

## 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:

Galactosemia is a rare metabolic condition in which a chemical called GALT does not work correctly in your body. As a result, you are unable to break down galactose (found in milk and all other dairy products). This causes a sugar called galactose to build up too much in your blood over time. When galactose builds up too much, it can cause serious health problems. You can manage galactosemia throughout your life with a special non-dairy diet and ongoing health care.

Other names for galactosemia are: GALT deficiency or classical galactosemia.

#### Medical Problems for Babies and Children:

- If galactosemia goes undetected, babies and children may have: tremors or convulsions, yellow skin and whites of the eyes (jaundice), and vomiting.
- Newborns with untreated galactosemia are at increased risk for a life-threatening illness called E. coli septicemia.
- All newborns in the US are now tested for galactosemia. If the condition is identified early and galactose (dairy) is taken out of the baby's diet, the most serious health problems can be avoided.

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

- Even with early treatment, many teens and young adults with galactosemia have some difficulty speaking or coming up with the right words to say, and some difficulty quickly understanding and processing what they hear or read.
- Other adult symptoms of galactosemia can include tremors and low bone density.
- Some teens and young adults with galactosemia have shyness, loneliness, anxiety, or depression. Counseling and medication can help. If you have anxiety or depression, *it is important to get in touch with your health care provider to get treatment.*

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

- Follow a non-dairy diet recommended by your dietician. This will include avoiding milk and other dairy products. You can replace dairy with soy or rice-based products.
- Check food labels and avoid these ingredients: nonfat dry milk solids, casein, sodium caseinate, whey, whey solids, curds, lactose, or galactose.
- Keep your immunizations up-to-date.
- Stay in regular contact with your health care providers and health specialists.

#### How To Get Support:

- Get education support from teachers and specialists at your school
- Join a support group with people who have galactosemia. The **Galactosemia Foundation** has very active groups for teens and for adults with galactosemia. <http://galactosemia.org/>
- A lot of research is being done on galactosemia. Get up-to-date information about new treatments and discoveries at the **Galactosemia Foundation** website: <http://galactosemia.org/>



#### Fertility and Pregnancy:

- Almost all teen girls and women with galactosemia experience a health condition called premature ovarian insufficiency (POI).
- When a woman has POI, her ovaries do not release eggs or hormones in the usual way. She may stop having her periods and may experience hot flashes.
- POI can make some women unable to get pregnant. This is called infertility.
- POI can be treated and some women with galactosemia have been able to have children. It is important for girls who have galactosemia to **visit an endocrinologist** by the time they are 12 years old.
- Men with galactosemia are able to father children. Their fertility is not affected.
- Galactosemia is a genetic condition. 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 galactosemia must follow a careful diet with guidance from a dietician.

#### 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://www.gottransition.org/>

Galactosemia Foundation

<http://galactosemia.org/>

National Institutes of Health – Genetics Home Reference – Galactosemia

<http://ghr.nlm.nih.gov/condition/galactosemia>

Parents of Galactosemic Children, Inc.

<http://www.galactosemia.org/>

Learn Genetics Galactosemia

<http://learn.genetics.utah.edu/content/disorders/whataregd/galactosemia/>

Moving Forward: Your Guide to Galactosemia and Primary Ovarian Insufficiency (POI)

<http://newenglandconsortium.org/for-families/galactosemia/galactosemia-and-primary-ovarian-insufficiency-poi/>

#### Genetics Referrals:

Clinical Services

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

Genetic Services

<http://www.acmg.net/gis>

## Transition Toolkit

### Metabolic Condition Basics: Galactosemia

Medical information you need to know as an adult with Galactosemia



#### 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.