Share Your Rare Journey

You've just received a diagnosis. Now what? A common next step is to learn as much as you can about your type of LC-FAOD, such as how to identify and manage symptoms, approaches to disease management and possible health complications that may occur in the future. You may also start to think about what the diagnosis means for you and your family and how it will impact daily life.

An important part of navigating life with LC-FAOD is identifying who needs to know about it and deciding how and when to explain it.

Telling your story is one of the most *powerful ways to advocate* for your needs. Sharing your personal experiences can help *educate* people about LC-FAOD and make an *emotional connection* with others by describing how it affects your life.

Who's Listening?

A first step is to think about the people with whom you interact frequently. What do they need to know? Do they need to know every detail, or would a broad explanation be enough? How might the emphasis of your story differ from one person to the next? Are there certain factors to consider such as your age, disease management needs, or other special circumstances?

FAMILY, FRIENDS, AND LOVED ONES

Keep in mind that you may need to have these conversations more than once before loved ones understand what LC-FAOD is and your needs. Learn to accept that your experiences are your own. While others may never be able to completely understand what your diagnosis is like, have patience with loved ones who make an effort to support you. Be patient and prepared for a potentially emotional conversation.

- ***Put it in context.*** Compare your experience to something they might already understand.
- ***Find time to have a one-on-one conversation*** in a casual setting, not at a large family or group gathering. This will give them, and you, the appropriate focus.
- ***Talk before a potential emergency*** when it will be harder to process and understand.
- ***Give them time to digest,*** knowing that some may not be sure what to say or how to help.
- ***Be open to discussing emotional and physical needs*** of other family members, particularly siblings of a diagnosed child.
- ***Leave the conversation open-ended*** and ask them if they have any questions.

Prepare for the future: Ask your geneticist or dietitian for an *emergency protocol letter* that can be given to school staff or emergency care personnel.

DOCTORS AND HEALTHCARE PROVIDERS

Because it's rare, you will need to continually educate healthcare providers who aren't familiar with LC-FAOD. To make this easier, build and maintain a care notebook/binder to keep all important information in one place. You may also choose to save some information on your phone or tablet for easy reference.

You'll most likely have regular visits with a variety of healthcare providers, each one playing a different role in the care of LC-FAOD. You may also interact with emergency care personnel who will need to quickly access certain medical information. You can help facilitate better care by making sure they have complete information. See Communicating with Healthcare Providers in this toolkit for additional tips.

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EMPLOYERS OR COWORKERS

You aren't legally required to tell your employer or coworkers. But, if you are in a supportive work environment, discussing your needs can be beneficial so you know about policies or accommodations that may be available to help you with your caregiving or disease management responsibilities. The Family Medical Leave Act (FMLA) is a federal law which allows an employee to take up to 12 weeks off per year for medical emergencies (this is unpaid time). Learn more about FMLA here: https://www.dol.gov/agencies/whd/fmla.

TEACHERS, SCHOOL STAFF, AND NURSES

Have your go-to resource (an article, pamphlet, toolkit, etc.) ready to help explain LC-FAOD and any specific needs resulting from the condition. There are accommodations required by law for people with medical needs. Be prepared to work with the school to develop a plan. It may take several conversations, but advocacy organizations have tools to help. See the Global Genes School Advocacy Toolkit for tips on navigating school systems with a rare condition here: https://globalgenes.org/wp-content/uploads/2018/10/School-Advocacy_ToolKit_spread_DIGITAL.pdf

While the information you decide to share may vary, *it's important to be specific*. For instance, explain that you or your child have certain needs, such as staying hydrated and sticking to a regular schedule of snacks, meals, and rest to avoid serious consequences, including hypoglycemia and rhabdomyolysis.

Advocate to a Broader Audience

Once you've mastered being an advocate in your everyday life, there are other ways you can make a broader impact – for yourself and for others living with LC-FAOD, or other rare diseases.

LEGISLATIVE OUTREACH

Reaching out to government representatives about your needs can influence and inform changes to healthcare policy. Reach out to EveryLife Foundation for Rare Diseases or the National Organization for Rare Disorders to get started.

AWARENESS BUILDING

Sharing information about LC-FAOD with reporters and community members in person and on social media can increase awareness and help raise funds for research. Some patient advocacy organizations have resources to kick off your efforts. For example, EURORDIS sponsors Rare Disease Day every year on the last day of February and provides many ideas for spreading the word.

RESEARCH PARTICIPATION

Clinical trials are one form of research, but there are many others such as registries, surveys, and advisory boards. To learn more about clinical trials visit ClinicalTrials.Gov or the Center for Information and Study on Clinical Research Participation (CISCRP) at ciscrp.org. Ask your healthcare teams or patient advocacy organizations for other types of research opportunities.