If you want to share medical information with others, your doctor will ask you to fill out a form that allows them to see your medical record and be with you during your visit.
- If you need help making decisions, talk to your family, your support team, and your doctor about who needs to be involved and what you need to do to make sure they can be a part of the conversations.

Additional resources

- If you want extra support managing your health or making decisions, the [National Resource Center for Supported Decision-Making](#) has information to connect you with resources in your state.










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PLANNING TO MOVE FROM PEDIATRIC TO ADULT CARE? HERE'S HOW THEY CAN DIFFER

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) |
|---|---|
| Your parent/caregiver is with you for most or all of your visit. |  You see the doctor alone unless you agree for others to be present. |
| Your parent/caregiver helps answer questions and explain your medical conditions, any medicines, and medical history. |  You answer questions and explain your medical conditions, medicines, and medical history. |
| Your parent/caregiver is involved in making choices about your care. |  You make your own choices about your care, asking your parents/caregivers as needed. |
| Your parent/caregiver helps make appointments and get your medicines. |  You make your own appointments and get your medicines. |
| Your parent/caregiver helps with your care and reminds you to take your medicines. |  You take control of your care and take medicines on your own. |
| Your parent/caregiver can see your health information, including test results. |  Health information is private unless you agree to let others see it. |
| Your parent/caregiver knows your health insurance and pays any charges at the visit. |  You keep your health insurance card with you and pay any charges at the visit. |
| Your parent/caregiver keeps a record of your medical history and vaccines. |  You keep a record of your medical history and vaccines. |
| Many pediatric specialists provide both specialty and some primary care. |  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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“The fact that I will have to go ... and not being familiar with it. That’s probably where the nervousness comes in.”

“I guess that’s one of the reasons I’m not jumping to change doctors is because I feel close to him and I trust him.”

From **youth** in **pediatric care**¹

From **young adults** in **adult care**¹

“They treat you more maturely. They expect you to know your responsibilities and stuff ... I like it. I like to have responsibility. I mean it’s knowing ... you have to know your medications and everything.”

“She gave me this big talk about some of the new things I’m going to encounter as an adult with a chronic condition. And she just opened my eyes to a lot of things.”

TIPS FOR PREPARING FOR YOUR MOVE TO ADULT HEALTH CARE

- Write down a list of questions and concerns you have before seeing your new doctor.
- Keep a list of your medicines, how much you take, and any allergies to medicines. You can take a picture of your medicines label and bring it with you to your visit.
- Keep your doctor’s phone number in your phone or somewhere you can easily find it.
- Keep your health insurance card with you always.
- Keep a record of your medical history, allergies and vaccines to share with your new doctor.
- Ask your doctor where to go if you need to get care after office hours or on the weekend.
- Ask your doctor to explain information you do not understand
- Ask your doctor if there is an online portal or an app you can use to look up your health information, contact information, or to make appointments.

TEST HOW READY YOU ARE TO MOVE TO ADULT CARE BY TAKING THIS QUIZ:

<https://www.gottransition.org/youthfamilies/HCTquiz.cfm>

¹Tuchman LK, Slap GB, and Britto MT. Transition to adult care: Experiences and expectations of adolescents with a chronic illness. *Child: Care, Health and Development*. 2008; 34(5):557-63.

