

CHECKLIST FOR THE NEWLY DIAGNOSED

FEEL

Allow yourself to feel sadness, anger, denial, grief, or other emotions that can occur. Know that these feelings are common and normal.

VISIT

Visit curemito.org and aboutleighsyndrome.com for information and resources. Join the patient registry.

SUGGEST

If friends or family ask how they can help, do not hesitate to give suggestions - some things families find helpful are making a meal or setting up a meal train, help with laundry, driving kids to activities, running errands. If coming up with ideas is too hard, assign one individual to be the contact person for others.

SELF-CARE

Do not neglect your self-care. This involves taking time for yourself, continuing to engage in activities that you love, growing spiritually, exercising, eating right, getting enough sleep and allowing others to help you.

REMEMBER

Remember that each person in the family may cope with the news differently. This is normal. Try to support and take care of each other, and get professional support if necessary.

FIND

Find a metabolic or a mito specialist. Ask your specialist for an emergency letter. Ask questions and learn as much as possible about your or your child's condition, available treatment options, medical interventions, and prognosis. Do not hesitate to advocate for yourself or your child and ask as many questions as necessary to allow you to make informed decisions and most optimal choices for your family.

CONSIDER

Consider having one friend or family member set up an information sharing website (such as CaringBridge) or send out weekly updates to the extended family, instead of you having to keep many people updated.



Preparing for a Doctor's Appointment

1

Get all logistical questions answered ahead of time. This includes knowing who you will be seeing, the duration of the appointment, whether any records need to be sent beforehand, as well as parking and other information.

2

Consider bringing a friend or a family member with you if that would be a source of support.

3

Make a list of questions to bring with you. Some families find it helpful to keep a running list of questions between appointments and write down questions as they come up.

4

Know that while the doctor is there to provide their knowledge, information, and recommendations, you are the one making all final decisions regarding yours or your child's care.

5

Speak up if you need clarifications on anything the doctor is explaining or if the information feels too overwhelming and you need time to pause and absorb it. Although speaking up may seem difficult, it will help you understand the information better and build a stronger partnership with your doctor and medical team.

6

Ask how to follow up, what is the expected response time, and who will answer your questions (doctor, nurse, other).



PARENTAL WELL-BEING GUIDE

Foundational ideas:

- In order to be a calm, robust leader for their families, parents need to prioritize time to care for their own physical and emotional needs.
- If parents can take a small action every day to support their own well-being, this supports the psychological and emotional health of the whole family.

Pay attention to physical and mental health basics:

- Adequate sleep
- Good nutrition
- Hydration
- Exercise
- Connection with people who care about you
- Time away from screens

Use cognitive strategies – develop a few scripts for managing difficult moments:

- “This is stressful but I’m not alone. I can tell _____ about it soon.”
- “I’m a good parent having a hard time. I’m going to try my best.”
- “I’m going to take 5 slow, deep breaths and then re-evaluate.”
- “This is an intense moment. I’m going to close my eyes and count to 20 so I can re-set.”

Consider which positive coping strategies worked best for you prior to getting your child’s diagnosis:

- Mindfulness, meditation, yoga
- Gardening
- Exercise – walk, dance, run, bike, swim
- Connect with friends or family – in person or virtually
- Read...or listen to an audiobook or podcast
- Take a bath or shower
- Play music or listen to a favorite play list
- Write, draw, or craft
- Therapy or parent coaching

Identify quick, 5-10 minute coping options that can serve as a daily well-being snack:

- Take a short walk
- Read one poem
- Play a quick game on your phone, such as Wordle
- Text a friend: “I have 5 minutes, are you free to say hi?”
- Use a meditation app (such as Calm, Headspace, or 10% Happier) for a 3 minute meditation
- Take a few slow, deep breaths
- Listen to one favorite song
- Ask a friend or family member to send you a silly meme or cartoon a couple of times a week (often a good job for a teen or young adult relative)

Mindfully manage your social media:

- Be thoughtful about the pros and cons of your social media diet
- Consider whether you generally feel better or worse after you spend time on a particular app
- Consider setting a daily time limit on some apps

