

Taking steps toward transition:

- Plan ahead!
- Know how to explain your disorder and your health care needs.
- Keep a record of appointments, medical history, doctors and phone numbers, medications and formulas.
- Begin to make your own medical appointments.
- Write down questions for your doctor before your visit.
- Spend time with your health care provider without your parents.
- Learn about your health insurance and health care finances.
- Take on responsibilities! Ask questions! Take your health care into your hands!

Who can help me plan my transition?

- Your metabolic doctor or nurse practitioner
- Your metabolic social worker or clinic nurse
- The medical staff of the Medical Home
- Your family, spouse, partner
- A friend who has been through the same process

Things to remember!

- Transition is a process. It occurs gradually and needs lots of planning.
- Transition is part of growing up. It can be challenging, but it can also be fun, exciting and rewarding!
- You are not alone. Your family and medical staff are here to help you when things seem confusing.

Adapted from materials developed by Children's Hospital, Boston as part of the Massachusetts Initiative for Youth with Disabilities, a Healthy and Ready to Work project of the Massachusetts Department of Public Health.

Transition to Adult Health Care

A Guide to Getting Treated as an Adult with PKU



Children's Hospital Boston Transition to Adult Care Education Initiative



Children's Hospital Boston

What is transition?

Transition means change. It is a time when changes in your life occur. And moving toward adulthood is a major transition. It can mean:

- Taking on new challenges
- Doing more things on your own
- Having more choices
- Gaining a new sense of freedom and independence
- Taking on more responsibility

Transition from youth to adulthood involves many factors, such as leaving home, finances, education, employment and recreation. At the same time, an important part of a transition process is preparing for health care.

As a young individual with PKU you will eventually need adult centered care. Adult health care for PKU means:

- Being seen by adult health care providers in an adult setting.
- Focusing on meeting the health care needs that adults have.
- Having a trained health care provider to answer, discuss and counsel you about adult issues and concerns regarding PKU and its treatment.
- Having the opportunity to network with others with PKU of your age.

Your adult Medical Home

A medical home is not a building, house, or hospital. It is primary care that is accessible, continuous, comprehensive, coordinated, compassionate, and culturally effective.

Currently, a health center in each New England State is being designated to become a medical home.

An initial first visit should include the following:

- Completion of forms about health and insurance
- A conversation with the health care provider about your medical history, health and metabolic disorder
- A physical examination
- A blood test and other routine tests
- Females may have a gynecological examination
- Referrals for further evaluation if needed
- A letter back from your doctor with the results of the examinations and blood levels that also is sent to the previous metabolic doctor
- A date for your next appointment

What do I need to bring with me?

You should have with you:

- A copy of your health records, including blood levels, physical examinations and other relevant information
- Name and address of metabolic physician
- Copies of the "Transition Intake Form," "Health Care Skills Checklist" and "PKU Wallet Card"