

## Welcome to the Boston Children's Hospital Transition Toolkit!

As a teenager getting ready for adulthood, or as a young adult, you can begin to take control of how you handle your metabolic condition and your health in general. This Toolkit is designed to help you! To start, read through these materials and fill out the forms. You can also begin to look for an adult-focused doctor to replace your pediatrician who only deals with childhood problems. This process of switching to an adult-focused doctor is called *medical care transition* and takes time and planning – but once it's done, it will be great for your future health and success.

### Use the following forms to help achieve your medical care transition



**Health Readiness  
Assessment**



**Metabolic  
Condition Basics**



**Medical Health  
Summary**



**Transition Plan**

What am I supposed to do with these **forms**?

**Measure** your health independence by taking the [Health Readiness Assessment](#) and over time try to answer yes to every question.

**Read** up on your [Metabolic Condition Basics](#) and discuss possible adult-health problems with your doctors or nurses.

**Ask** a doctor or social worker for help filling out the [Medical Health Summary](#) and [Transition Plan](#) at your next appointment.

**Save** these forms on your computer and USB flash drive and bring the Transition Toolkit to every medical appointment.

**Keep** the flash drive in your wallet or purse and save any changes or updates.



Save these forms and bring them to future medical appointments



Ask a doctor to help you fill out your forms

How will The **Transition Toolkit** help me? With the Toolkit you can –

**Decide** when you're ready to act as your own health spokesperson.

**Prepare** for doctor's appointments and fill out health forms.

**Talk** to doctors and nurses about your medical condition and what roles they should play in your medical care.

**Keep track** of all of your important medical and condition information.

To get started, fill out the [Health Readiness](#) form.

# Transition Toolkit

## Health Readiness Assessment

Are You *Ready* to Handle Your Own Health Care as an Independent Adult?



To know if you are ready for a health care transition, answer the following questions:

1. I know my height, weight, birth date, and social security number  Yes  No
2. I know the name of my condition  Yes  No
3. I know my genotype or genetic status  Yes  No
4. I can tell you about my condition and explain my health care needs  Yes  No
5. I know what kind of medical insurance I have  Yes  No
6. I know where to find my medical records  Yes  No
7. I know who to ask about getting my own health insurance  Yes  No
8. I know the basic treatment for my condition  Yes  No
9. I know what my diet should include and not include  Yes  No
10. I know how to prepare my own food  Yes  No
11. I know how to shop for my own food  Yes  No
12. I know the names of my supplements and medicines  Yes  No
13. I know how to order or get my medications filled  Yes  No
14. I know the symptoms and medical problems related to my condition  Yes  No
15. I visit my metabolic specialist regularly  Yes  No
16. I have discussed issues about sex with my doctor  Yes  No
17. I know how to get birth control and how to stay protected against sexually transmitted diseases/infections (STDs)  Yes  No
18. I have discussed the use of tobacco, alcohol and drugs with my doctor  Yes  No
19. I know how to schedule a doctor's appointment  Yes  No
20. I keep a schedule of medical appointments on my calendar  Yes  No
21. I can get myself to medical appointments (or can arrange transportation myself)  Yes  No
22. I know who to call in case of an emergency  Yes  No
23. I prepare questions for my health care provider before appointments  Yes  No
24. I have a support network for my condition  Yes  No

## Transition Toolkit

### Health Readiness Assessment

Are You *Ready* to Handle Your Own Health Care as an Independent Adult?



Now count the number of times you checked YES.

If you checked YES for:

#### **17 to 24 statements – great work!**

You are already taking full responsibility for your health care. The transition forms in this Toolkit will help you become a stronger health advocate.

#### **8 to 16 statements – you are on the right path!**

You are actively taking on many important responsibilities in your health care. The following Transition Toolkit forms will help you answer YES to many more of these questions.

#### **0 to 7 statements – let's get started!**

Transitioning health care to adult providers and becoming a better health advocate for yourself takes time and planning. Now's a perfect time to start! Pick a few of the previous responsibilities from the list and spend the next month doing them. The Toolkit forms will make this much easier.

Now what?

Update and save this assessment every month until you've answered all of the tasks with a YES!

Next, take a look at some [basic information about your metabolic condition](#).



#### Overview of the Condition:

Homocystinuria is a rare metabolic condition in which a chemical called CBS does not work correctly in your body. This can cause two chemicals, homocysteine and methionine, to build up in your blood over time. When these build up too much, they can cause serious health problems. You can manage homocystinuria throughout your life with a special low-protein diet, drug therapy with betaine and other medicines, and ongoing health care.

Another name for homocystinuria is CBS Deficiency.

#### Medical Problems for Babies and Children:

- Babies with homocystinuria usually have no or few apparent symptoms.
- Babies and children with homocystinuria who do not get treated for it are at greater risk for serious health problems later in life.
- Children with this condition may have learning delays, seizures and eye problems.
- Eye problems can include partial dislocation of the lens, severe nearsightedness, and quivering of the iris.
- Newborns in the US are now tested for homocystinuria. If the condition is identified early and treatment and diet are followed carefully, many health problems can be prevented or lessened.

