

# Living Their Best Life

Learn what to expect with long-chain fatty acid oxidation disorders (LC-FAOD) during **infancy and childhood**



Advice and tips from other parents and families who have walked your path.



Ultragenyx has had the privilege of meeting with people and families living with LC-FAOD and gathering a collection of insights and tips directly from the community.

**In these booklets, we aimed to:**

- Capture the collective voices and experiences of the LC-FAOD community
- Provide key information to help you feel more prepared and supported

We would like to acknowledge and thank the Ultragenyx LC-FAOD Patient Leadership Council and the healthcare providers who provided substantive feedback and input on the development of these materials. We would also like to thank those community members who provided specific feedback to help ensure relevance for those living in Canada.

# Congratulations

on your new baby and a new chapter in life!



## A MESSAGE FROM PARENTS LIKE YOU

Welcoming a new child is a special time. Your family is growing, and things are changing. However, hearing the news that your child has an LC-FAOD, a rare disease that few people know about, can be very unexpected.



## WE'VE BEEN THERE TOO

As parents and caregivers, we know the time of diagnosis is filled with many emotions such as uncertainty, fear, stress, guilt, and grief. You and your family have many questions, and the around-the-clock commitment to caring for your child's special needs may be stressful and overwhelming at times.

**All of these feelings are completely normal.**

There's a lot of information to learn, especially in the beginning.



Be patient, take your time, and remember this is not a sprint—it's a **lifelong journey**.

From our experience, the more we learned about LC-FAOD and what our children needed to be healthy, the better and stronger we felt. **Over time, we partnered with our healthcare team to educate ourselves and became a source of knowledge, often sharing disease information and facts with loved ones, friends, healthcare providers and others.**

As we established routines, we were able to maintain a positive and hopeful focus on our children's future. **You are your child's best advocate when they are so little.** Trust your abilities. And remember, you will need to take care of your own well-being, too; it will be just as important to establish practices and routines that help nourish and support your needs.



**This booklet will help you learn what to expect during **infancy and early childhood**.**

The goal is to help prepare you for important issues that may arise, empower you to take action and communicate with your child's care team, and make the best decisions for your child and your family. Keep in mind this booklet is not designed to be a comprehensive roadmap for the coming years, but it will address key information you may need for the journey.

# Understanding the diagnosis



## A PERSONAL EXPERIENCE

*When I found out my baby's diagnosis, I felt lost and completely alone.*

Our care team was able to provide the information we needed about LC-FAOD and how to manage it, but I wished I could have talked to someone who knew what I was going through.

That's why I'm so passionate about sharing my story—to give others the guidance I wish I had back then! It may not always be a smooth road, but you are not alone on this journey.



## FROM ONE PARENT TO ANOTHER

*The first months may be the hardest.*

Most people haven't heard of LC-FAOD, and you're probably trying to talk to others about it while you're still learning about it yourself. Remember that it's up to you to determine what you feel comfortable sharing with others and in what situations.

For some of us it was very difficult to share at first, but it got easier over time once we knew how to talk about it and explain it in a way that other people could understand.

## TIPS FROM THE LC-FAOD COMMUNITY

Here are key points you should know about LC-FAOD:



**LC-FAOD are a group of rare metabolic disorders** that prevent the body from breaking down *long-chain fatty acids* to produce energy



**LC-FAOD affected approximately 455 people** in Canada in 2020. There are approximately 14 babies born with LC-FAOD in Canada per year.



**LC-FAOD are inherited (genetic) conditions.**

You may have questions about how your baby could have been diagnosed with LC-FAOD, especially if you and the other biological parent do not have the condition—**learn how a person inherits LC-FAOD at [FAODinfo.ca](https://www.fadinfo.ca)**



**LC-FAOD prevent the body from breaking down long-chain fatty acids to produce energy.** This is especially important during times of increased energy demand, such as fasting, illness, exercise, or other activities that require excess energy. Long chain fatty acids are an energy source that is critical for the proper function of organs, such as the heart and skeletal muscle



Learn more in the **Understanding LC-FAOD brochure** included in this toolkit



**LC-FAOD are chronic conditions** that may also have acute episodes which can happen at any time, and may require emergency trips to the hospital



**LC-FAOD often have recognizable signs and symptoms.** In young children, these may include muscle weakness, extreme sleepiness, lethargy or crankiness, changes in heartbeat, and/or changes in appetite. Talk with your doctor about what symptoms to watch for in your child

# Relying on your healthcare support network

## A PERSONAL EXPERIENCE

*In the beginning, I called my child's metabolic geneticist and dietitian all the time.*

When I spoke to them, sometimes I'd ask the same question three times to make sure I fully understood their answers. I always wrote it down and sometimes repeated it back just to be sure. I was fearful of making mistakes.



