Living Well While Caring for Someone with LC–FAOD

Being a parent or caregiver to a child or adult with a long-chain fatty acid oxidation disorder (LC-FAOD) requires around-the-clock commitment, which can include:

- Carefully managing diet and nutrition
- Monitoring energy levels
- Watching for hard-to-predict and frequently changing symptoms

This can make it extremely hard to entrust your child or loved one's care to another person. Additionally, the relationship with your child's doctor may change over time as they transition out of pediatric care and into an adult setting. It can feel overwhelming, stressful, and unsettling. It's normal to worry. But it's important to remember that you can better care for your child if you also take care of yourself.

Inside find information on how to ***prepare*** and ***educate*** others to care for your child and ***help you*** get the breather you need. As your child gets older, you may use or reference the materials in this toolkit differently.

> "LC-FAOD is complex but manageable and these children can have a good life with the right care."
>
> -Michelle, mom to Jake, who is living with LCHAD deficiency

A first step may be identifying who can help. **For example, are there certain people who regularly visit with your child or loved one? Do you have extended family or close friends who live nearby? Are there certain people with whom you have built a close, trusted relationship?**

Prepare Others

EXPLAIN LC-FAOD

☐ ***Help your designated caregivers understand what LC-FAOD is and how it affects the body.*** Provide disease information (find some at informnetwork.org/inform-families) in advance; give caregivers enough time to digest the information and to ask questions.

☐ ***Describe how LC-FAOD affects your child.*** Explain the specific signs and symptoms that *your child* experiences, what actions or circumstances might trigger a crisis, and what may indicate that something could be wrong.

☐ ***Invite potential caregivers over to prepare meals or medical formulas together.*** After you've done this a few times, have the caregiver do most of the work while you're there.

☐ ***Carefully explain disease management needs.*** If you prepare food, medical formula, and/or dietary supplements in advance, mark each item with the time your child should take it, the amount they should take, and place the items in a designated area.

CREATE "CHEAT SHEETS"

Laminated cheat sheets or files on your phone that are easily shareable can be helpful tools for quick reference. Separate out the most important information so it is easy to spot and find. Arming your caregivers with this information will give them (and you) more confidence.

Be sure to include:

☐ A meal/feeding schedule: While most children snack during the day, you know it's even more important for kids with LC-FAOD to eat at regular intervals. Specify the times at which your child will need to eat something and indicate whether it's a full meal or snack.

☐ A list of dietary supplements or medical formulas, including doses, and when and how they should be prepared and/or taken

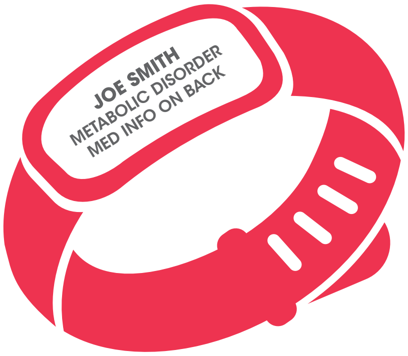
☐ A list that explains:
  - Foods they cannot have
  - Foods they can eat in limited amounts
  - Foods they can eat as much of as desired
  - Food preferences and favorites

☐ A list that explains limitations your child may have regarding certain activities, for example:
  - How far or long they are able to walk before they may experience pain or become unable to return without assistance
  - Specific activities or exercises they can enjoy in moderation

☐ Warning signs/symptoms to watch out for and what to do when they occur

☐ Key phone numbers (family, doctors, nearby hospitals)

TAKE THESE HELPFUL STEPS



There are additional ways to make sure others know how best to care for your child:

☐ ***Make sure they wear a medical alert tag or bracelet.*** This is a great way to inform others of their condition, which could require immediate attention in an emergency.

☐ ***Have an emergency protocol letter.*** If your child needs to visit the emergency room, an emergency letter provides the healthcare team with relevant medical and contact information. Your physician may already have a template they use. If not, MitoAction, a patient support organization, provides details about all of the information you might need in an emergency (https://www.mitoaction.org/planning-for-emergencies/). Work with your healthcare team to make sure you have all of the information you need.

☐ ***Request to meet with your child's school.*** It's important that teachers and other professionals in the school and educational setting understand if a child may have a specific medical diagnosis that could affect their physical or learning abilities. For example, you may choose to discuss any specific accommodations that the child may need at school. Accommodations may include allowing the child to have fluids or snacks during the day, limiting strenuous exercise in physical education class, providing excused absences for medical appointments, or allowing extra time to complete assignments or exams.

☐ ***Inform care providers about the emotional impact of LC-FAOD.*** Following a strict diet or eating regimen can be difficult and isolating, especially for a child. Ask that caregivers be sensitive and try to minimize calling unneeded attention to the situation.

> "Being a caregiver for a person with LC-FAOD is about learning how to step outside your comfort zone and continuously put the needs of another person above your own. Take each day one hour at a time, one feeding at a time. Remember to take care of yourself and your other relationships. Learn how to navigate the healthcare system and advocate for your family."
>
> – Jennifer, mom to Ava, living with VLCAD deficiency

Focus on Your Health

Forty percent (40%) of rare disease caregivers report having fair or poor emotional or mental health. Although you likely realize how important it is to take care of yourself, it may not always feel like something you ***can*** do.
But taking care of yourself is just as important as taking care of your child.

Taking some time for yourself can be an important way to recharge and de-stress, ultimately helping ensure that you have the energy and focus to care for your child.

It may help to:

☐ ***Talk to a healthcare provider or mental health professional,*** such as a counselor, psychologist, or psychiatrist if you're experiencing symptoms of depression. These symptoms may include a persistent sad, anxious, or "empty" mood, loss of interest in or pleasure from activities you enjoy, feeling hopeless or helpless, difficulty concentrating or making decisions, or difficulty sleeping, among others.

☐ ***Connect with other caregivers.*** Talking to other people who share similar experiences can be a powerful way to cope with stress and anxiety.

☐ ***Find a stress-reducing activity*** you like and try to make time for it or incorporate it into your routine; exercising, meditating, going for a walk, making art – or whatever works best for you.

☐ ***Do what you can to stay well,*** even if it's just one small activity a day until it becomes a habit - eat a balanced meal, go to bed early to get enough sleep, or take a few deep calming breaths in a quiet place.

☐ ***Get annual medical check-ups for yourself.*** It can be easy to focus on your loved one's medical appointments, but make sure that your calendar also includes visits with your own healthcare team.

☐ ***Find a respite care program.*** This can provide a temporary break for primary caregivers, whether in the home or at another facility.

Resources

- "The Respite Care Notebook" from the Child Neurology Foundation (childneurologyfoundation.org)
- "Rare Disease Caregiving in America" report from National Alliance for Caregiving (caregiving.org)
- "10 Tips for Family Caregivers" from The Caregiver Action Network (rarecaregivers.org)
- "Parenting a Child with a Life-Limiting Illness" toolkit from Global Genes (globalgenes.org)