



NAVIGATING
NMOSD

**CONNECTING YOU
TO A MENTAL HEALTH
PLAN**

ALEXION[®]
AstraZeneca Rare Disease

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The information provided in this guide is intended as a source of general education to support patients and caregivers living with Neuromyelitis Optica Spectrum Disorder (NMOSD). It is not intended for any self-diagnosis purposes nor to replace the advice of your doctor or healthcare professional. Please consult your doctor or healthcare professional for further information about NMOSD and its management.

A ROADMAP TO BETTER MENTAL HEALTH

This guide has been developed to help you reflect on your mental wellness and raise your awareness of how important good mental health is to your overall well-being.

In these pages, you'll find:

- clear explanations about what mental health encompasses
- the potential challenges it may pose to you as a NMOSD patient
- how to monitor it effectively and the support available to you

If you have concerns about your well-being, consider consulting a mental health professional who can provide support tailored to your unique situation.



GETTING THE SUPPORT YOU NEED

Throughout our lives, various individual, social and structural factors either interact to safeguard or compromise our mental well-being. Our mental health needs are dynamic, fluctuating over time, and the same individual may cope differently at various points in their life.

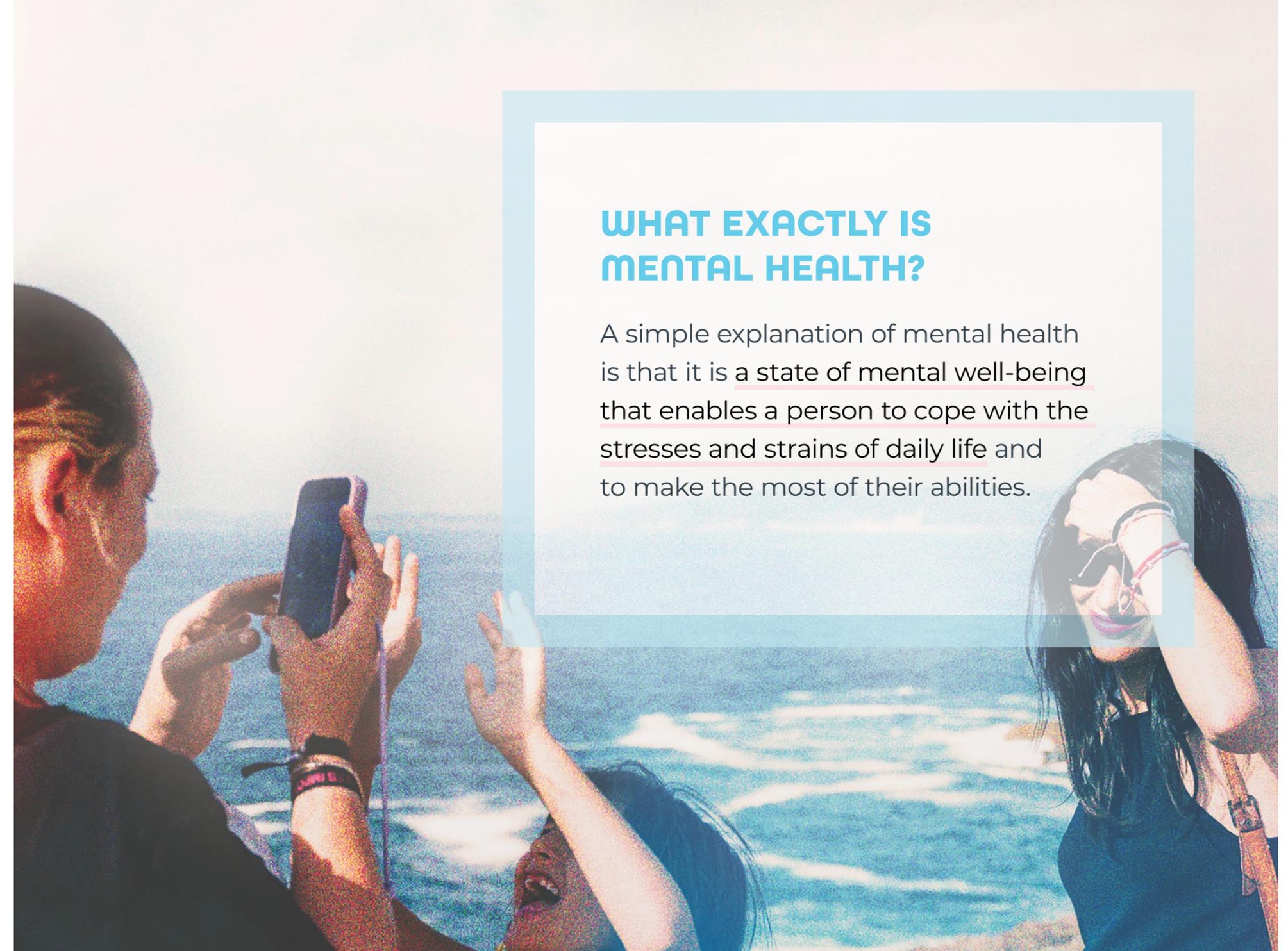
For many people, adapting to life with a rare disease is an ongoing journey rather than a singular event. It may sometimes fall into the background, only to resurface during different transitions, such as receiving a diagnosis, or initiating treatment.

The mental health support needed by any one person exists on a spectrum, ranging from low to high. Though each person's response to the same risk factors may differ, it has been well-established that the mental well-being of individuals living with rare diseases is substantially impacted.

That's why it's important for you to be able to recognize any mental health concerns and seek help early in order to ensure you have the support you need.

