

What to Expect from Mental Healthcare: A Guide for People with MS



DAMIAN
DIAGNOSED IN 2015



National
Multiple Sclerosis
Society

What to Expect from Mental Healthcare: A Guide for People with MS

Contents

What is mental health?.....	2
Unwanted and challenging emotions	2
Resilience	2
Depression, anxiety and other common mental health concerns	3
What is depression?.....	3
What is anxiety?.....	4
Overlapping symptoms	5
Other challenging emotions.....	5
Suicidal feelings.....	5
How to seek professional help.....	6
Who treats mental health conditions?	6
Types of mental healthcare for MS	7
4 questions to ask yourself before seeking treatment	8
Where to find a mental healthcare provider.....	8
11 questions to ask a potential provider	9
What to expect from a provider	10
Things you can do right now	11
Exercise	11
Engage in activities.....	12
Build coping skills and resilience	12
Health insurance	14
If you don't have health insurance	14
If you have health insurance	14
Resources	16
Support for people living with MS	16
Carepartner support.....	16



Multiple sclerosis can have a significant impact on a person’s emotions and mental health (or well being). Not only can MS be challenging to live with, but it can also affect the parts of the brain that control mood. For these reasons, it’s important to pay attention to mental health — as well as physical health — when living with or treating MS.

The following guide outlines some basic information on mental health (also referred to as “emotional health”), types of mental health diagnoses, and options for seeking providers, including ones covered by insurance. It also includes strategies you can use right now to improve your emotional well-being, even if you do not have a mental health condition, as well as resources for further investigation.

“I feel anxious sometimes, even sad occasionally, but that seems normal. What is mental health?”

What is mental health? »

“I feel nervous or unhappy. Everything just feels hard.”

Depression, anxiety and other common mental health concerns »

“Where do I find a therapist? How do I know if they’re the right one for me?”

How to seek professional help »

“Most of the time I feel OK. But what can I do to take care of my mental health?”

Things you can do right now »

“How do I find a therapist who takes my insurance? What if I can’t?”

Health insurance »

“Where else can I go for support?”

Resources »



What is mental health?

“Mental health” is a phrase used to describe our emotional, psychological and social state. It touches every aspect of our life — how we feel, think and act, and our overall health. Without good mental health, we may struggle to handle stress, relate well to others, take care of ourselves and make good choices.

Mental health is influenced by our situation and environment. The people around us, our community, the barriers — and the supports — in our lives all affect how we feel. Mental health is not just about challenging emotions. It also includes positive feelings like joy, contentment and confidence.

Unwanted and challenging emotions

At times, we will all have uncomfortable or unwanted emotions like anxiety, worry, sadness, grief, anger and frustration. Sometimes these emotions can be helpful. They can tell us that we need to pay attention to what we are feeling, doing and thinking. They can motivate us to make changes in our thoughts or behavior, to seek support or to take a different approach to a situation.

Uncomfortable or unwanted emotions can also be problematic, however. If they stick around for long periods of time and interfere with our ability to conduct our lives and take care of ourselves, it is a sign that we need help.

Resilience

Resilience is the ability to bounce back from difficult circumstances — to find happiness and life satisfaction despite challenges with relationships, finances, health or any of the many stressors that we face in life. Resilience is not about acting happy all the time or ignoring real difficulties. In fact, it’s quite the opposite: A significant part of being resilient involves what researchers call “positive adaptation” or “realistic optimism” — remaining hopeful about the future while making plans that enable us to cope with our actual reality. It requires both hope and courage. Learn more in the Society’s booklet, **Resilience: Addressing the Challenges of MS / Resiliencia: Cómo enfrentar los desafíos de la esclerosis múltiple**.

Everyone — including people with MS — can benefit from nurturing their mental health and focusing on emotional wellness. Strategies to manage challenging emotions can help prevent more serious mental health conditions or help you tackle them when they show up. Learn more in the sections that follow about what you can do on your own or by connecting with others — either a professional or other people in similar situations.