You can use the **Notes** pages at the back of the booklet to write down questions for your care team

## FROM ONE PARENT TO ANOTHER

*We can't stress enough how important it is to find a care team that you feel comfortable with.*

This way, you can work with them to learn all you can about LC-FAOD and how to manage the condition.

Your care team will be with you and your child over the course of your journey, so communicate often, and don't be afraid to speak up and raise any questions or concerns. Ask questions if you do not understand something completely. It makes a big difference and allows you to give your baby the best possible care.



See more tips in the **Communicating with Healthcare Providers** piece in this toolkit

## TIPS FROM THE LC-FAOD COMMUNITY

In the first year, every few months will bring a new stage as eating behaviors and sleep patterns evolve. Here are some important milestones and questions you might want to ask your dietitian:



### Infant to 3+ months: Sleep

- My baby is starting to sleep through the night. How frequently do I need to wake them for feedings?



### Around 6 months: Transitioning to solid foods

- How might the transition to solid foods impact my child's dietary management of LC-FAOD?
- How do I introduce new foods?
- Are there foods I should avoid giving my baby?
- What do I do if my baby isn't finishing solid foods?
- Are there any additional supplements that my baby needs to take?



### Around 9 months: Appetite

- Will my baby's appetite change if they become ill or are teething?
- Are there any precautions I need to take if my baby eats less?



### Around 12 months: Baby to toddler transition

- How do I transition to a low-fat, toddler-friendly formula or drink?
- How can I get my child to finish drinking all the contents of the sippy cup?
- My child is beginning to walk and be more active...how much activity is too much?

# Entrusting your child to the care of others

## A PERSONAL EXPERIENCE

*I went back and forth a million times trying to decide if I should send my child to daycare.*

I worried about a lot of things. *Would the daycare providers ensure my child was eating and drinking adequately? Would they recognize the warning signs and symptoms and know what to do?*

Ultimately, daycare was the right decision for me, my child and our family; however, it's a personal decision and one that may take some time to consider.

## FROM ONE PARENT TO ANOTHER

*It can be hard for any parent to leave their young child with another person—daycare, a babysitter, or a family member—but this is especially true when your child has LC-FAOD.*

You may wonder if the care provider understands the seriousness of the condition, if they will know what symptoms to look for in case of an emergency, and whether they can handle any issues that may arise. These concerns are perfectly normal and completely valid.

**Communication and planning are crucial** to ensure your child's health and safety and allow you to identify who you can entrust with the care of your child.

## TIPS FROM THE LC-FAOD COMMUNITY

Here are some tips that we've found helpful for others to understand how best to (or safely) look after your child. This information can help make the child's needs known by all who may come in contact with them:



**Explain LC-FAOD** and be open with caregivers and teachers so that they know the child's needs. Partner with your clinic for help with how to best explain the condition to others



**Write simple and clear lists** of what your child can and should not eat or drink, including preferences, and how often to eat or drink



**Share the types of games** that your child enjoys playing, as well as the **physical activities that are most appropriate**



**Provide information about warning signs and symptoms**, and advise about any triggers or activities to avoid



**Provide emergency contacts** and equip them with an emergency letter or instructions they may need in case of acute symptoms



**Make yourself available** if they have any questions about the child's diet and care



**Offer to talk** to all potential care providers, teachers, or school staff about LC-FAOD; in some cases, your child's healthcare team may be willing to speak with them and/or provide a letter



Read more tips on the "Prepare Others" page of **Living Well While Caring for Someone with LC-FAOD** in this toolkit

# Empowering your child



## A PERSONAL EXPERIENCE

*Starting at age 4, my child began to develop a growing sense of independence—but still had little self-control.*

I found this to be a good age to start involving them in the management of LC-FAOD and to help them better understand their body and how to keep it healthy.