SYSTEM DIFFERENCES BETWEEN PEDIATRIC AND ADULT HEALTH CARE

| System Characteristics | Pediatric | Adult |
|--|---|---|
| Orientation to Care | Growth and development | Maintenance of well-being with aging |
| Practice Approach | Family-centered; shared decision-making with parents | Patient-centered; shared decision-making with young adult |
| Primary Care Practice Patient Population | Majority of patients do not have chronic conditions | Majority of patients have chronic conditions |
| Specialty Clinic Affiliation/Location | Most pediatric specialty clinics located in children's hospitals | Most adult specialty practices located in private office-based settings |
| Multidisciplinary Staffing | Most pediatric specialty clinics are co-located with other specialists and can offer ancillary therapies | Most adult specialty clinics are not co-located with other specialists and need to refer out to other specialists and ancillary therapists |
| Availability of Care Coordination | Most pediatric subspecialty clinics and many pediatric primary care practices have care coordination services. Several public care coordination programs (e.g., State Title V program) are available for youth with specific chronic conditions | Few adult specialty clinics and even fewer adult primary care practices have the availability of care coordination services. Few public care coordination programs are available for adults with chronic conditions |
| Length of Appointment | Longer time | Shorter time |
| Time Alone | Sometimes for part of visit | Legally required for confidentiality over age 18, unless young adult gives permission for others to be present |
| Patient Role as Self Advocate | Less, given parental support/presence during visit | Essential |
| Patient Role in Making Appointments and Medication Refills | Parent handles | Patient handles |
| Adherence to Care | Offer more reminders and work arounds (e.g., using shots or intravenous medications); provider has legal option of contacting protective services if needed | Expectation of adherence; up to patient to follow treatment/medication recommendations; provider has no legal options |
| Medication Dosage | Depends on weight | Commonly one adult dose, but occasionally related to weight |
| Use of Pain Medications | More liberal availability | More restrictive availability |
| Time in Care System | Usually about 20-25 years | Average 50+ years |

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Sample Transition Readiness Assessment for Youth

Six Core Elements of Health Care Transition 2.0

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

Date:

Name:

Date of Birth:

Transition Importance and Confidence

On a scale of 0 to 10, please circle the number that best describes how you feel right now.

How important is it to you to prepare for/change to an adult doctor before age 22?

| | | | | | | | | | | |
|---------|---|---|---|---|---|---|---|---|---|-----------|
| 0 (not) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 (very) |
|---------|---|---|---|---|---|---|---|---|---|-----------|

How confident do you feel about your ability to prepare for/change to an adult doctor?

| | | | | | | | | | | |
|---------|---|---|---|---|---|---|---|---|---|-----------|
| 0 (not) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 (very) |
|---------|---|---|---|---|---|---|---|---|---|-----------|

My Health

Please check the box that applies to you right now.

Yes, I know this

I need to learn

Someone needs to do this... Who?

| | | | |
|---|--------------------------|--------------------------|--------------------------|
| I know my medical needs. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I can explain my medical needs to others. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know my symptoms including ones that I quickly need to see a doctor for. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know what to do in case I have a medical emergency. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know my own medicines, what they are for, and when I need to take them. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know my allergies to medicines and medicines I should not take. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I carry important health information with me every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I understand how health care privacy changes at age 18 when legally an adult. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I can explain to others how my customs and beliefs affect my health care decisions and medical treatment. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Using Health Care

| | | | |
|---|--------------------------|--------------------------|--------------------------|
| I know or I can find my doctor's phone number. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I make my own doctor appointments. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Before a visit, I think about questions to ask. | <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"/> |
| I know to show up 15 minutes before the visit to check in. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know where to go to get medical care when the doctor's office is closed. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I have a file at home for my medical information. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I have a copy of my current plan of care. | <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 referrals to other providers. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know where my pharmacy is and how to refill my medicines. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know where to get blood work or x-rays if my doctor orders them. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I have a plan so I can keep my health insurance after 18 or older. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My family and I have discussed my ability to make my own health care decisions at age 18. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |



Sample Transition Readiness Assessment for Parents/Caregivers

Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what your child already knows about his or her health and the areas that you think he/she needs to learn more about. After you complete the form, compare your answers with the form your child has complete. Your answers may be different. We will help you work on some steps to increase your child's health care skills.

Date:

Name:

Date of Birth:

Transition Importance and Confidence

On a scale of 0 to 10, please circle the number that best describes how you feel right now.

How important is it for your child to prepare for/change to an adult doctor before age 22?

| | | | | | | | | | | |
|---------|---|---|---|---|---|---|---|---|---|-----------|
| 0 (not) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 (very) |
|---------|---|---|---|---|---|---|---|---|---|-----------|

How confident do you feel about your child's ability to prepare for/change to an adult doctor?

| | | | | | | | | | | |
|---------|---|---|---|---|---|---|---|---|---|-----------|
| 0 (not) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 (very) |
|---------|---|---|---|---|---|---|---|---|---|-----------|

My Health

Please check the box that applies to your child right now.

Yes, he/she knows this

He/she needs to learn

Someone needs to do this... Who?