Depression, anxiety and other common mental health concerns

Approximately 50% of people with MS will experience a depressive episode in their lifetime. The high rate of depression among people with MS results in part from the anxiety, uncertainty, grief and fear caused by having MS. Brain lesions that develop because of the disease can also cause depression.

What is depression?

Depression might manifest as a period of deep sadness and/or loss of pleasure in previously enjoyed activities. It may be accompanied by symptoms such as:

- Sadness and or irritability
- Loss of interest or pleasure in everyday activities
- Changes in appetite
- Sleep disturbances (either insomnia or excessive sleeping)
- Agitation or slowing in behavior
- Fatigue and lack of energy
- Feelings of worthlessness or guilt
- Problems with thinking or concentration
- Persistent thoughts of death or suicide

Everyone experiences low periods from time to time. Challenging emotions may increase when people with MS are first diagnosed or they experience significant changes in their functioning. You should talk to your healthcare provider if you have periods of distressing emotional experiences that:

- Stick around for weeks or months
- Interfere with your everyday life, activities or relationships
- Get in the way of taking care of your health
- Feel out of your control

What is anxiety?

Everyone has felt anxious at some point. Feeling nervous, tense, panicked or worried are typical of anxiety. Anxiety may lead to increased heart rate, sweating, trembling, fatigue, sleep disturbance, GI problems or difficulties with concentration and memory.

Like depression, anxiety symptoms and disorders are common in people with MS. Approximately one in three people with MS will have an anxiety disorder at some point in their life. Even more people with MS experience anxiety or stress at various times throughout their lives. Anxiety understandably tends to be more common during and after diagnosis, during MS relapses or after changes in functioning. Anxiety often goes along with depression, too.

Anxiety disorders occur when the symptoms are pervasive, last for months or longer and interfere with your daily life, your health and your quality of life. There are different types of anxiety disorders such as:

- **Generalized anxiety disorder** involves persistent, excessive anxiety, dread and worry out of proportion to your actual circumstances. It is more severe than simply worrying about stressful life events or experiencing occasional anxiety.
- **Panic disorder** involves frequent, unexpected (out of the blue) panic attacks, which are sudden episodes of intense anxiety, discomfort, fear or terror. During a panic attack, people may have feelings of impending doom, sweating, trembling, tingling, shortness of breath, chest pain or a rapid, fluttering heartbeat or heart palpitations.
- Some people with MS may have **phobias** such as a fear of needles or medical procedures that may provoke a panic attack or lead the person to avoid treatments out of fear.
- **Agoraphobia** involves a fear of being out in public, being in a crowd, being in enclosed spaces, or in situations or places that might trigger a panic attack or make you feel trapped, embarrassed or helpless.
- **Social anxiety** entails high levels of fear and avoidance of social situations due to self-consciousness or concerns about being judged negatively by others.

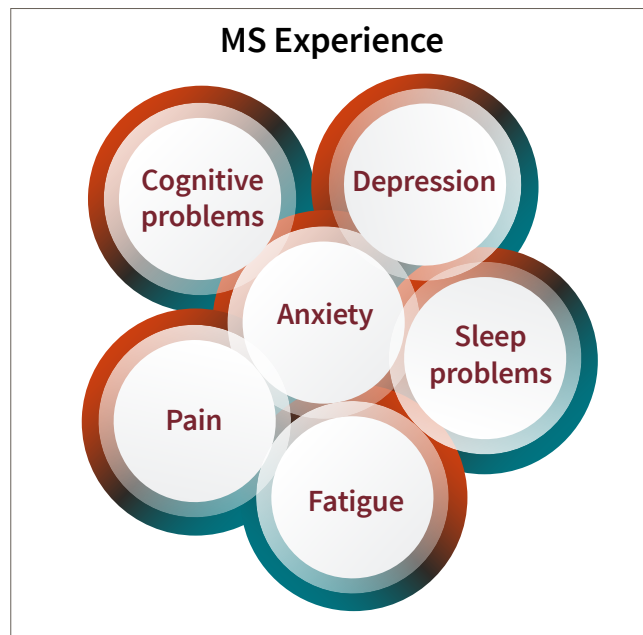
The good news is that anxiety is particularly responsive to therapy, as described in the next section.

