

Living Your Best Life

Learn what to expect with long-chain fatty acid oxidation disorders (LC-FAOD) during **your teenage years**



Hear from teens—like you—living with LC-FAOD. Your parent, caregiver, or family will also find tips to help support you during this time.



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

Let's talk Teen to Teen

Welcome to your pre-teen and teen years

As you may already know, these years are filled with big changes in many areas of your life—from your social life to your developing body and self-image. These changes are normal, and can be awkward but everybody goes through them. For you, living with LC-FAOD will also play an important role in how you navigate these changes.



IT'S NORMAL TO FEEL UPS AND DOWNS

As teens, we often feel a mixture of emotions throughout this time. It's common to experience a range of feelings such as:

- Excitement about exploring new friendships
- Curiosity about physical changes happening to your body
- Fear about fitting in
- Potential anxiety about becoming more independent and taking more of a role in your health



EVERY BODY IS UNIQUE

It is during these years that you may become very aware that your body works differently than your peers. At times, you may feel angry about having LC-FAOD and maybe resentful about all the things you need to do to manage it. But the truth is everybody feels like they are different at some point, and that's because everyone has something truly unique about them.

The important thing is to move past the anger and stay focused on being you and taking care of yourself. And to do that while living with LC-FAOD—as hard as it might be at times—will require following the disease management and treatment plans recommended by your healthcare team.



This booklet will help you learn what to expect with LC-FAOD during your teens.

The goal is to **help prepare you for important issues** that may arise, **empower you to take action**, and **keep your health on track** together with your parents and care team. Keep in mind this booklet is not designed to be a comprehensive roadmap for the coming years, but it may help you process key information you may need for the journey.

Remember, now is the time to learn about yourself, what your body needs, and what things to avoid so that you can stay as healthy as possible.

By taking the right steps for you and your health, you can more easily become who you want to be.

Learning to accept life with an LC-FAOD is important

It's okay to feel anger, disappointment, or frustration that your life may not look like your friend's. **Consider if talking to someone, such as a counselor, might help you to understand and accept these feelings.** Talking about how you feel may help you stay focused on being you and taking care of yourself.



Tips from our parents to yours

These are crucial years as your child transitions into adolescence. With your love and support, you can help prepare your child and empower them as they **work toward becoming more independent.**

It might be challenging to relax some control over your child's life, but by doing this you are **giving your child the opportunity to take charge of their health and practice self-management, while building confidence in their abilities.**

Growing from a child into a teen



A TEEN'S EXPERIENCE

When I was 12, I felt like my parents treated me like a little child.

They wouldn't let me make simple choices about the foods I could eat, and I got the feeling they didn't trust me. I know that they were worried about my health and just wanted to do what's best for me. But I really wish they'd included me in some of the decisions—especially since they affect my body.



TEEN-TO-TEEN TIPS

It can be frustrating when your parents make all decisions for you.

But try to view it from their perspective: **they want to keep you safe and healthy.** Also, it may be hard for them to see that their "baby" is growing up and can do more for themselves. If you're feeling upset, talk to your parents and together you can come up with ideas to help you take a bigger role in decisions about your health.

You may already be able to keep track of some aspects of your health on your own, and with time and practice you will be able to do more and more without assistance from your parents. The best way to help them feel comfortable about allowing you more independence is to show them you are able to be more responsible for your health. But **it's important you keep the lines of communication open** with them, so that you are all in agreement.

Here are a few topics you may find helpful to talk about with your parents as you take steps towards becoming more independent and managing your condition.

- Foods that are OK and foods to avoid
- Bringing home uneaten food in your lunch box so that you and your parents can review what you've eaten
- How to track and monitor diet intake
- Not swapping lunch food or drinks with friends
- How to explain LC-FAOD and diet to friends, teachers, and coaches
- What to do if you are teased or embarrassed about your diet
- What safe and fun social activities could you take part in
- What to do if an unexpected situation arises
- Reviewing treatments that you need to take and demonstrating you know the doses and when to take them



Tips from our parents to yours

- **Keep the lines of communication open.** Give your teen the opportunity to ask for help or prompt them to let you know when they are ready to talk. Be there when they need you
- **Respect your teen's request** to not be treated as a child, allowing or encouraging some level of independence over their own health and care
- **Talk about how to handle their diet at school.** Explain that you will feel more secure if your child understands and is able to help manage their diet appropriately
- **Try to avoid handling all of your teen's care.** If there is something they are able to do on their own (eg, taking their own treatment, grabbing a healthy snack), let them do it

Understanding your unique body

A TEEN'S EXPERIENCE

When I was going through puberty, I was really shy about asking my parents any questions.

Sometimes, it was even hard for me to talk to my friends. I just assumed that since I had LC-FAOD what I was going through would be so different from everyone else. But the truth is, it wasn't all that different. Just find someone you feel comfortable talking to—whether it's a parent, teacher, friend or doctor—and speak up. You'll see what I mean!

TEEN-TO-TEEN TIPS

Your body is growing and changing in many ways during your adolescent years.