## FROM ONE PARENT TO ANOTHER

*We recommend involving your child as much as possible in all aspects of their care.*

Try to educate them in simple terms they are able to understand. Involve them in things such as grocery shopping and meal preparation to give them some control over their food choices. Allow them to make decisions when possible. Starting this early and continuing to empower them to be more independent and responsible prepares them to be successful at managing their disorder on their own when they are older.

## TIPS FROM THE LC-FAOD COMMUNITY

When speaking to your child about LC-FAOD, be sure your tone conveys positivity and hope.



### Use simple examples to explain ideas

- When explaining why a nutritional plan is important, they should understand that they need to eat the right food so they don't run out of energy



Learn more in the **Understanding LC-FAOD brochure** included in this toolkit

- Show them that everyone has their own nutritional needs. "You know Grandma has to eat ABC every day" or "your best friend can't eat XYZ." Everyone needs different things to get the proper nutrition for their own body to grow and thrive



**Let your child know they can say "no."** Teach them to ask you before eating unfamiliar foods. Reassure them that it's OK to say no to food or drink that is unfamiliar or off limits



**Adopt a "no-pressure" attitude toward food and begin to involve your child in food choices.** Empower your child from an early age by including them in meal preparation, such as mixing ingredients or washing vegetables



**Talk about exercise.** Explain which activities will keep them healthy and strong and what they need to do to prepare for certain activities



**Help them learn how LC-FAOD may affect their body.** Encourage them to talk about anything that they may notice, feel or see that may be related to their condition



**Reassure your child that it isn't their fault.** They may not understand why they have LC-FAOD and may think that they did something to "deserve" it

# At school

## A PERSONAL EXPERIENCE

*School can be a tough decision—there's no 'right way,' and every situation is different.*

Our family decided home schooling wasn't the right choice for our son since he is outgoing and social. But we also knew that sending him to a day school would have challenges, like missed days for doctor visits or hospital stays, ensuring nutritional needs were met throughout the day, etc. So, we had to carefully plan how to best prepare the school for a child with LC-FAOD.

 See page 2 of **Share Your Rare Journey** included in this toolkit

## FROM ONE PARENT TO ANOTHER

*Anyone who comes in contact with your child will need a basic understanding of how LC-FAOD impacts daily life.* Be sure they know the signs and symptoms to look out for, what types of experiences can trigger a metabolic crisis, and how quickly it can occur. **Some important things to keep in mind:**

- **Share a copy of the emergency protocol** you've developed with your care team with the school in case of crisis
- **A medical ID tag (bracelet, necklace, shoe tag, etc.) for your child** to wear may also offer further peace of mind when you are not around
- Consider how the staff may be responding to all this information. **Keep the lines of communication open, but at the same time, set boundaries** to ensure they know to only contact you when it's necessary

 See "Take These Helpful Steps" in **Living Well While Caring for Someone with LC-FAOD** included in this toolkit

## TIPS FROM THE LC-FAOD COMMUNITY

Modifications to classroom rules may help your child adhere to their diet. You may suggest that the teacher:



Creates a **"no-swapping"** rule to prevent children from trading or sharing food



**Packs any leftover food** in your child's lunchbox so you can determine how much was eaten



**Keeps appropriate snacks** that you have provided at school for special events like class birthday parties



Allows child to **eat or drink as needed** in the classroom



### Sick days

**Talk to your care team and determine when to keep your child at home.**

Be sure to discuss their unique or individual symptoms and triggers that may cause or indicate a crisis that would require a trip to the emergency room.

*In addition to considering your employer's policies, consider what is provided in the federal or provincial/territorial employment standards legislation, as applicable.*

# Educating friends



## A PERSONAL EXPERIENCE

*I recall the first time I overheard my child explaining their condition to a classmate.*

I remember thinking that they tried their best, but their friend didn't quite get it. I spent that evening thinking about the best way to help them get the message across to their peers.



## FROM ONE PARENT TO ANOTHER

*Friends can be a wonderful source of support for your child, not to mention a healthy part of growing up.*

It's important that friends are educated about your child's conditions so that they can provide support during situations like lunch or playtime.

