



LIMB-GIRDLE MUSCULAR DYSTROPHY Caregiver Guide

“There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers.”

– Rosalynn Carter



LGMD-info.org

Caregivers play a vital role in the lives of many individuals living with limb-girdle muscular dystrophy (LGMD). Caregivers are often a spouse, parent, sibling, child, other family member, friend, or an employee. They all become important members of the LGMD community as they assist individuals with LGMD to live productive lives!

Being a caregiver is a tough, yet fulfilling, role that can be hard for others to fully understand. A caregiver has many important responsibilities during the course of a day. The role can feel overwhelming at times.

You could make the point that your most important overall responsibility is taking care of yourself. That may sound counter-intuitive, however a caregiver must stay in tip-top shape to successfully accomplish all the roles in a day, week or month. For these reasons, ignoring your own mental and physical health isn't an option because it leaves you unable to provide the level of care a loved one needs.

“Caregiving often calls us to lean into love we didn't know possible.”

— Tia Walker

While caregivers get great joy from their role, it can be isolating. When someone you love struggles with activities of daily living, it can be a heartbreaking experience for the whole family. As a caregiver, you see their struggles up close and personal in a way others don't, which can be a huge emotional burden to bear.

“Doctors diagnose, nurses heal, and caregivers make sense of it all.”

— Brett H. Lewis

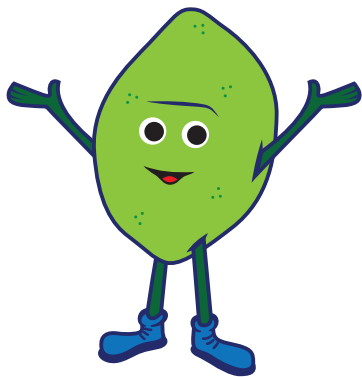
ADVOCATE

Take Care of Yourself

It can feel overwhelming to take care of a person with LGMD. Neglecting your own well-being can be harmful to you both. Trying to handle everything by yourself can lead to burnout, depression and health problems. Talk to others about your feelings. Holding in your feelings will only make you feel detached and neglected. It's always okay to open up.

See Your Doctor

Are you overeating? Unable to sleep? Always feeling tired? Not keeping up with routine health care appointments? Take these signs seriously. Seeing your doctor as needed helps you keep your own health in check.



EDUCATE

Mental Health and Caregivers

Caregivers are often so focused on their loved one that they neglect to take care of themselves. It is important for caregivers to be aware of their own mental and emotional health. Below are descriptions of common mental health concerns, which caregivers can use to recognize when a mental health issue may be developing. If you notice any of these signs, it may be time to check in with a family member, friend or healthcare professional.

Depression: Feeling sad, helpless, or hopeless most of the day, nearly every day.

Symptoms of depression may include:

- ✓ Loss of interest or pleasure in things that used to be enjoyable
- ✓ Less energy
- ✓ Sleep problems (trouble falling asleep or staying asleep, or sleeping too much)
- ✓ Changes in appetite
- ✓ Negative thoughts about yourself
- ✓ Feeling restless, jittery or wound up
- ✓ Easily distracted
- ✓ Difficulty making decisions
- ✓ Thoughts of ending your life

“It isn’t what we say or think that defines us, but what we do.”

— Jane Austen

Anxiety: An excessive amount of stress or worry most of the day that you have trouble controlling.

Symptoms of anxiety may include:

- ✓ Being more tired than usual
- ✓ Edginess or restlessness
- ✓ Being afraid of losing control
- ✓ Disturbed sleep
- ✓ Having trouble paying attention
- ✓ Feeling nervous or afraid
- ✓ Muscle tension
- ✓ Nausea
- ✓ Headaches
- ✓ Chest tightness
- ✓ Pounding or racing heart
- ✓ Difficulty breathing

Some of these symptoms may be signs of other medical conditions; it is important to see a healthcare provider to understand the symptoms and rule out other medical conditions.

Recognize caregiver burnout

Burnout occurs when a caregiver feels physically exhausted, emotionally worn out and overwhelmed. Often, the individual is under a lot of stress with little or no assistance.

Causes of burnout can include:

- ✓ Having unrealistic expectations for yourself
- ✓ Not taking adequate care of yourself (physically, emotionally and spiritually)
- ✓ 24/7 workload
- ✓ Balancing your work and a loved one's needs
- ✓ Demands from the loved one, such as not wanting help from anyone but you
- ✓ Exhaustion (emotional and/or physical)
- ✓ Lack of respite or breaks

How to prevent caregiver burnout

- ✓ Give yourself permission to take breaks.
 - ✓ Plan reprieve time, such as going away to visit a friend or family member while another family member, friend and/ or someone fills in to care for your loved one.
 - ✓ Talk to a friend, spiritual advisor or therapist you trust.
 - ✓ Ask for or accept offers of help.
 - ✓ Consider attending a support group or communicating with others in a similar situation.
 - ✓ Take care of your own health.
 - ✓ Set realistic goals for yourself.
 - ✓ Use smartphone apps for guided meditations.
 - ✓ Make sure your primary care provider is aware that you are the caregiver for your loved one.
 - ✓ If your feelings become overwhelming or you feel hopeless or helpless, contact your primary care provider or a mental health professional.
 - ✓ If you are employed, research family leave benefits offered by your employer.
 - ✓ Take slow, deep breaths; take a walk; read a book; take a bath; or practice yoga, meditation, or prayer.
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CELEBRATE

Understanding Resiliency

Just like the individuals living with LGMD, caregivers are adaptive and resilient. Those achievements are something to celebrate! Resiliency is your ability to recover and sometimes grow when faced with adversity; it is an active process of enduring and successfully coping. Resilience is bouncing back after a crisis. It's also bouncing forward to adjust to a 'new normal.'

It is not something that simply comes to you. Rather, it is the accumulation of behaviors, thoughts and actions that you can develop over time with focused, intentional work. Developing resiliency should not be equated with “becoming tough.” Resilient people show emotions, but are able to control them, move past painful feelings and remain positive.

Ways to Develop Resiliency

Developing resiliency is a goal often suggested by professionals as a positive way of dealing with and adapting to the realities of caregiving. Resilience is what makes the overwhelming seem bearable, transforms the senseless into an opportunity for growth and creates lasting stamina and strength throughout the caregiving journey.

For a practical approach, consider the following tips:

- ✓ Focus your energies by prioritizing what you need to address and letting go of the distractions.
- ✓ Reflect daily on what you have learned and accomplished.
- ✓ Seek guidance coming up with your own personalized resiliency-building strategy.
- ✓ Join a caregiver support group to connect with others and explore community resources.
- ✓ See what happens when you take small risks or try a creative approach to solve a recurring problem.
- ✓ Try to accept, rather than resist against, your role as a caregiver.
- ✓ Challenge yourself, even in the most difficult times, to find meaning, hope and possibilities.

You make the world better by simply being you!

CAREGIVER RESOURCES:

Angel Aid:

angelaidcares.org

Family Caregiver Alliance:

caregiver.org

National Family Caregivers Association / Caregiver Action Network:

caregiveraction.org

Raregivers:

raregivers.global

Today's Caregiver:

caregiver.com

Well Spouse Association:

wellspouse.org

"We love to Educate, Advocate and Celebrate our caregivers.
Thank you for all that you do! You are an LGMD Rockstar."

— LGMD Awareness Foundation



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