You probably have lots of questions about whether what you are experiencing is normal, especially as it relates to your LC-FAOD. You might not want to bring up your concerns because it can feel awkward. **However, it's important to speak up! Talk to whoever you feel most comfortable with—your parents, friends, and/or doctor.**

You can ask questions directly to the care team at your visits. You might be a bit nervous at first, but it will become more comfortable over time. Take it from us: you will learn so much, and you will be glad you did!



REMEMBER, if you have questions about your body, your health, or anything you are experiencing or feeling, talk about it. Find someone you can trust and start a conversation. While it might not be easy to raise some topics, it's better to address it rather than avoiding it and not getting answers.

Here are some questions about LC-FAOD you might want to bring up with your doctor or anyone else on your care team:



Signs and symptoms

- What symptoms will I have when I don't feel well?
- How do I recognize the early signs of a metabolic crisis? What can I do to be prepared?
- What do I do if I think my symptoms are becoming worse?



Physical activity

- What physical activities are OK for me to participate in? Which ones aren't OK?
- What do I need to do for my body before and after I exercise? (Or other physical activity?)



Managing your disease

- As a teenager with LC-FAOD, are there special considerations I should be aware of? Will my dietary needs change, and if so, how?
- What are the most important aspects of managing my disease? Besides my diet, is there anything else I need to focus on?
- Do you recommend that I wear a medical bracelet? What information should I have written on it?



Tips from our parents to yours

You can **help your teen understand their body changes and also empower them to take action at the same time.**

- Provide your child the opportunity to meet with their healthcare team one on one
- Encourage your child to speak up and ask their own questions during appointments

Enjoying your social life



A TEEN'S EXPERIENCE

On Saturday nights, my high school friends and I like to go the local arcades and then grab a bite to eat. Before leaving, my parents would ask me a million questions.

I knew that they wanted to make sure I was prepared for the outing and would be sticking to my LC-FAOD diet, but it really annoyed me! **So, I decided to talk to my parents about their concerns.** I assured them I'd eat properly before leaving, wouldn't exert myself, and would bring an extra snack in my pocket, just in case plans changed. I also let them know I'd call if I wasn't sure about something. After that discussion, I felt that my parents trusted me more and they felt confident I'd be making smart decisions.



TEEN-TO-TEEN TIPS

Building up your social network is a healthy and important part of being a teen and a positive step towards becoming more independent.

It is also beneficial having people who understand your needs and can advocate for you.

During these years, you might be making new friends, interested in dating or being in a relationship, or participating on a sports team or other extracurricular activity. You can enjoy these fun experiences the most if you make careful choices and prepare with your health in mind.

- **Talk with your healthcare team** to choose activities and prepare for them
- Make sure organizers of formal activities are **aware of your medical needs and have a copy of your emergency protocol**

Many social gatherings involve food! Whether going out for a meal or snacking at a friend's house, it helps to be prepared. You might consider:



Talking to your friends ahead of time about what LC-FAOD is, what foods are safe and healthy for you, and how you decide when you participate in a social activity



Preparing a list of foods that are appropriate for snacks. If you are invited somewhere unexpectedly, it will be easy to determine what you can have



Checking out a restaurant menu in advance or calling ahead and finding out what is available to meet your needs



Always carrying snacks on you so you may still be able to participate in the social activity, even if you are not able to eat what is being served

Remember, it's always OK to say no to foods that you are offered if you're unsure or you know they don't fit in to your diet.



Tips from our parents to yours

You can **help prepare your teen to handle different social situations** through encouragement and support of their independence.

- Talk to your teen about questions that they may get asked in social situations so they can **prepare in advance**
- Let your teen know that they can talk to you about their feelings and how they're managing their LC-FAOD—even if it's something they think you won't want to hear. Make sure they know **no matter what, you're there to help!**
- At the same time, don't force them to share their feelings when they're not ready. **Allow them space and let them come to you**

Testing boundaries



A TEEN'S EXPERIENCE

I was feeling stressed by my diet.

All day, every day, I thought about what I had to eat, what I couldn't eat, and what I wanted to eat. I just wanted to feel 'normal' for a day so one morning I woke up and decided to go ahead and try eating whatever I wanted. I thought I'd feel free and relaxed and maybe it wouldn't be so bad for me.

Instead, I noticed I felt fatigued by the end of the day, I wasn't able to think as clearly at school and didn't have the energy to hang out with my friends. I regretted my decision, and was grateful that my symptoms hadn't turned out to be worse. From then on, I decided that I wanted to change my mindset, so I never felt trapped by my diet or LC-FAOD.



TEEN-TO-TEEN TIPS

We all push boundaries and test our limits.

Maybe it's trying new foods, changing the types of people you hang out with or trying out a new style. At this age, when it comes to LC-FAOD, you may want to resist your disease management and treatment approaches. But those aren't areas you should push, because it can make you sick and have serious consequences. When it comes down to it, a health plan helps you stay well and be the best you can be!

Here are some suggestions to build a sustainable meal plan:



Get involved in meal planning and preparation. The more control you have, the more sustainable your diet will be (or feel)



Choose your snacks or pack your own lunch so that you decide what you are eating during the day



Ask your parent or whoever makes the food to **keep your LC-FAOD meals similar to family meals** so that you feel a part of and included in the foods that your family eats

We also found that **talking to our healthcare team about ways to take ownership of our LC-FAOD really helped**—we definitely recommend you doing the same! It may feel awkward or uncomfortable at first to ask for this type of help, but once you start the conversation, it will feel so much better.