Overlapping symptoms

The symptoms of MS can also overlap, intersect or impact the mental health symptoms. For example, pain might make it harder for someone with MS to sleep, or fatigue may make the experience of depression even more draining.

Mental health symptoms can also worsen MS symptoms such as fatigue, pain, spasticity and attention or memory problems. Treating your mental health concerns can improve your MS symptoms, which is why it is so important to address your mental health when you have MS.

It can be overwhelming to think about how to manage all these different problems. The good news is that you can learn skills to manage any troubling symptom, including ones associated with mental health.



Other challenging emotions

Not every challenging emotion is caused by MS. You may have emotional experiences unrelated to MS that require more specialized mental health treatment. For example, some people with MS have a history of trauma or other longstanding mental health difficulties, that may not be a direct result of their MS, but may contribute to how they feel overall. Take this into consideration as you look for a mental healthcare provider.

Suicidal feelings

Severe depression can be a life-threatening condition because it may include suicidal feelings. One study found that the risk of suicide was 7.5 times higher among persons with MS than the general population. If you are having thoughts of harming yourself or feel you are at risk of hurting yourself or someone else, call the National Crisis Hotline at 1-800-273-TALK (800-273-8255). You can also text HOME to 741741 to connect with a crisis counselor at the Crisis Text Line. **For an emergency, call 911.**

Individuals with MS may experience emotional symptoms that are a direct result of their diagnosis, are related to MS but not a direct result, or have nothing to do with MS. It may be helpful to have a one-time visit with a mental health provider and ask them to make recommendations for treatment. If they refer you to someone else, try not to feel frustrated. Just like your primary care provider, they may be referring you to the specialist who can help you the most.

How to seek professional help

Whether you are depressed or you just want to develop some new coping skills, mental healthcare providers can help. Take some time to consider what kind of professional you might need and to define your goals for treatment. Then use the resources that follow to begin your search.

Who treats mental health conditions?

Mental health specialists — experts in emotional and mental health — have specializations, just like physicians. These specializations can be grouped into 1) those who practice only therapy (also referred to as “talk therapy” or “counseling”) and 2) those who prescribe medication, who may also practice talk therapy.

Different types of specialists have different training. Some of the specialists you might consider include:



Psychologist

A psychologist has a doctoral degree and treats conditions with therapy. Those with MS may consider seeing a rehabilitation or health psychologist. These specialists evaluate, diagnose and treat mental health conditions in people with conditions such as MS. They will help manage physical symptoms such as chronic pain and fatigue, and will help people cope with losses resulting from the disease. Psychologists do not prescribe medications.



Neuropsychologist

A neuropsychologist has a doctoral degree and specialized training in the evaluation of cognitive functions. They use a battery of standardized tests to assess specific cognitive strengths and impairments. Some neuropsychologists also treat mental health conditions, although most focus on evaluation rather than treatment.



Clinical Social worker

A clinical social worker focuses on the assessment, diagnosis and treatment of mental health conditions. Individual, group and family therapy are common treatment modalities. Social workers help people cope with losses and other symptoms and changes resulting from the disease. They do not prescribe medications. Social workers who provide these services are required to be licensed or certified at the clinical level in their state of practice.



Psychiatrist

A psychiatrist is a physician who diagnoses and treats mental health conditions, most commonly through medication.



Other mental health providers include marriage and family therapists, licensed professional counselors, licensed clinical alcohol and drug abuse counselors, and psychiatric or mental health nurse practitioners.

Many of these specialists will have received more in-depth training in specific areas of mental healthcare. Before you decide to work with someone, learn more about their training and practice to determine whether or not they are the right fit for you.

Types of mental healthcare for MS

Cognitive Behavioral Therapy (CBT)	Acceptance and Commitment Therapy (ACT)	Mindfulness-based Interventions	Dialectical Behavior Therapy (DBT)
------------------------------------	---	---------------------------------	------------------------------------

Just as when you see a physician, the type of treatment you need depends on your symptoms. Medications, psychotherapy or both are commonly used to treat mental health conditions. Clinical trials have shown that the treatments that are effective for mental health conditions in the general population are also effective for people with MS. However, it is useful to have a provider with at least some experience working with MS.