My child knows his/her medical needs.

My child can explain his/her medical needs to others.

My child knows his/her symptoms including ones that he/she quickly needs to see a doctor for.

My child knows what to do in case he/she has a medical emergency.

My child knows his/her own medicines, what they are for, and when he/she needs to take them.

My child knows his/her allergies to medicines and medicines he/she should not take.

My child carries important health information with him/her every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).

My child knows he/she can see a doctor alone as I wait in the waiting room.

My child understands how health care privacy changes at age 18.

My child can explain to others how his/her customs and beliefs affect health care decisions and medical treatment.

Using Health Care

My child knows or can find his/her doctor's phone number.

My child makes his/her own doctor appointments.

Before a visit, my child thinks about questions to ask.

My child has a way to get to his/her doctor's office.

My child knows to show up 15 minutes before the visit to check in.

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

My child has a file at home for his/her medical information.

My child has a copy of his/her current plan of care.

My child knows how to fill out medical forms.

My child knows how to get referrals to other providers.

My child knows where his/her pharmacy is and how to refill his/her medicines.

My child knows where to get blood work or x-rays if his/her doctor orders them.

My child has a plan to keep his/her health insurance after ages 18 or older.

My child and I have discussed his/her ability to make his/her own health care decisions at age 18.

My child and I have discussed a plan for supported decision-making, if needed.

This document should be completed by youth with intellectual or developmental disabilities who are under the age of 18 years old in order to assess their readiness to transition to an adult health care provider. If a youth's intellectual or developmental disabilities prevent him or her from independently filling out this document, the youth's caregiver should fill out the caregiver version of this Transition Readiness assessment form instead.

Please fill out this form to help us see what you already know about your health and using health care and areas that you need to learn more about. If you need help completing this form, please let us know.

Date: _____

Name: _____ **Date of Birth:** _____

Legal Choices for Making Health Care Decisions

- I can make my own health care choices.
- I need some help with making health care choices (Name: _____ Consent: _____).
- I have a legal guardian (Name: _____).
- I need a referral to community services for legal help with health care decisions and guardianship.

Personal Care

- I care for my all my needs.
- I care for my own needs with help.
- I am unable to provide self-care, but can direct others.
- I require total personal care assistance.

Transition and Self-Care Importance and Confidence *On a scale of 0 to 10, please circle the number that best describes how you feel right now.*

How important is it to you to take care of your own health care and change to adult doctor before age 22?

| | | | | | | | | | | |
|---------|---|---|---|---|---|---|---|---|---|-----------|
| 0 (not) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 (very) |
|---------|---|---|---|---|---|---|---|---|---|-----------|

How confident do you feel about your ability to take care of your own health care and change to an adult doctor before age 22?

| | | | | | | | | | | |
|---------|---|---|---|---|---|---|---|---|---|-----------|
| 0 (not) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 (very) |
|---------|---|---|---|---|---|---|---|---|---|-----------|

My Health *Please check the box that applies to you right now.*

| | <i>Yes, I know this.</i> | <i>I need to learn.</i> | <i>Someone needs to do this... Who?</i> |
|---|--------------------------|--------------------------|---|
| I know my medical needs. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I can tell other people what my medical needs are. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know what to do if I have a medical emergency. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know the medicines I take and what they are for, and when I need to take them without someone reminding me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know what medicines I should not take. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know what I am allergic to, including medicines. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I can name 2-3 people who can help with my health goals. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I can explain to people how my beliefs affect my care choices. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Using Health Care *Please check the box that applies to you right now.*

| | <i>Yes, I know this.</i> | <i>I need to learn.</i> | <i>Someone needs to do this... Who?</i> |
|--|--------------------------|--------------------------|---|
| I know or I can find my doctor's phone number. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I make my own doctor appointments. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Before a visit, I think about questions to ask. | <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"/> |
| I know I should show up 15 minutes before the visit to check in. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know where to get care when my doctor's office is closed. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| Using Health Care | <i>Please check the box that applies to you right now.</i> | <i>Yes, I know this.</i> | <i>I need to learn.</i> | <i>Someone needs to do this... Who?</i> |
|---|--|--------------------------|--------------------------|---|
| I have a folder at home with my medical information, including my medical summary and emergency care plan. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I have a copy of my plan of care. | | <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 ask for a form to be seen by other doctors or therapist. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know where my pharmacy is and what to do when I run out of my medicines. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know where to get a blood test or x-rays if the doctor orders them. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I carry my health information with me every day (e.g. insurance card, allergies, medications, and emergency phone numbers). | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know that when I am 18 the rules about my health privacy change. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I have a plan so I can keep my health insurance after 18 or older. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (If applies) I have a plan so I can keep my disability benefits (SSI) after 18. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

