

**DOCTOR DISCUSSION GUIDE:**

# Managing Galactosemia by Life Stage

## Galactosemia Conversation Starters for You and Your Doctor

Asking the right questions during conversations with your healthcare provider can help you navigate the issues that may occur at different life stages.

This guide is meant to help you make the most of your time with your medical team by providing sample questions, specific to different life stages, to help facilitate the discussion and share the impact Galactosemia has on your family.

**The sample questions contained in this document may not be applicable to all people living with Galactosemia or their caregivers. This guide is not intended to be a substitute for medical advice from your healthcare team.**

## General Conversation Starters for Your Metabolic Team

**01**

I understand that while a restricted diet can limit the amount of galactose my child takes in, their body is still making high levels of galactose on its own.

**Can you recommend any resources that can help guide me in reducing as much galactose as possible from my child's diet?**

**02**

I understand that Galactosemia affects learning, growth, and motor skill development.

**Can you help me understand how Galactosemia may influence my child's learning, growth, and motor skill development, and which specialist(s) they may need to see?**

**03**

I'm trying to understand what resources are available to help me learn more about Galactosemia.

**Are there any resources or patient groups that can help me navigate my child's Galactosemia?**

LIFE STAGE

# Newborns



## Conversation Starters for Your Metabolic Team

01

After my newborn's Galactosemia diagnosis, I began looking into the long-term complications my child may face in the future.

**Can you tell me about the types of complications my child may face and what can be done to reduce the impact of Galactosemia in the future?**

02

Given all the different symptoms my child may experience, I want to make sure they're receiving the care they need.

**Are there other types of specialists or tests you recommend to make sure my child is receiving the best possible care for their Galactosemia?**

03

My newborn had liver and kidney issues in the NICU.

**Since my newborn had liver and kidney issues in the NICU, what signs of complications should I be on the lookout for moving forward?**

04

I had already selected my newborn's pediatrician before they were diagnosed with Galactosemia.

**Will I need to find a new pediatrician who is more familiar with my newborn's Galactosemia, or can the pediatrician I've already selected work with you and your staff?**

05

After my newborn's Galactosemia diagnosis, I stopped breastfeeding.

**How long after stopping breastfeeding might it take to see improvements in my newborn's complications (jaundice, liver failure, edema, etc.)?**

LIFE STAGE

# Infants & Toddlers



## Conversation Starters for Your Metabolic Team

01

My toddler doesn't seem to be growing at the same rate as the toddlers of some of our friends.

**What can be done to aid their growth and development?**

02

My toddler isn't making as much speech progress as expected for their age, and their words sound slurred or mumbled.

**Can you recommend a speech therapist to help my toddler with their slurred and mumbled speech?**

03

My toddler's balance and coordination don't seem to be improving despite our strict diet management.

**Would now be a good time to begin speaking more regularly with a neurologist or occupational therapist to help my child's balance and coordination? Are there other doctors or resources you can recommend?**

04

I want to start giving my toddler solid foods, but I'm afraid I may be unknowingly giving them something with galactose, especially if it's not obvious.

**Is there anyone on your team who can help me prepare my toddler for solid foods and understand which ingredients I should specifically look to avoid?**

LIFE STAGE

# Primary School Children



## Conversation Starters for Your Metabolic Team

01

My child is old enough to begin kindergarten, but I'm not sure if they're ready to begin school.

**Is there a way to evaluate if my child is ready to begin kindergarten or if they will need additional help in some areas before starting school?**

02

I understand that difficulty with speech can be a long-term effect of Galactosemia.

**Could you refer me to a specialist who can assess my child's speech issues?**

03

Learning and performing well in school seem to be difficult for my child.

**Are there any tests that can evaluate my child's cognitive abilities and identify how to potentially improve their learning and performance in school?**

04

I've read that ADD/ADHD and other attention issues can be symptoms of Galactosemia.

**How can I have my child assessed for ADD/ADHD?**

05

I've read that tremors and issues with balance, as well as difficulty with tasks like handwriting, can be symptoms of Galactosemia.

**How can I have my child assessed for these issues?**

06

I've been told that my child has been acting out and disruptive in school.

**Can you refer me to a specialist who can help to evaluate and potentially manage this behavior?**

07

I've noticed that my child doesn't seem to be able to be aware or process what's going on around them as I'd expect for a child at their age.

**Can you refer me to a specialist who deals with cognitive issues who can help to evaluate and potentially treat my child in this area?**



LIFE STAGE

# Teenagers



## Conversation Starters for Your Metabolic Team

01

My child is a teenager, and I want to make sure they're continuing to get the care they need for their Galactosemia.

**Can you recommend any specialists for additional neurological or psychological testing/monitoring for my teenager with Galactosemia?**

02

Staying focused in school is a struggle for my teenager.

**How can I have my child assessed for ADD/ADHD?**

03

My teenager is experiencing ongoing anxiety or depression and has been socially isolated and withdrawn.

**Could you refer my teenager to be seen by a psychiatrist or a specialist in this area?**

04

My teenager wants to begin taking charge of their diet on their own, but I'm concerned about not being as closely involved.

**Can you refer me to someone who can help my teenager become more independent with their diet management?**

05

I've read that women with Galactosemia can have fertility issues and may not be able to conceive.

**What types of tests should my daughter undergo to determine the potential impact of Galactosemia on her development during puberty and her ability to have children?**

LIFE STAGE

# Adults

## Conversation Starters for Your Metabolic Team

01

I know that some adults with Galactosemia develop cataracts because of their condition.

**Could scheduling more regular ophthalmologist appointments help keep adults with Galactosemia ahead of cataract development, and are there any other specialists you can refer me to?**

02

I'm the caregiver of an adult whose hands have been shaking uncontrollably, making it difficult for them to hold onto smaller items.

**Are there any tests that can be run in adults to determine whether hand shaking and difficulty grasping small objects is related to their Galactosemia, and if so, which specialist could help?**

03

I'm the caregiver of an adult who has started to experience seizures.

**Can you explain how Galactosemia leads to seizures in adults, and which specialist can help me understand what to be on the lookout for?**

04

I'm the caregiver of an adult with Galactosemia, and I'm concerned they're experiencing anxiety and/or depression.

**Can you refer me to a psychiatrist or psychologist who can help an adult with Galactosemia better deal with anxiety/depression?**

05

I've noticed that my loved one doesn't seem to be able to be aware or process what's going on around them as I'd expect for someone at their age.

**Can you refer me to a specialist who deals with cognitive issues?**

**Other things I may want to ask or share with my doctor:**

(Use this space to write down concerns between appointments to help you remember them)