Cognitive Behavioral Therapy (CBT), Acceptance and Commitment Therapy (ACT), mindfulness-based interventions and Dialectical Behavior Therapy (DBT) have all been shown to be effective for people living with MS. In these treatments, the therapist not only listens to you, but also teaches you specific skills to use with your symptoms. For example, if you are anxious, the therapist will teach you relaxation or mindfulness techniques to decrease your anxiety. Depending on your condition and treatment goals, psychotherapy may involve a variety of therapeutic techniques such as CBT.

For specific problems, very structured treatments may work best. For example, a treatment called **CBT for Insomnia** can be quite effective for sleep problems. If you have a needle phobia that interferes with infusions or DMTs, a structured **program for injection phobia** may be warranted. For anxiety disorders, targeted psychotherapy treatments that involve **cognitive behavioral treatments** are useful, as are ACT and mindfulness interventions. Severe depression usually warrants **psychotherapy combined with medication**.

Your healthcare provider can help you determine the best course of action. You may have to talk to a few specialists before you decide.

4 questions to ask yourself before seeking treatment

- 1 What are your goals for treatment?** Do you want help coping with the symptoms of MS? Or is MS triggering uncomfortable emotions related to relationship stress? The answers to these questions impact whether you should seek out a health or rehabilitation psychologist or someone with expertise in marriage counseling, for instance.
- 2 What kind of treatment is best for you and for achieving your goals?** As outlined above, mental health providers use different treatments in therapy. Do you want someone to just listen? Or do you want to learn strategies to help you cope with or decrease your anxiety or depression?
- 3 Do you want one-on-one therapy or group therapy?** We traditionally think of therapy as being an individual, one-on-one experience. However, group therapy can be very powerful, and may be a more affordable option.
- 4 Do you prefer in-person or virtual therapy?** Both kinds of therapy can be effective. Some people feel it's important to physically be in a room with the provider. However, telemedicine vastly increases access to care, and it's been used for over 15 years with people who have MS. Some therapists and clients prefer to have the first session or two in person and use telemedicine after that.

You can also discuss these questions when you first talk with a mental health provider.

Where to find a mental healthcare provider

Finding a mental health provider who understands MS or chronic illness can be difficult. You want someone who has the experience and expertise to help you. It may take some time and effort to find the right person, but it's worth it. Don't be afraid to reach out. Even if a provider can't help you, they may refer you to someone who can.

- Start with the Society's **Find Doctors & Resources** online tool. There, you can search for counseling resources near you and designate the type of provider you want. Look for "Partners in MS Care" — healthcare providers who have demonstrated knowledge and expertise in treating MS patients — and "Centers for Comprehensive MS Care," which provide coordinated, multidisciplinary care.
- **Ask one of your medical providers.** Often neurologists and primary care providers keep a list of mental health professionals and make referrals.
- **Contact your insurance provider.** Call your insurance company or use their online portal to find out if there are any providers near you experienced with MS or chronic illness.

- The **American Psychological Association (APA)**, the **American Board of Professional Psychology, Clinical Social Work Association (CSWA)** and **Psychology Today** all maintain online lists of nationwide psychologists. You may also search your state's psychological association directory.
- **Find Empathy** is a free online directory of mental health professionals who specialize in health populations or those experiencing a serious medical diagnosis. This list is relatively new and still growing, so keep checking back. To find a therapist working virtually, try **OnlineTherapy's** directory of providers.

11 questions to ask a potential provider

- 1 Are you accepting new patients?
- 2 Are you licensed?
- 3 What treatment methods do you use?
- 4 Do you have experience treating MS or other chronic illnesses?
- 5 What is the focus of your group or practice?
- 6 How many years have you been in practice?
- 7 Do you work in person or online?
- 8 What are your rates and what kind of insurance do you accept?
- 9 What is your cancellation policy?
- 10 How close is parking to your office?
- 11 Is your office accessible?

