

CAREGIVER'S GUIDE

TIPS AND STRATEGIES FOR SELF-CARE



ONWARD

THIS BROCHURE AIMS TO SUPPORT YOU AS A CAREGIVER BY EXPLORING THE FOLLOWING TOPICS:



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THE IMPORTANCE OF CAREGIVING

Caring for someone with a rare and serious condition like thymidine kinase 2 deficiency (TK2d) can be highly demanding.

You may worry about understanding and living with your loved one's diagnosis and, at the same time, feel hopeful about the possibilities of new treatment options. You also might be concerned about navigating day-to-day life and planning for the future of your loved one, your family, and yourself.

Despite the stress and strain that can come from a lack of awareness and resources, rare disease caregivers feel empowered as they grow their advocacy abilities and help others learn about TK2d. They also acknowledge the positive aspects of being a caregiver to a loved one.





THE BIG PICTURE: UNDERSTANDING SELF-CARE

The Importance of Self-Care

There may be moments when you feel overwhelmed by the responsibilities of caregiving. You are not alone: Feeling the physical and emotional effects of caring for another person is normal.

There are things you can do to recharge so that you stay strong for your loved one when facing complex care situations or increased stress and strain.

Learn to identify the effects that caregiving may have on your physical health or emotional well-being. If you begin to feel the pressures of caregiving, explore outlets of support such as your healthcare provider or therapists.

EMOTIONAL & PHYSICAL STRATEGIES

The toll of being a caregiver can be significant. It's important that you address these burdens to maintain your mental and physical health. Here are some strategies for managing your feelings and thoughts:

Emotional Self-Care Strategies

- **Mindfulness Exercises:** A type of meditation where you focus on being very aware of what you're sensing and feeling right now, without judging or interpreting those feelings. This practice includes breathing techniques, guided imagery, and other activities that help relax your body and mind, reducing stress.
- **Journaling:** Write down your thoughts and feelings to process your emotions.
- **Seeking Emotional Support:** Reach out to friends, family, or support groups for emotional support.

Physical Self-Care Strategies

- **Time Management:** Develop a daily or weekly schedule to organize your tasks and activities efficiently. This helps you prioritize your responsibilities, stay on track, and make the most of your time.
- **Setting Boundaries:** Define clear limits on your time and energy to ensure you have dedicated moments for yourself. This helps prevent burnout and maintains a healthy balance between work and personal life.
- **Engaging in Hobbies:** Pursue personal interests or hobbies to maintain a sense of normalcy and joy.



FINDING MOMENTS FOR SELF-CARE

While it may feel overwhelming to think about working self-care into your busy schedule, there are steps you can take to get started. Here are some methods to introduce self-care into your daily activities in small but meaningful ways:

Plan for Healthy Eating

- Consider weekly meal planning. Meal planning provides opportunities to save time. Pick your recipes for the week, organize your shopping list, and consolidate preparation activities.
- Have healthy snacks on hand.
- Consider using a meal planning or delivery service to lighten your load.
- Everyone needs an occasional break. It's OK if you need to grab takeout or a prepared meal to save time when you're busy.



Schedule Exercise

- Coordinate with a friend to attend an exercise class.
- Block off time in your day, like you would an appointment.
- Start where you can. Even a 20-minute walk can be physically and mentally refreshing.

Get Adequate Sleep

- Aim for 6-8 hours of sleep per day.
- Put your phone away. Studies have shown evidence of improved sleep for those who stop using their phones 80 minutes before bedtime.
- Set up your bedroom to be a calm, relaxing environment.
- Consider blackout curtains so you can grab a quick nap during the day.

Studies have shown that those who plan their meals in advance are more likely to have a better-quality diet





PRIORITIZING YOUR PERSONAL WELLNESS

When taking care of others, caregivers tend to put their needs on pause. It is important to prioritize your personal wellness.

Stay on Top of Your Personal Health

- Don't minimize your physical needs or wellness.
- Listen to your body. Not sleeping well, lack of energy, and changes in weight are a few of the indicators that you may be burned out.
- Monitor your own nutrition and physical symptoms with the same care and attention you give to your loved one.
- Don't push yourself to the point of exhaustion.
- Make and keep your medical wellness appointments.



THE IMPORTANCE OF MAKING CONNECTIONS

Caregiving can feel isolating, so it's important to focus your energy on building connections outside of the home, too.