This document should be completed by caregivers of youth with intellectual or developmental disabilities who are under the age of 18 years old in order to assess their youth’s readiness to transition to an adult health care provider. If a youth’s intellectual or developmental disabilities do not prevent him or her from independently filling out this document, the youth should fill out the youth version of this Transition Readiness assessment form instead.

Please fill out this form to help us see what your youth already knows about their health and using health care and areas that you think they/you need to learn more about. If you need help completing this form, please let us know.

Date: _____

Patient Name: _____ **Date of Birth:** _____

Caregiver Name: _____ **Are you the main/full-time caregiver?** Yes No

Decision-making/Guardianship

- My youth can make my own health care choices.
- My youth needs some help with making health care choices (Name: _____ Consent: _____).
- My youth has a legal guardian (Name: _____).
- My youth/I need a referral to community services for legal help with health care decisions and guardianship.

Personal Care

- My youth can care for all his/her needs.
- My youth can care for his/her own needs with help.
- My youth is unable to care for himself/herself, but can tell others his/her needs.
- My youth requires help for all his/her needs.

Transition Importance and Confidence *On a scale of 0 to 10, please circle the number that best describes how you feel right now.*

How important is for your youth to prepare for and change to an adult doctor before age 22?

| | | | | | | | | | | |
|---------|---|---|---|---|---|---|---|---|---|-----------|
| 0 (not) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 (very) |
|---------|---|---|---|---|---|---|---|---|---|-----------|

How confident do you feel about your youth’s ability to prepare for and change to an adult doctor before 22?

| | | | | | | | | | | |
|---------|---|---|---|---|---|---|---|---|---|-----------|
| 0 (not) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 (very) |
|---------|---|---|---|---|---|---|---|---|---|-----------|

Your Youth’s Health

Please check the box that applies to you right now.

| | Yes, my youth knows this. | My youth needs to learn this. | I need to learn this. |
|--|---------------------------|-------------------------------|--------------------------|
| My youth knows his/her medical needs. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth can tell other people what his/her medical needs are. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth knows what to do if he/she has a medical emergency. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth knows the medicines he/she takes and what they are for. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth can take his/her medicine by himself/herself without a reminder. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth knows what medicines he/she should not take. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth knows what he/she is allergic to, including medicines. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth can name 2-3 people who can help him/her with his/her health goals | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My teen can explain to people how his/her beliefs affect his/her care choices. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| Using Health Care | <i>Please check the box that applies to you right now.</i> | <i>Yes, my youth knows this.</i> | <i>My youth needs to learn this.</i> | <i>I need to learn this.</i> |
|--|--|----------------------------------|--------------------------------------|------------------------------|
| My youth knows or can find his/her doctor's phone number. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth makes his/her own doctor appointments. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Before a visit, my youth thinks about questions to ask. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth has a way to get to his/her doctor's office. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth knows he/she should show up 15 minutes before the visit to check in. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth knows where to get care when his/her doctor's office is closed. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth has a folder at home with his/her medical information, including his/her medical summary and emergency care plan. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth has a copy of his/her plan of care. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth knows how to fill out medical forms. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth knows how to ask for a form to be seen by other doctors or therapists. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth knows where his/her pharmacy is and what to do when he/she runs out of his/her medicines. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth knows where to get a blood test or x-rays if the doctor orders them. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth carries health information with him/her every day (e.g. insurance card, allergies, medications, and emergency phone numbers). | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth knows when he/she is 18 the rules about his/her health privacy change. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My youth has a plan so he/she can keep his/her health insurance after 18 or older. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |



**Are you ready to transition
to adult health care?**

Take the quiz here:

bit.do/HCTquiz

