

Mental Health Considerations for Caregivers

Mental health, or emotional resilience, can be defined as an individual's ability to cope with normal life challenges, manage a range of emotions — both positive and negative — and adapt to changing circumstances.

When an individual becomes overwhelmed and experiences the inability to cope in certain situations, they might move from emotional resilience to emotional distress.

Sometimes, emotional distress can lead to making choices that have adverse effects, leading to more challenging situations. During these times, it is critical to get help from a trusted friend or family member, medical provider, or spiritual advisor. In addition, paying attention to one's feelings and practicing self-care on a regular basis can improve emotional resilience and mental health.



Get help from a trusted friend or a medical provider.



Mental health and caregivers

Caregivers play an important role in the neuromuscular disease community. Often, they are responsible for the physical care and emotional support of a loved one. Sometimes, caregivers are 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. The next page has descriptions of common mental health concerns, which caregivers can use to recognize when a mental health issue may be developing. If they notice any of these signs, it may be time to check in with a family member, friend, or healthcare professional.



TYPES OF MENTAL HEALTH CONCERNS

Depression

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

Depression can also include:

- ▶ Loss of interest or pleasure in things that used to be enjoyable
- ▶ Sleep problems (trouble falling asleep or staying asleep, or sleeping too much)
- ▶ Having less energy
- ▶ Feeling discouraged about the future
- ▶ Changes in appetite
- ▶ Feelings of guilt over things you did or didn't do
- ▶ Feelings of being punished
- ▶ Negative thoughts about yourself
- ▶ Crying or wishing you could cry
- ▶ Feeling restless, jittery, or wound up
- ▶ Having trouble staying focused
- ▶ Having a hard time making decisions
- ▶ Feeling that you have no value
- ▶ Loss of interest in intimacy
- ▶ Wishing you were dead or having thoughts of ending your life



Anxiety

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

Anxiety can also include:

- ▶ Edginess or restlessness
- ▶ Having trouble paying attention
- ▶ Being more tired than usual
- ▶ Feeling nervous or afraid
- ▶ Being afraid of losing control
- ▶ Disturbed sleep

Anxiety can also show up in the body as:

- ▶ Muscle tension
- ▶ Nausea
- ▶ Shakiness
- ▶ Headaches
- ▶ Chest tightness
- ▶ Pounding or racing heart
- ▶ Feeling hot
- ▶ Difficulty breathing
- ▶ Diarrhea
- ▶ Feeling like you're choking



Some of these symptoms also can be signs of other medical conditions, so it is important to see a healthcare provider to understand the symptoms and rule out other medical concerns.



Some people find the following tips helpful in dealing with feelings of depression and anxiety:

1. Get plenty of sleep.
2. Eat well and drink plenty of fluids.
3. Stop to find joy and positive experiences each day.
4. Exercise.
5. Practice deep breathing.
6. Use a stress ball or fidget gadget.
7. Try an activity such as knitting, cooking, or gardening, even if it is new to you.
8. Perform a random act of kindness.
9. Play with a pet.
10. Record your thoughts through journaling or creative writing.
11. Listen to music you enjoy.
12. Use creative outlets, such as playing an instrument, painting, or crafting.
13. Challenge your negative thoughts by thinking about something you do well, something others think you do well, or something you are thankful for.
14. Recognize your efforts by giving yourself a reward.
15. Organize your day so you don't feel overwhelmed.
16. Set a routine and follow it.

If these steps do not work, contact your primary care provider or a mental health professional.