Build a Support Network

- Participate in support groups – local or online.
- Stay connected with extended family and friends.

RESOURCES

Finding resources can make a significant difference in your caregiving journey. Here are some resources that may be helpful:

Caregiver Networks*

Caregiver Action Network (CAN) serves a broad spectrum of family caregivers. This includes parents of children with significant health needs.

Visit www.caregiveraction.org.

National Alliance for Caregiving (NAC) is a nonprofit coalition of national organizations who share a vision of a society that values, supports, and empowers family caregivers to thrive at home, work, and life.

Visit www.caregiving.org.

Today's Caregiver is the first national magazine dedicated to caregivers that's a leading provider of information, support, and guidance for family and professional caregivers.

Visit www.caregiver.com.

Rare-Patient Advocacy Groups*

United Mitochondrial Disease Foundation promotes research and education for the diagnosis, treatment, and cure of mitochondrial disorders and provides support to affected individuals and families.

Visit www.UMDF.org.

MitoAction is a nonprofit organization founded by patients, parents, and Boston-area hospital healthcare leaders who had a vision of improving the quality of life for children and adults with mitochondrial disease.

Visit www.mitoaction.org.

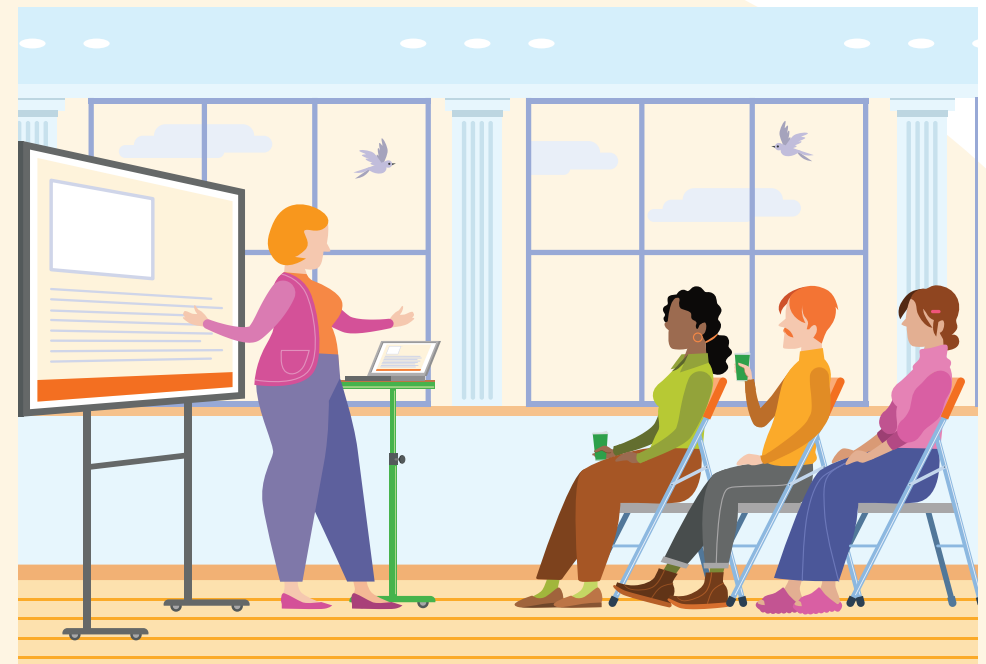
International Mito Patients is a network of national patient organizations that support and advocate for patients, fund research, increase awareness, and improve education in their countries.

Visit www.mitoaction.org.

The **Muscular Dystrophy Association (MDA)** is a voluntary health organization in the United States for people living with muscular dystrophy, ALS, and related neuromuscular diseases. MDA's mission is to empower the people they serve to live longer, more independent lives.

Visit www.MDA.org.

*This is not intended to be an exhaustive list of available resources and is being provided for informational purposes only. Be sure to look for local support groups that may be in your area. If you need help finding them, reach out to your ONWARD Care Coordinator.





HOW CAN YOU BEST TAKE CARE OF YOUR LOVED ONE? BY TAKING CARE OF YOURSELF.

Keep in mind that your health and emotional well-being are valuable and your role as a caregiver is important.

Make sure you take care of yourself so you may continue caring for your loved one.

This brochure is designed to nurture and empower TK2d caregivers, encourage self-care, and strengthen their endurance. For more information and support, contact your ONWARD Care Coordinator or scan the QR code to visit **ucbONWARD.com**.



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