Family Tip Sheet: Youth who Experience Special Health Care Needs

Your Medical Home ~ Transition Planning

Congratulations! You are ready to take charge of your own health care! Here are some things other youth with special health needs suggest you think about:

How is my health care paid for if I need to go to a doctor or hospital?

- o Carry your health insurance card with you.
- o Find out if you have to pay for office visits at the time you go, or if you will be billed.
- o Make a friend in the doctor's office who will answer your questions about bills.

Do I want to stay with my pediatrician or get health care in an adult setting?

- o Your parents may want you to stay with a pediatrician, but you can help decide this for yourself.
- Ask your friends with special health needs where they go to get health care.

Do I feel completely comfortable with my doctors?

- o If your doctors don't have experience with your condition, teach them. If they don't want to learn, find another doctor who does. Remember that *you* are the patient!
- o Make sure you ask for enough time to get all your questions answered.
- Tell your doctors a little about yourself (your interests, hobbies, goals, etc.) so they get to know you
 as a person, not just a patient.

Do I need help keeping track of all the appointments and instructions?

 Some practices have care coordinators who can help you to get the services and information you need. Ask your doctor's office if they have one, or ask your health plan by calling the number on the back of your insurance card.

How well do I understand my own health condition?

- Join on-line groups of people with similar conditions for support, conversation, and ideas about how they stay healthy. If your disorder is rare, contact the <u>National Organization for Rare</u> <u>Disorders.</u> <u>www.rarediseases.org</u>
- Do what it takes to stay healthy: don't smoke, eat well, and exercise. If you have trouble with keeping healthy, ask for help.
- Don't neglect your mental health. If you think you might want to talk to a counselor, your doctor's office can help you find one.

These tips were compiled from various resources, including the Oregon Center for Children and Youth with Special Health needs, www.gottransition.org, and The Idaho Dep't. of Health and Welfare publication, Take Charge of your Transition.



The Oregon F2F HIC is a family-led effort, funded by a grant from the Health Resources and Services Administration/Maternal and Child Health Bureau. It is affiliated with the Oregon Center for Children and Youth with Special Health Needs at the Institute on Development & Disability at OHSU.