Recognizing caregiver burnout

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

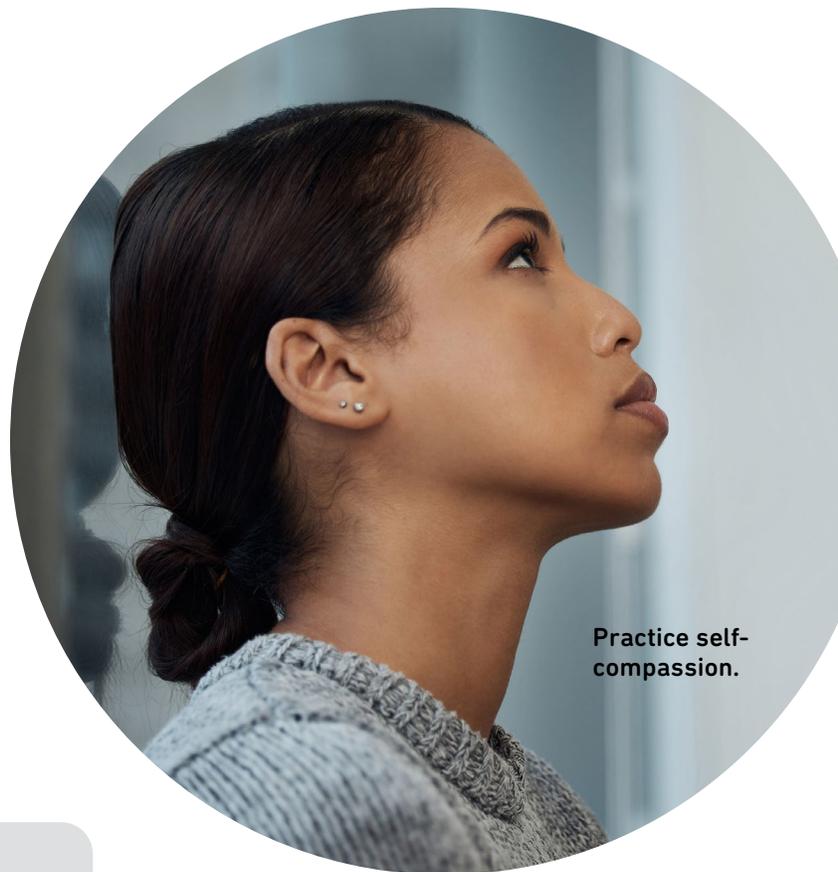
Causes of burnout can include:

- ▶ 24/7 workload
- ▶ Not taking adequate care of yourself (physically, emotionally, and spiritually)
- ▶ 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
- ▶ Having unrealistic expectations for yourself

Signs and symptoms of burnout include:

- ▶ Fatigue and/or lack of energy
- ▶ Becoming angry, irritable, impatient, and/or argumentative
- ▶ Changes in eating patterns
- ▶ Sleep problems (trouble falling asleep, staying asleep, or sleeping too much)
- ▶ Neglecting self-care needs (physically, emotionally, or spirituality)
- ▶ Social withdrawal and lack of interest in things you used to enjoy
- ▶ Anxiety, worry, or feeling on edge
- ▶ Sad or depressed mood
- ▶ Physical symptoms such as headaches, stomach aches, muscle tension or pain, or body aches
- ▶ Feeling you are losing control of your life
- ▶ Difficulty concentrating and coping with daily activities
- ▶ Finding little pleasure or interest in doing things
- ▶ Guilt or feeling selfish for taking care of yourself
- ▶ Denial about your loved one's diagnosis and/or prognosis
- ▶ Excessive use of alcohol, tobacco, or other drugs

If you experience any of the above symptoms for more than a week consistently, contact your primary care provider or a mental health professional.



Practice self-compassion.

How to prevent caregiver burnout:

- + Set realistic goals for yourself, which include taking care of yourself.
- + If you are employed, look into family leave benefits offered by your employer.
- + Practice self-compassion.
- + Recognize your physical and emotional limitations and be honest with yourself about them.
- + Use smartphone apps for guided meditations.
- + Give yourself permission to take breaks.
- + Take slow, deep breaths; take a walk; read a book; take a bath; or practice yoga, meditation, or prayer. These activities do not have to take long, but they may help you relax and regroup.



- + Plan respite time, such as going away to visit a friend or family member while another family member, friend, and/or sitter fills in to care for your loved one. You may feel renewed after taking a little time for yourself.
- + Talk to a friend, spiritual advisor, or therapist you trust.
- + Ask for or accept offers of help.
- + Accept what you are feeling. Having negative feelings does not mean you are a bad person or caregiver.
- + Consider attending a support group or communicating with others in a similar situation.
- + Take care of your own health.
- + 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. Insurance companies usually offer lists of covered mental healthcare providers.



Resources for caregivers

Visit these websites to find more tips and resources for caregivers:

[16 Ideas for Recharging Your Caregiving Energy in 15 Minutes](#)

[AARP's Family Caregiver Resource Guides](#)

[Caregiver Burnout: Steps for Coping With Stress](#)

[Community and Culture Help Black Caregivers Cope With the Challenges of Family Caregiving](#)

[How Family Caregivers Can Determine if They Are Drinking Too Much](#)

[MDA Engage: Caring for the Caregiver](#)

[MDA Guide for Caregivers](#)

[Respite Care: Create a Plan to Give Yourself a Caregiving Break](#)

[The Nonstop Juggle of Compound Caregiving](#)

[The Sandwich Generation Feels the Caregiving Crunch](#)



Give yourself permission to take breaks.

To learn more about mental health resources, contact the MDA National Resource Center at **833-ASK-MDA1 (275-6321)**.

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