

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

Parents are familiar with the many transitions their children experience as they grow and gain more independence – their first steps, first words, first day of school, and last day of high school. But for parents who have navigated the journey of childhood cancer, the transition from treatment to general practice – and the further transition to adult care can require more care and planning. What about the last visit to the cancer center or the first visit to a pediatrician or an adult doctor? What about the planning that could make that transition less stressful and more successful? Many parents and youth do not consider this transition until it is suddenly upon them.

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 “[Supporting the Transition of Health Care from Adolescence to Adulthood in the Medical Home.](#)” While designed for a broad audience, 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 and is especially relevant for cancer families.

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 is particularly important for childhood cancer survivors, who will have, or may develop, serious medical or psychosocial needs. These youngsters and young adults require more in-depth planning and on-going support because a variety of specialists can be involved. If a young adult requires 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 primary care doctors:

1. Can I work with you to include a cancer survivorship and emergency care plan for my child?
2. When does my child start to meet with you alone for part of the visit to become more independent in their health care?
3. 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?
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 specialists for my child to transfer or be referred to?

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

FOR YOUTH AND YOUNG ADULTS:

QUESTIONS TO ASK YOUR DOCTOR ABOUT TRANSITIONING TO ADULT HEALTH CARE

DURING YOUR ADOLESCENT YEARS:

- Can I work with you to prepare a maintain a cancer survivorship plan for me and, if needed, a plan for what to do case of late effects or an emergency?
- 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 more independent health care? Do you have a checklist of self-care skills that I need to learn?
- 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 specialists to be referred 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 a 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 survivorship plan or medical records from my oncologists or pediatric doctor? (Be sure to have records of your treatment transferred to a new pediatrician or adult doctor. Methods of documenting your care are available *here.*)
- Do you have an online portal in which I can record and track my survivorship plan, the results of tests, plan appointments and ask questions?
- What should I bring to the first visit?
- Who can help me when you are not available?

NOTES: _____

FOR PARENTS/CAREGIVERS:
**QUESTIONS TO ASK YOUR CHILD’S DOCTOR ABOUT TRANSITIONING
TO ADULT HEALTH CARE**

DURING YOUR CHILD’S ADOLESCENT YEARS:

- Can I work with you to prepare and maintain a cancer survivorship plan for my child and, if needed, a plan for what to do in case of late effects or an emergency?
- 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 independent health care? Do you have a checklist of self-care skills that my child needs to learn?
- 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 primary, 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 and survivorship plan 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: _____



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.

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 explains 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.