### Some things to consider:

- Invite friends over individually and **talk about LC-FAOD in simple language.** Make sure to give them a chance to ask questions!
- **Connect with advocacy groups** who can help introduce you to other families who have children in a similar age group
- **Role-play with your child** to help get them comfortable answering questions and explaining their condition

## TIPS FROM THE LC-FAOD COMMUNITY

Below are some pointers for talking to your child's friends about their condition.



**Be direct and honest about LC-FAOD and talk in simple language that children can understand**



**Clarify that no one can "catch" it**—people are born with it and it's no one's "fault"



**Discuss that people with LC-FAOD have to eat regularly** and eat certain foods to stay healthy



**Explain how some foods or certain types of physical activity can make the child sick—both immediately and over time,** and they can become extremely ill



**Focus on the positive by sharing "can do" activities instead of emphasizing the "can not do" activities**

- Discuss how there are some activities that are not safe, but with proper planning, there are plenty of activities that are!



## Building a community of support

For rare conditions like LC-FAOD, it can be challenging to find and connect with others who share similar experiences and challenges, and who can offer support—but this is also something most people seek out.

Refer to the **Building Your Support Network** brochure in this toolkit to find organizations that can help you make these connections and facilitate conversations.



# Playdates and sleepovers



## A PERSONAL EXPERIENCE

*The first time my daughter was invited to a slumber party, I couldn't bring myself to let her attend—there just seemed to be too many unknowns, and I worried about her safety.*

But when the next invite came, she wouldn't stop talking about it. I wanted to allow her to have fun social interaction while at the same time not experiencing separation anxiety. I knew I had to figure out a way to make it work...I did, and I hope this information can help you as well.



## FROM ONE PARENT TO ANOTHER

*New experiences like playdates or sleepovers can be stressful for a parent.*

You may worry about whether your child will be able to eat anything, or that they may eat or do something that's not good for them. It can also be stressful for the friend's parents, knowing that the child in their care needs special attention.

Keep in mind that these social interactions are a normal and healthy part of childhood. Encourage your child to attend, but make sure to discuss with them how they feel about it first. Ask if they are nervous or scared about anything. Getting these concerns out in the open will help them feel more confident and ease anxiety.

## TIPS FROM THE LC-FAOD COMMUNITY

Suggestions to help prepare for a safe playdate/sleepover at a friend's house.



**Call or meet with the friend's parents before the scheduled date** and review important information. Be sure to specify appropriate snacks or provide your own



**If your child will be with them for a meal**, help them with ideas to prepare simple foods that are nutritious and appropriate for your child



**Encourage your child to speak up as needed**



**Assure the parents** that they can reach you at any time



**Share a copy of the emergency protocol** you've developed with your care team



### Creating a LC-FAOD cheat sheet

A cheat sheet that includes signs, symptoms, and tips can be a helpful resource for friends' parents and can help them feel more comfortable when your child is in their care.

For suggestions on creating a cheat sheet, see "Prepare Others" in **Living Well While Caring for Someone with LC-FAOD** in this toolkit.

# Notes



Use this space to keep track of how your child is growing up and/or questions for your child's care team.

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# Goals to consider

## as your child transitions to their pre-teen years

You can help your child prepare for the next stage in life and gain more independence, and help set them up for continued success. Below are some suggestions to keep in mind as your child nears their pre-teen years.

### My child...

- Can explain LC-FAOD and the basics of what they need to do to keep their body healthy*
  - Is comfortable expressing their feelings about what they do or do not want to do*
  - Understands dietary restrictions and knows to ask when unsure about a food or drink item*
  - Knows how often they need to eat*
  - Can name their medications and supplements and can communicate what they are for*
- Understands healthy choices for physical activities*
  - Is comfortable reaching out to teachers if any LC-FAOD issues arise at school*
  - Is able to recognize symptoms that may indicate they need to stop their current activity and/or seek medical attention*
  - Feels empowered to talk about their life with LC-FAOD to their peers*
  - Is able to prepare/measure out medications and supplements with minimal assistance*



### Keep at it

**Not every child will accomplish these goals at the same time.**

Don't get discouraged—it's a process, so keep working towards achieving these goals. Remember, LC-FAOD is a lifelong journey.