

OHSU INSTITUTE ON DEVELOPMENT AND DISABILITY

Transitioning to adult health care

Guide for teens and families





What is transition and why is it important?

Transition is the process of moving from adolescence to adulthood. It's important to maintain your health care as you age in order to stay healthy. As an adult, you will see health care providers and use health care services that are different from those you used as a child.

PARENTS OF TRANSITION-AGE YOUTH

- Taking charge of your health care is important and your health care providers are here to help!
- This guide offers suggestions to help with the transition of moving from child-based health care services to services for adults.
- As an adult, providers will work with your son or daughter directly. Planning ahead will ease this transition and better support your teen's future health care.
- A few tips in this booklet may be challenging for some teens and some may move through these tasks at a different pace. Find unique ways to support your son or daughter to accomplish these tasks on their own.
- It is never too late to start on this journey. Make sure you are discussing the transition process with your teen's health care providers and asking them any questions you may have.

From Age 12

- Understand your disability diagnosis and how it affects you. Practice sharing this with others.
 - Learn the names of your prescriptions and the reasons you take them. Start helping with refill reminders.
 - Make sure you know who to call for medical help.
 - Take charge of your health by eating right, exercising, bathing regularly, and getting a good night's sleep.
 - Talk with a health care provider or trusted adult if you have questions about relationships, sex, or sexuality.
 - Talk with your school nurse, if you have one, about your health needs at school.
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“While I’ve gone with [my daughter] to most appointments, I make sure the doctor or nurse speaks to her directly, and asks her questions, rather than me.”

— Susan, parent

FOR PARENT / GUARDIAN

- Help your teen understand and practice communicating their own disability and/or diagnosis.
- Make sure your teen knows the names of and reasons for taking all prescriptions.
- Encourage your teen to practice speaking up about their needs and asking questions at health care appointments.
- Allow your teen to be responsible for their own health care needs as appropriate.
- Have regular conversations about sexual health with your teen. Make sure they feel comfortable asking you questions about relationships, sex, and sexuality.

From Age 14

- Read through the things from age 12 and continue to work on activities that will help you become more independent.
 - Start making and keeping track of health care appointments. Write appointments on a calendar.
 - Make sure you know who to call for medical help.
 - Take charge of your health by eating right, exercising, bathing regularly, and getting a good night's sleep.
 - Talk with a health care provider or trusted adult if you have questions about relationships, sex, or sexuality.
 - Talk with your school nurse, if you have one, about your health needs at school.
 - Learn how to refill your prescriptions. Keep track of when and how much you should be taking.
 - Start planning for health care visits by writing down notes. Use a phone, notebook, or a Health Passport.*
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One of the most important aspects of becoming an adult is understanding what your strengths and challenges are. This will help determine the best path for you.”

— **Joe, self-advocate**

FOR PARENT / GUARDIAN

- Read through the previous sections of this guide with your teen and focus on items for ages 12+ that still need work.
- Start involving your teen in making health care appointments.
- Have your teen manage their prescriptions.
- Research resources that are available in your community to help your teen with the health care transition.

* See resource section.

From Age 16

- Read through the previous sections of this guide and continue to work on activities that will help become more independent.
 - Before all health care appointments, understand the reason for the visit and make a list of questions for your provider.
 - Take the lead when talking to your provider. If you would like to meet with him or her by yourself, you can ask to meet privately.
 - Talk to your provider about how your health care will change after you turn 18.
 - Be as independent as possible with your medical routines.
 - Take charge of filling prescriptions and taking your own medication.
 - Know how to access and maintain your medical record.
 - Carry your insurance card and a list of your prescriptions at all times.
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“Try to understand as much of your healthcare coverage as you can. It does not matter what kind of coverage you have, it will change once you transition to adult care and you have a right to understand what it covers.”

— **Emily, self-advocate**

FOR PARENT / GUARDIAN

- Read through the previous sections of this guide with your teen and focus on anything that needs work.
- Give your teen the opportunity to make decisions such as managing medications, making appointments, and meeting with their provider privately.
- Explore health care insurance coverage and providers for adults.
- Have and practice a safety plan. Make sure your teen knows how to get help in an emergency.
- Encourage your IEP team to develop health-related transition goals.

From Age 18

- Read the previous sections of this guide. Work on anything that will help you become more independent.
- Be prepared to take care of your medical needs at home, school, and work.
- Take charge of your health and well-being. Don't be afraid to ask for help when you need it.
- Start making appointments with health care providers you like and trust and who see adult patients.

Things I want to work on:

FOR PARENT / GUARDIAN

- Read through the previous sections of this guide with your young adult and make sure they are comfortable with their responsibilities.
- Finalize transfer of medical care to adult provider with your young adult.
- Finalize health coverage for your young adult.



Transition beyond health care

Health care is important, but it's not your whole life. Here are some things to consider as you prepare to transition into your life as an adult:

- Stay connected with others. Friends are important for mental health.
- Participate in hobbies and social activities that you enjoy.
- Start doing things for yourself around the house (laundry, dishes, etc.).
- Attend your IEP meetings at school. Discuss your goals and needs.
- In public, make sure you are aware of your surroundings.
Let someone know about plans if you are doing something unfamiliar.
- Learn about money: earning, saving, and spending.
Practice making purchases.
- What are your neighborhood's transportation options? Know how public transit can accommodate you on the bus, the MAX, Street car, etc.
- Explore what living away from home would be like by talking to your family and friends who live independently.
- Start planning for what you will do after high school.
Apply for college, a job, or housing.

FOR PARENT / GUARDIAN

- Encourage your teen's independence. Facilitate social activities they can do on their own.
- Support independence at home (laundry, pet-care, self-care, increased responsibility, etc.).
- Introduce paying bills and financial planning.
- Talk with your teen about career interests and educational goals.
- Inquire about your teen's school transition services. Include transition planning in the IEP by age 16.
- Consider opportunities for your teen to find work and participate in volunteer activities.
- Assist your teen with applications for college, employment or housing.

Resources

Social Security Administration

800-772-1213 | www.ssa.gov/disability

To enroll in any financial benefits you may be eligible for depending on your disability.

Developmental Disabilities Services

503-945-9774 | www.oregon.gov/dhs/dd/pages

Provides support for people with developmental disabilities in school, at home, in their community, and at work.

Got Transition

www.gottransition.org

Resources and information for people with disabilities and their families on transition from pediatric to adult health care.

Oregon Family to Family Health Information Center

855-323-6744 | 503-931-8930 (español)

www.oregonfamilytofamily.org

Parents and transitioning youth can contact the OR F2F HIC to speak with an experienced Parent Partner for free transition coaching.

Health Passport

flfcic.fmhi.usf.edu/resources/materials/health.html

A resource provided by University of South Florida's Center for Inclusive Communities. You can complete the Health Passport and bring it along to medical visits.





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