FAOD IN FOCUS

LC-FAOD Self-Care Assessment

CPT I • CACT • CPT II • VLCAD • TFP • LCHAD Enzyme Deficiencies

This assessment will help you monitor your LC-FAOD symptoms and identify topics for you and your LC-FAOD healthcare teams to discuss.

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Patient name _____ Date _____

How is LC-FAOD impacting you or your loved one's life?

Take this assessment to find out and to identify topics to discuss with your healthcare team.
Contact your healthcare team if any symptoms concern you.

Activity and Symptoms

Are you/your loved one happy with your/their current level of activity?

☐ Yes ☐ No

Are you or your loved one missing, avoiding or limiting physical activities (i.e. walking, exercise, social activities, school, work, etc.)? If so, which ones?

_____

_____

How often? ☐ All of the time ☐ Sometimes ☐ Not at all

Are you/your loved one experiencing any of the following symptoms? Check all that apply.

Ongoing/Always (Chronic) Symptoms

- ☐ Loss of muscle strength or firmness
- ☐ Muscle pain
- ☐ Nerve pain
- ☐ Jaundice (yellowing of the skin) or other symptoms of liver dysfunction
- ☐ Vision problems
- ☐ Other

Occasional/Sometimes (Acute) Symptoms

- ☐ Irregular heartbeats or chest pain
- ☐ Shortness of breath
- ☐ Dark urine
- ☐ Muscle pain or weakness
- ☐ Dizziness or shakiness
- ☐ Digestive problems
- ☐ Other

When do you/your loved one experience these symptoms? Circle all that apply.

Mornings Mid-day Evenings All day During sleep

Symptoms last for: Circle all that apply.

0–60min 1–2hrs 2–4hr 4+hrs All day Only during physical activity

Are any of these symptoms new or have they recently changed?

☐ Yes ☐ No Explain further:

_____

_____

_____

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How would you rate your recent pain level? Circle one.

Min pain 1 2 3 4 5 6 7 8 9 10 Max pain

What typically triggers these symptoms? Check all body parts affected.

- ☐ Head
- ☐ Teeth/Jaw
- ☐ Neck
- ☐ Shoulders
- ☐ Arms
- ☐ Hands/Wrists
- ☐ Spine
- ☐ Torso
- ☐ Hips
- ☐ Legs
- ☐ Knees
- ☐ Feet
- ☐ Other

Please specify:

_____

_____

_____

Clinical Follow Up

How often do you meet with your LC-FAOD healthcare team (i.e., dietitian, genetic counselor, nurse, metabolic geneticist, other physician, etc.)?

- ☐ Weekly
- ☐ Monthly
- ☐ Every 3 months
- ☐ Every 6 months
- ☐ Yearly
- ☐ Other

Do you have an appointment scheduled?

☐ Yes ☐ No Date of next appointment: _____

Are you seeing any other specialists?

☐ Yes ☐ No Please specify: _____

Preparation for Discussion

Have you/your loved one experienced any other issues or challenges (social situations, mental health, school, workplace issues, etc.) while living with LC-FAOD?

☐ Yes ☐ No Please describe:

_____

_____

Thinking back on your last several visits with your healthcare team, what else would you like to share about living with LC-FAOD?

_____

_____

Are there any life goals you have that LC-FAOD has limited you from achieving? List any additional questions or issues to discuss with your healthcare team:

_____

_____

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