

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.

