

Communicating with Healthcare Providers

“Be as knowledgeable as you can on all topics. Don’t be scared to do the research.”

– Christy, mom of two children diagnosed with LCHAD deficiency

Living with or caring for someone with one of the long-chain fatty acid oxidation disorders (LC-FAOD) can be an overwhelming responsibility. It will require navigating the healthcare system, which can be complex and confusing.

LC-FAOD can affect multiple organs and **you may need to see many healthcare providers** including, but not limited to:

- Metabolic dietitian
- Neurologist
- Geneticist
- Ophthalmologist
- Cardiologist
- Gastroenterologist

As a result, you will likely need to learn how to **serve as a coordinator and self-advocate**. It’s important to provide each member of your healthcare team with consistent, detailed information so they can get a complete picture.

It may not always be easy to talk to healthcare providers, but creating a partnership with them based on mutual trust and respect can lead to better care. It can also potentially reduce some challenges and frustrations.

Your conversations may change over time based on your understanding of and experience with the disease, and can vary depending on the type of provider and their experience with LC-FAOD. Here we provide some tips that may help you **feel empowered** so that you can successfully communicate and collaborate with providers.



TAKE TIME TO PREPARE

- **Note questions or discussion points.** Write down any questions you may have and think about what information you want to learn at this visit. Bring this list with you and write down the answers, taking time to repeat them back to ensure you’ve captured everything.
 - What symptoms should I expect? Could these change over time?
 - Am I at risk for developing other health conditions because I’m diagnosed with LC-FAOD?
 - What lab tests or procedures should I expect to regularly undergo?
 - How do you prefer to communicate with your patients and families in between visits?
 - What should I do in the case of an emergency, both when in my local area and while traveling?
- **Do your homework.** Learn as much as possible about the disease and current research. Your healthcare team, government agencies, patient advocacy organizations, peer-reviewed journals that offer free, open access to scientific articles, and professional organizations are good resources for reliable information.

One example is the **International Network for Fatty Acid Oxidation Research and Management** (INFORM). It’s INFORM **Families** section has information about all of the LC-FAOD types and stories of people living with LC-FAOD. (<https://informnetwork.org/inform-families/>)

See the **Building Your Support Network** section of this toolkit for more detailed information about resources from advocacy organizations.



- **Create a complete medical history.** Some ideas may include:
 - A list of your current providers and their contact information.
 - Details about all medications, exact doses, when you take them, and who prescribed them.
 - A simple reference or description of your condition to share with new providers.
 - Organizing your information in one place such as a notebook, binder, or online file. Be sure it is easy to access and make extra copies to share with your healthcare providers.

Knowing the information that is important to your healthcare team and what to include in your medical history can be a challenge. This toolkit includes a **Medical History Template** you can use to get started.



GET THE MOST FROM YOUR VISIT

- **Be thorough, honest, and factual.** You may be tempted to downplay or perhaps exaggerate symptoms; instead, be realistic about your experiences.
 - Tell healthcare providers your specific symptoms, how often you experience them, how those symptoms interfere with your daily activities, and whether they impact your emotional or mental health.
 - Use numbers to explain symptoms like fatigue, energy level or pain. For example, many healthcare providers use scales or pictures to understand if your symptoms are not noticeable, mild, or at their absolute worst.
- **It's okay to repeat yourself, speak up, ask questions, and take notes.** If there is something you want to make sure your healthcare providers know, repeat it. It is also important that you understand the information the healthcare providers share with you, including lab and test results. Ask your providers clarifying questions, to repeat what they said or for a print out of the information discussed. Be mindful of your words and use statements like "I don't understand" or "I would like to discuss this further."
- **Let your child speak for him/herself when possible.** This can ease a child into the adult transition down the road. It is important for a child to learn about how the disease affects them and how to advocate for themself.



CREATE YOUR BEST TEAM

- **Build mutual respect.** Trusting and respecting your team's medical expertise helps to form the foundation for a strong partnership. Carefully consider your team's medical expertise while making sure to state what you disagree with or would like to further discuss.
- **Feel comfortable with your healthcare team.** You should feel confident in how a healthcare provider is managing your child's or your care. It may take some time to establish a connection with your team. Maximizing your time at the office by preparing questions in advance and ensuring questions are answered will help you gain confidence in your team.
- **It's okay to ask for a second opinion and explore your options.** If you're happy with your healthcare team but unsure about their advice or recommendations, you may want to seek a second opinion.
 - Be upfront about your desire to gain a few perspectives to make an informed decision.
 - Be sure to check with your insurance company first to understand if you have coverage for a second opinion.



For more information, check out the "Keys to Effectively Communicate with Healthcare Providers" **webinar** from **Global Genes**.
(<https://vimeo.com/178253392>)