#### Medical Problems for Teens and Young Adults:

- Teens and young adults with homocystinuria who have been identified young and treated from early on may have few or none of these health complications.
- Blood clots are a serious health risk for teens and young adults with homocystinuria. You must monitor your blood homocysteine levels to avoid blood clots, which could cause life-threatening blockages to your heart or lungs.
- Low bone density (osteoporosis) can be a problem for about half of people who have homocystinuria. Some teens or young adults develop scoliosis, a curving of the spine. Osteoporosis often occurs by age 20.
- Adults with homocystinuria may be at risk for developing serious neurological or mental health problems including depression, anxiety, psychosis, or seizures. Counseling and medication can help. If you have trouble with your mental health, *it is important to get in touch with your health care provider to get treatment.*

#### How to Minimize Medical Problems and Complications:

- Follow a low-protein/low-methionine diet recommended by your dietician.
- Take betaine and other medicines recommended by your health care providers.
- Some people with homocystinuria do well taking vitamin B6 (pyridoxine). Your doctor can help you learn if vitamin B6 works for you.
- If you have poor vision, visit your eye doctor for regular exams. Be sure to let your eye doctor know you have homocystinuria.
- Keep your immunizations up-to-date
- Stay in regular contact with your health care providers and health specialists.



#### Fertility and Pregnancy:

- Homocystinuria does not affect your ability to have children.
- Genetic counseling can help you and your partner understand the risks to your children. Your doctor can refer you to a genetic counselor who has a special understanding of your health issues.
- Pregnant women with homocystinuria must follow a careful diet with special guidance from a dietician and health care providers.
- Pregnancy is considered high risk because of the possibility of blood clots, especially after the baby is delivered. Some women may need anti-blood-clotting medicine.
- Women with homocystinuria should not use birth control pills that contain estrogen, as these increase the risk of blood clots. Talk with your doctor about non-estrogen birth control.

#### How To Get Support:

- Get education support from teachers and specialists at your school
- Join a support group with people who have homocystinuria.
- Join this Facebook group for families affected by homocystinuria <https://www.facebook.com/pages/Homocystinuria-ClimbHq/159167817553965>

#### Resources:

AAP/AAFP/ACP Transition Clinical Report  
<http://aappolicy.aappublications.org/cgi/reprint/pediatrics;128/1/182.pdf>

Transition Toolkit (New England Consortium of Metabolic Programs)  
<http://newenglandconsortium.org/for-families/transition-toolkit/>

Got Transition  
<http://gottransition.org/>

National Institutes of Health – Genetics Home Reference – Homocystinuria  
<http://ghr.nlm.nih.gov/condition/homocystinuria>

#### Genetics Referrals:

Clinical Services  
<http://www.ncbi.nlm.nih.gov/sites/genetests/clinic?db=genetests>

Find Genetic Services  
<http://www.acmg.net/gis>

#### What Next?

Now you can fill out the [Medical Health Summary](#), print it, and save it. This will help you keep important medical information in one place.

This guide was adapted with permission from the American College of Medical Genetics ACT Sheet  
<http://www.acmg.net/>

**Transition Toolkit**  
**Medical Health Summary**

Use this form to save important health information



Date Updated: \_\_\_\_\_

Last Name		First Name	
Birthdate	Gender	Weight	Height
Address			
City		State	Zip Code
Insurance Name			
Insurance ID & Group #			
Insurance Address & Phone Number			
Metabolic or Genetic Condition			
Medications/Supplements and Dosages			
Allergies to Food, Drugs and Other Substances			

Emergency Contact Name & Relationship		Emergency Contact Phone Number
Pharmacy Name		Pharmacy Phone Number
Immunizations:	Type	Date



**Transition Toolkit**  
**Medical Health Summary**

Use this form to save important health information



Other medical information:

What next?

A final step toward completing your medical transition is meeting with your health care providers to discuss and fill out your [Transition Plan](#).



## Transition Toolkit

### Transition Plan

Make an ongoing health plan with your health care provider



Fill out this plan with your health care provider, to help you transition to being in charge of your own health

**Patient Name:** \_\_\_\_\_

**Boston Children's Hospital Medical Record #:** \_\_\_\_\_

Primary Care Physician	Phone Number
	Email
Pediatrician	Phone Number
	Email
Metabolic Specialist	Phone Number
	Email
Other Health Care Provider	Phone Number
	Email
Emergency Contact Name & Relationship	Phone Number

#### Medical Findings

Genotype/Laboratory Findings
Treatment Status
Current Medications/Treatments
Allergies/Adverse Reactions
Past Medical Concerns or Hospitalizations
Living Situation/Employment
Mental Health Status/Cognitive Status





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### Transition Plan

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Other Health Risks

#### Contract:

To enhance collaboration, each person should agree on the following responsibilities:

Metabolic Specialist will:

- Obtain labs and tests: For example...
- Prescribe condition-related medications:
- Work with PCP to develop an emergency protocol:

Patient will:

- Remember to take medications: For example...
- Order and pick up supplies/supplements:
- Show-up to appointments:

Primary Care Physician will:

- Monitor patient's general health:
- Update metabolic specialist with important patient information:
- Contact metabolic specialist with medical concerns: For example...
- Other:

When you're done filling out this Transition Plan, print it and save it in a safe place.

Congratulations! You are well on your way to being in charge of your own health.