You may be able to find answers to some of these questions on the provider's website. Most providers will be willing to speak briefly with you on the phone to answer questions. Even a short conversation can give you a sense of their working style.

You may go through a similar process while looking for a group. Just as there are different types of therapists, there are different types of groups. For instance, **support groups**, often led by someone with MS, are not geared towards improving symptoms. They simply provide a safe place with people who understand. **Treatment groups** often involve learning and applying specific coping skills (e.g., mindfulness or deep breathing). If you aren't sure what the focus of a group is, ask!

What to expect from a provider

Your first appointment with a new mental healthcare provider will be an intake session or an assessment. Be prepared to talk for 45 minutes or more, mostly about yourself, and to answer a number of questions. Some of these may be very personal. It's normal to feel somewhat uncomfortable with this process.

Ultimately, though, you should feel safe and understood by your therapist. If you aren't comfortable by session 3, or you don't like their style of treatment, consider looking for a new provider. Therapists will understand if you explain that it's just not a good fit. More than likely, they will already have picked up on this themselves.

Even when you do not have a mental health diagnosis, therapy can help you learn skills to manage the ups and downs of life and of MS. It is highly recommended that you seek a professional if uncomfortable or unwanted emotions stick around for weeks or months; interfere with your everyday life, activities or relationships; get in the way of taking care of your health or feel out of your control. There are many people and organizations you can turn to in finding a mental healthcare provider. You may have to speak with a few before you find the right one.

Things you can do right now

There is much you can do immediately to feel better or build your resilience for the future. Studies have shown that exercising and making time for activities you love can help you maintain good mental health. And you can always work on your coping skills. A number of online resources are designed to help people do this on their own.

Exercise

Exercise, and physical activity in general, has a positive impact on mood and quality of life in individuals living with MS. The collective evidence indicates that exercise training can reliably reduce symptoms of depression and decrease anxiety and stress.

When you are experiencing depression, it may be hard to motivate yourself to exercise. An exercise specialist with expertise in MS can help you:

- Stay motivated
- Set parameters for your individual level of functioning
- Feel more confident in your approach to exercise
- Manage fatigue, heat intolerance and other symptoms that may affect your exercise program



The Society's **Find Doctors & Resources** tool can help you find an exercise specialist. Group exercise programs, which can often be adapted to meet your needs, may also help you get started and stay engaged.

No one type of exercise has been shown to be more beneficial than others in helping with depressive symptoms. Whether it's walking, yoga, aquatic exercises, cycling (arm or leg) or some other form of activity, the important thing is to get moving. It will help elevate your mood and keep it up.

Engage in activities

It is important to continue engaging in activities that bring you comfort, fun and meaning. This could be a sport or hobby, volunteer work, or even just a good book and a cup of tea. Make sure to work in something enjoyable, even if it is small, each day.

Not sure where to start? Read through the pleasurable activities table below and pick something that appeals to you.

PLEASURABLE ACTIVITIES



Talk to a friend, talk on the phone, meditate or pray

Sing, take a nap, daydream

Play cards, listen to music, work a jigsaw puzzle, watch a movie or favorite TV show, read a magazine



Sit in a garden, spend time with a pet

Enjoy a cup of coffee, soak in a bath



Try a new recipe, play an instrument



Visit a library, go to a museum, visit a flower market

See a movie or a play, take yourself out to lunch

Sit in a park, people watch



Take a walk, go birdwatching, go to a yoga class, shoot some pool

Go to the gym, play a sport, take a hike



Listen to a podcast, do a crossword puzzle, watch a ballgame



Go fishing, go camping, take a trip

Build coping skills and resilience

Many people living with chronic diseases, including MS, say that resilience is the secret to not just coping with the disease, but thriving with it. They consciously practice behaviors that promote this quality. A number of resources can help you develop coping skills and build resilience. These are just a few:

- To build resilience, see **Resilience: Addressing the Challenges of MS** which has a workbook in English and Spanish that covers tips for building resilience.
- The **Living Well with MS** section of the Society's website provides tips and resources for developing these life skills. A healthy lifestyle is important not only for your overall health, but also for your mental health.
- **My MS Toolkit** offers symptom self-management resources — with an emphasis on managing emotions — for people with MS.

