

# Caring for Your Mental Health

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. For example, someone who is under stress because they are facing changing circumstances — like a new diagnosis, loss of function, or impaired decision-making — may begin to develop unhelpful patterns. During these times, it is critical to get help from a trusted friend, 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.

## Mental health and neuromuscular disease

Being diagnosed or living with a neuromuscular disease is difficult and can lead to stress and grief. These issues can worsen one's current health, cause new medical problems, and increase inflammation in the body.



## Stress and strong emotions can cause physical symptoms, such as:

- ▶ Digestive problems
- ▶ Headaches
- ▶ High blood pressure
- ▶ Chest pains
- ▶ Sore muscles
- ▶ Skin problems
- ▶ Shaking
- ▶ Increased heart rate
- ▶ Fatigue
- ▶ Nausea
- ▶ Trouble sleeping and/or changes in sleep patterns
- ▶ Oversensitivity to noise and light



These symptoms may go away in time. However, they can get worse or come back when you experience stress again.

Every person is unique in how they react to situations; the same event may be experienced differently by different people. In addition, neuromuscular diseases vary in their symptoms and progression. Some people are affected from an early age, while others are diagnosed later in life.

Some people are more likely to experience a serious mental illness whether or not they have a neuromuscular disease. Risk factors for developing mental illness can include but are not limited to:

- ▶ Personal history of mental illness
- ▶ Family history of mental illness
- ▶ Social isolation
- ▶ Lack of a support system

Having a neuromuscular disease can affect the direction of one's life and may force a person to change some of the hopes and plans they had for the future. This could include adjusting their living situation, work or school plans, and relationships. All of these changes can add up to an increased risk of mental health issues.



## Cognitive changes with neuromuscular disease

Some neuromuscular diseases can cause changes in how a person thinks, which can have an effect on their daily routines.

Cognitive changes can affect:

- ▶ Language, such as difficulty with communication and trouble thinking of the words you want to use while talking
- ▶ Memory
- ▶ Organization skills, such as starting, planning, or completing tasks
- ▶ Control over emotions or impulses
- ▶ Judgment of what is appropriate behavior
- ▶ Attention span
- ▶ Self-awareness

Family members need to be aware that cognitive impairment can affect their loved one's medical care. Those living with neuromuscular disease may have a hard time communicating and may lack awareness, leading to poor compliance. If someone with a neuromuscular disease experiences any of the above symptoms, caregivers should bring it to the attention of their treatment team. Many caregivers find it helpful to write down their observations to have on hand at doctor's visits.

A person with a neuromuscular disease faces unique challenges. They may experience frustration, anger, embarrassment, self-pity, and anxiety. These feelings may be perfectly natural reactions to living with the effects of their disease — if the feelings are temporary and do not interfere with daily living. They may experience these negative reactions at different times as they go through developmental stages and as their disorder progresses.

If you are living with a neuromuscular disease and notice any of the symptoms or feelings discussed here, share that with your caregiver. If you are not comfortable letting your caregiver know how you feel, talk with a trusted friend, family member, or spiritual advisor who will listen and offer support. If your feelings are overwhelming or you do not feel safe in your environment, it may be time to reach out to someone else, such as your primary care provider or a mental health 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
- ▶ Having less energy
- ▶ Feeling discouraged about the future
- ▶ Changes in appetite
- ▶ 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
- ▶ 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 include:

- ▶ Edginess or restlessness
- ▶ Having trouble paying attention
- ▶ Being more tired than usual
- ▶ Feeling nervous or afraid
- ▶ Fear 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 can also be signs of other medical conditions, so it is important to see a healthcare provider to understand the symptoms and rule out other medical issues.



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. Set a routine and follow it.

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

## Recognizing suicidal thoughts

If you or a loved one is saying things such as, "Life is not worth living," or "I can't do this anymore," seek immediate psychiatric intervention, which could include calling 911, going to the emergency room, or calling the **National Suicide Prevention Lifeline** at **800-273-8255**.

Thoughts of suicide or self-harm can be triggered by:

- ▶ Loss of friends and social connections
- ▶ Recognizing that your life is taking a different path from those around you
- ▶ A new, serious medical diagnosis for you or a loved one
- ▶ Pain
- ▶ Disability
- ▶ Loss of independence
- ▶ Feeling different from others

Statements and behaviors indicating suicidal thoughts should always be taken seriously. It is important to bring this information to the attention of medical and mental health professionals as soon as possible.

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

Each state has its own regulations for obtaining an evaluation for someone unable or unwilling to request one. These regulations cover the steps for involuntary assessment and/or commitment if someone may be a danger to themselves or others.

## How caregivers can help

It is not uncommon to notice a loved one with a neuromuscular disease experiencing a period of frustration, anger, self-pity, or anxiety. If these feelings have developed recently, you may be able to help by asking about their feelings and encouraging them to talk about what they are going through. You may be able to make some changes to their environment that can help them cope better with challenges.

However, if those feelings persist or your loved one is exhibiting signs of a mental health concern listed on the previous page, it is vital to ask for help from a trusted friend, family member, spiritual advisor, or medical provider.



### Mental health resources

These resources can help you find a mental health professional or other mental health support:

American Psychological Association  
Psychologist Locator

Child and Adolescent  
Psychiatrist Finder

MDA Mental Health Hub

MDA Resource Center

National Alliance on Mental Illness  
(NAMI) HelpLine  
**800-950-NAMI (6264)**

National Suicide Prevention Lifeline  
**800-273-8255**

Psychology Today

Substance Abuse and Mental Health  
Services Administration (SAMSHA)  
National Helpline  
**800-662-HELP (4357)**

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