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. At first, it may be hard to even know what types of questions you should be asking your doctor.

Here, you will find a list of meaningful questions that are designed to help you get the conversation started about LC-FAOD. Getting answers to these questions may help you understand more about this rare disease so that you ***feel empowered*** and get the best care possible.

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

- Cardiologist
- Geneticist
- Nurse
- Gastroenterologist
- Metabolic dietitian
- Ophthalmologist
- Genetic Counselor
- Neurologist
- Rheumatologist

You may find that it will be hard to schedule appointments with these healthcare providers from time to time. For example, you may need to schedule appointments up to a year in advance and sometimes may only be able to communicate with specialists through another healthcare provider, such as a dietitian. 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. Be patient as you wait for answers and make sure to always be proactive about your care so that you can get the most out of your communications with your healthcare team.

Keep in mind, 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. For example, as a parent, your child will become responsible for making healthcare decisions as they get older. Refer to the Living Your Best Life: Pre-teen & Teen booklet within this toolkit to help you better understand what this transition may look like.

TAKE TIME TO PREPARE

- ***Do your homework.*** Learn as much as possible about the disease and current research so you can determine what questions you want to ask to your doctor. 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). The 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/)
- ***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.
  - Are there any open LC-FAOD clinical trials or research studies? Can you tell me about them?
  - 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?

- ***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 to 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

- ***It may take time to build your healthcare team.*** The doctors and hospitals you visit can vary greatly depending on where you live. It may also be hard to schedule appointments with specialists as quickly as you might like to. Tap into your community, LC-FAOD network, and insurance to learn more about your options.

  When meeting with a provider:
    - Come prepared to appointments and know that some providers may not be familiar with LC-FAOD since it is a rare disease
    - Be upfront about your desire to gain a few perspectives so you can make an informed decision

For more information, check out the "Keys to Effectively Communicate with Healthcare Providers" webinar from Global Genes.
(https://www.youtube.com/watch?v=_R2GqT-G474)

- ***Know your options.*** Specialists may differ greatly in each province or territory. Learn about specialists in your area to see who may be the best fit for you. Consider contacting a patient organization or asking other LC-FAOD community members for recommendations.
- ***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.