- Some apps are designed to help people create healthy new habits. Check out two from the U.S. Department of Veterans Affairs: **Mindfulness Coach** and **CBT-i Coach**. To find others, review recommended apps from **Momentum Magazine** as well as tips on finding reliable apps.
- Many episodes of the **Ask an MS Expert** program series, produced by the Society and available on YouTube, focus on emotional well-being.
- The Society's guide, **Resilience: Addressing the Challenges of MS**, includes many tips for building emotional wellness and resilience.

Whether you're feeling down or just want to maintain good mental health, there are things you can do now. Make time to exercise, engage in enjoyable activities and strengthen your coping skills. Take advantage of resources designed to help you become more resilient.

Health insurance

One of the most common barriers to accessing mental health services is health insurance coverage — or the lack thereof. For those without insurance, paying out of pocket for therapy can be cost prohibitive. For those with insurance, out-of-pocket costs and high deductibles might also keep you from seeking help.

If you don't have health insurance

These resources can help you on your journey if you don't have health insurance:

- Many mental health facilities or community health centers offer **sliding scale therapy**, in which a provider offers treatment priced according to each person's income. At some centers, access to a therapist in training is free.
- The **Association of Psychology Training Clinics** locator tool can help you find clinics associated with pre-doctoral graduate training programs in professional psychology at regionally accredited universities.
- **NeedyMeds.org** can connect you with free/low-cost/sliding-scale mental health clinics.
- An **MS Navigator** may be able to suggest a provider who offers reduced fees.

If you have health insurance

The Affordable Care Act (ACA) significantly increased insurance coverage in the U.S. by mandating that large- and small-group plans cover 10 essential health benefits, including mental healthcare. Regardless of how you obtain insurance, getting insurance companies to approve and pay for care can be challenging.

- **When insurance denies therapy:** If you meet the criteria for a specific therapeutic service and were denied, federal and state laws can help protect you. Many people receive the care they need after appealing the decision with the insurance company. See **nationalMSsociety.org** for advice and appeals templates. The **National Alliance on Mental Illness** also provides tips for **appealing an insurance decision**.
- **When your network does not meet your needs:** If you find that your insurance's network of providers is inadequate, you can call your insurance company and request a **coverage gap exception waiver**. This will allow you to get the care you need from an out-of-network provider without paying more than you should have to.

Refer to the section “**How to seek professional help**” for assistance in finding a provider who takes your insurance.

A number of obstacles can get in the way of obtaining help — even after you’ve made the difficult decision to seek it. You may be afraid to talk about your decision to seek care because of the stigma attached to mental health problems in our culture. You may encounter barriers to access, including the problem of paying for treatment. Luckily there are ways to approach all of these challenges and ensure that you get the help you need.



Resources

The National MS Society hosts a number of support groups and services for people living with MS and their caregivers, listed below. Visit [nationalMSSociety.org](https://www.nationalmssociety.org) or contact an MS Navigator for more information. You don't have to face MS alone.

Support for people living with MS

- **Local MS Support Groups:** All over the country, Society members host support groups for people living with MS, either in person or online. Search your area to see what options are available.
- **Online Communities:** National MS Society online communities provide people affected by multiple sclerosis the support, information and connections they need —when they need them.
- **MSFriends®:** Connect with a supportive, empathetic volunteer who understands life with MS and can say, “I’ve been there too.” MSFriends meet one-on-one for up to six months via phone, email or video calls based on your preference.
- **Puertorriqueños Unidos por la EM:** This virtual support group is open to all Spanish speakers.

Carepartner support

The Society also hosts groups for caregivers and families living with MS. Look for one in your area, or join a virtual group. Also visit [nationalMSSociety.org](https://www.nationalmssociety.org) to download guides for caregivers and support partners, as well as **Someone You Know Has MS: A Book for Families.**