Tips from our parents to yours

Encourage your teen's involvement with their health plan to establish lasting behaviors.

You might consider:

- **Empowering your teen** to ask for what they want so they don't make a habit of sneaking foods
- Reinforcing that they're healthy *because* they follow their treatment plan that their healthcare provider has set
- **Explaining how following their LC-FAOD protocol will help your teen grow** and be able to do the things they want to do
- **Talking about your teen's goals** may help them see how diet, exercise, and treatment are essential to achieving their life's goals

Creating a positive self-image

A TEEN'S EXPERIENCE

I used to think the other kids in school thought I was weird or different because of my LC-FAOD.

At lunch, I was the one who couldn't swap food. In gym, I was the one who needed to take more rests. And at parties, I was the one who brought my own snacks. After mentioning it to a few friends, I realized that what I was feeling wasn't how they looked at it at all. In fact, most of it was in my head and they hardly noticed the differences. My friends assured me while I need special care for my health, it doesn't get in the way of our friendship. They like me for me and just want to be my friend.

TEEN-TO-TEEN TIPS

As teens, we think a lot about how others look at us.

We may feel different because we have a rare condition. The people you spend a lot of time with can affect how you feel about yourself. Even how you talk to yourself can play a big part in how you feel about yourself. Try to think positive and surround yourself with people who understand and accept you the way you are. **Focus on what is most important—taking care of your body to stay strong and healthy.**

Talking about what's on your mind and the stresses that come with a chronic condition can also help. Some of us found it useful to speak with a **counselor or therapist, an adult you trust, or someone on our care team** to learn ways to cope with our personal challenges.



Learn from other people with LC-FAOD at ultrarareadvocacy.com

Here are some tips to help you see yourself in the best light possible:



Find physical activities that work for you: Regular exercise is not just good for your body—it's good for your mind too. It gives you more confidence in yourself and the way you feel about your body. Check with your doctor about what exercises are safe before starting a new routine



Avoid diets for quick weight loss: Healthy bodies come in all sizes. Learning about what's healthy for your body is important. Notice if your peers spend a lot of time talking about body shape or weight and how this makes you feel. You may decide that it doesn't feel good and you don't want to be part of those conversations. Talk to your dietitian about the diet that is right for you



Learn about what makes you unique and engage in positive activities for yourself. For example, *are you a good listener? Can you play the piano?* What activities do you find yourself immersed in for hours at a time?



Tips from our parents to yours

Teenagers who have a positive self-image are more likely to manage their health properly and may even avoid other risky behaviors. Here's how you can help your teen:

- **Set an example** by watching what you say about yourself and your own body
- Encourage your teen to **look at themselves as a whole person**, not just their outward body, and focus on your child's unique talents or skills
- **Discuss whether appearance is important to be successful.** Think of role models and those who made contributions to the world and examine if appearance was a significant factor
- Talk to your teen about how **having a rare disorder is nothing to be ashamed of.** This makes them unique and they can feel empowered by educating others about the condition
- **Allow space** to decompress and understand their own emotions, especially after something tough or hurtful happens
- Work together to **craft your teen's story** about LC-FAOD. It will empower them and give them a boost of self-confidence as they hone it and share with others. Refer to the "Crafting Your Story" resource in this toolkit.

Notes



Use this space to jot down your own notes and/or questions for your parents or care team.

My body

My LC-FAOD management plan

My physical activity

My thoughts and feelings

Other

Goals to consider

as you enter into adulthood

As you transition from your teen years to young adulthood, here are some ideas to help prepare you for this more independent stage in your life.

- I can talk with my friends about LC-FAOD and my diet.*
 - I speak confidently about my diet needs and restrictions.*
 - I can pack a bag of healthy foods to take to school or to a friend's house.*
 - I know to eat before an event to avoid being hungry or overdoing it later.*
 - I'm comfortable ordering food and beverages independently at restaurants and know what to look for.*
 - I can plan my meals or track my diet independently.*
 - I can discuss my feelings with a trusted person.*
 - I know what my treatment plan is.*
- If I feel overwhelmed or worried, I know I can talk to my parents or my care team, and they will help me or find someone who can.*
 - I feel comfortable talking to my parents/family about the help or support I want or need from them.*
 - I feel comfortable speaking for myself at my medical appointments and communicating directly with healthcare providers.*
 - I am learning how to make doctor's appointments and what questions or topics are important when it comes to having health insurance.*
 - I wear a charm/bracelet that identifies my disorder and gives access to my emergency protocol letter and medical history.*



Working towards independence

It is never too early or late to take part in managing your health. Don't get discouraged if you haven't achieved these goals yet. Achieving these goals is a process, and everyone has their own pace. Keep working at it.

Teens advance at different speeds. If you feel there is more information you are looking for at this age, such as preparing for college, please review the third booklet in this series, which supports young adults as they transition to adulthood.