

Navigating Crisis Responses for Caregivers in the Rare Disease Community



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Caring for individuals with rare diseases comes with unique challenges and emotional burdens. Here are some practical steps and considerations to help you navigate your emotions and maintain your well-being during times of crisis.

Crisis in the Rare Community

A crisis isn't always a single dramatic event. For caregivers, it can be a series of moments that evoke intense emotional responses due to:



Diagnosis

The moment of diagnosis can activate feelings of shock, grief, and fear.



Progression or Flare-ups

Worsening symptoms or unexpected medical issues can create significant stress.



Losses

Whether it's the loss of a trusted doctor, a critical medication, or financial stability, these changes can destabilize your sense of security.



Life Changes

Moves, changes in care routines, or shifts in family dynamics can all be sources of stress.

Key Reminders During a Crisis

Respond Don't React

Taking action can feel like you're doing something to exert control over a frightening & uncertain situation, but it can lead to impulsive decision making.

Pause Before Acting

Avoid making big decisions or offering more support during a crisis. Take time to process and stabilize first.

Acknowledge the Emotional Burden

Recognize and validate your own emotional responses. It's normal to feel overwhelmed, anxious, or depressed when dealing with the constant demands of caregiving.

Avoid Unhealthy Coping Mechanisms

Substance use or excessive drinking can exacerbate stress. Seek healthier alternatives.

Practical Steps for Emotional Wellbeing



Create a Crisis Plan

Have a list of trusted contacts, self-care routines, and coping strategies ready for times of crisis.



Set Boundaries

It can be hard to say no to family & friends. You don't need to "earn" or seek permission to stay home & rest.



Limit Caffeine & Alcohol

Caffeine & alcohol can make anxiety worse so cap your caffeine and alcohol intake, and avoid them altogether after 4 PM.



Plan for Caregiver Fatigue

Recognize that even the most supportive individuals can experience fatigue. Have a backup plan for additional support.



Educate Your Support System

Use resources like this to help friends and extended family understand the unique challenges of caregiving to foster compassion and long-term support.



Take Regular Breaks

Taking regular breaks from caregiving duties is crucial. Respite care can provide temporary relief, rest & recharge.



Prioritize Self-Care

Engaging in activities that bring joy and relaxation can help maintain emotional balance.

Emotional Challenges for Rare Caregivers

Guilt & Resentment



Caregivers often struggle with feelings of guilt, especially regarding the genetic aspects of rare diseases or the level of care they can provide. Open communication and family therapy can be helpful in addressing these emotions.



Hypervigilance

The constant state of alertness and worry about the care recipient's wellbeing can lead to chronic anxiety. Strategies like mindfulness, regular exercise, and engaging in hobbies can help mitigate these feelings.

This toolkit was co-developed by Patient Health Alliance in collaboration with Give an Hour, a national nonprofit whose trauma-informed mental health frameworks informed the structure and tools included.

For more information visit GiveAnHour.org/ContactUs



www.giveanhour.org/rarecaregivers