WHAT EXACTLY IS MENTAL HEALTH?

A simple explanation of mental health is that it is a state of mental well-being that enables a person to cope with the stresses and strains of daily life and to make the most of their abilities.



THE IMPACT OF NMOSD ON MENTAL HEALTH

Depression, anxiety, sleep disturbances and cognitive impairment as well as chronic pain all affect the daily lives of people living with NMOSD.

In a study of 166 patients nearly 4 in every 10 patients reported depression and in this group more than half described their symptoms as moderate to severe.

Depression also remains undertreated – research found antidepressants were prescribed to fewer than 1 in every 3 NMOSD patients with moderate to severe depression.

A major review of studies published in 2023 found that 45 in every 100 NMOSD patients reported anxiety and 55 in every 100 reported disturbed sleep.

A simple explanation of anxiety and depression is described below.



ANXIETY

Anxiety is excessive worry, fear or nervousness that is often out of proportion to what triggers these feelings. Anxiety can impair how a person can function day to day.



DEPRESSION

Depression is a persistent low mood or loss of interest in activities together with specific symptoms like changes in appetite, sleep disturbances, fatigue, feelings of worthlessness and impaired concentration.



PHYSICAL RESPONSE TO STRESS

When your body experiences something really stressful or frightening it can respond with a “fight or flight” kind of reaction.

The physical response of the body to perceived threat involves the activation of the body’s stress response system.

However, if these reactions remain long-term after the event, it can be a sign that the body’s stress response is out of balance.

Here’s what happens in simpler terms:



HEART RACING

Your heart beats faster to pump more blood and oxygen, getting your body ready for action.



BREATHING FASTER

You start breathing quicker to take in more oxygen, helping you be more alert and ready.



MUSCLES TENSING UP

Your major muscles tense up as their blood supply increases. As a result your hands and feet may be undersupplied with blood and feel cold.



EYES WIDENING

Your pupils might get bigger, helping you see better and notice things around you.



SWEATING

Your body might start sweating to cool you down during this heightened state.



FEELING NERVOUS OR JUMPY

You might feel on edge or easily startled because your body is ready for anything.

If you experience long-lasting stress-related symptoms, it’s important to talk to someone who can help, like a mental health professional.

MENTAL HEALTH SUPPORT OPTIONS

A variety of support options exist for addressing mental health concerns. Some commonly used therapies are listed here.



PSYCHOTHERAPY

Psychotherapy involves meeting with a trained mental health professional, such as a therapist, to talk about your thoughts, feelings and behaviors. Cognitive behavioral therapy (CBT), psychodynamic therapy as well as acceptance and commitment therapy (ACT) are some approaches that may be beneficial.



PSYCHOEDUCATION

Psychoeducation usually involves giving patients and their families basic information about a particular mental concern. These lessons can be changed to fit the needs of the people involved and the specific mental health concern being addressed.



FAMILY THERAPY

Family therapy focuses on improving relationships among family members, and can also help treat specific mental health concerns. Family therapy can involve any combination of family members.



MINDFULNESS

Mindfulness, meditation and relaxation exercises can help individuals manage stress, reduce anxiety and improve overall mental well-being.



SELF-CARE

Self-care encourages people to focus on how they can enhance their emotional, social and functional well-being rather than simply avoiding or managing their condition. This can involve engaging in regular physical activity, maintaining a balanced diet, nurturing positive relationships or pursuing hobbies that bring you joy.



SUPPORT GROUPS

Support groups provide a platform for people living with rare conditions to connect with others facing similar challenges. Sharing experiences, coping strategies and emotional support within a group setting can be incredibly helpful.



MEDICATION

In some cases, medication can play a role in treating anxiety, depression or other mental concerns which are often used in combination with psychotherapy. If medication is recommended, the healthcare provider will conduct a thorough assessment to determine the most suitable medication, dosage, and treatment plan based on the specific needs.

COMPLEMENTARY THERAPIES

Complementary therapies can play a supportive role in addressing the holistic well-being of individuals. Here are some complementary therapies to consider.



YOGA

Yoga is a complementary approach for stress, anxiety and mental health disorders. It's been shown to enhance many aspects of life, including relaxation, self-confidence and positivity.



ART THERAPY

Art therapy involves engaging in creative activities, such as drawing, painting, or sculpture to address and manage mental health symptoms. Also, music therapy is a recognized clinical intervention that is used to assist individuals impacted by injury, illness, or disability. All forms of art therapy help patients to explore and process their emotions.

If you are considering incorporating complementary therapies like those mentioned above, you should speak openly with your healthcare team to ensure a coordinated and integrated approach to your care.



YOUR ROADMAP TOWARD A MENTAL HEALTH PLAN

It's good to know that while there are many different options to address dealing with mental health, there is no one-size-fits-all approach. Each approach has the potential to provide valuable insights and solutions for individuals confronting mental health challenges within the context of living with a rare disease like NMOSD.

Your mental health journey is unique and so is the support you need. This is where your personalized mental health plan comes in. Think of it as a roadmap, guiding you toward better mental well-being and ensuring that you receive the appropriate care and support.

Your mental health plan should be adjusted to fit your particular concerns and suit your needs. It should be a collaborative approach, where mental health professionals, such as therapists and counselors, work closely with you to create a personalized plan based on your unique challenges, preferences and goals.



YOUR MENTAL HEALTH PLAN OUTLINE

A mental health plan is a care plan outlining your needs, the support available to you and the steps and progress toward your personal recovery.

1

IDENTIFY THE PROBLEM

Are you currently facing any mental health challenges or concerns?

2

AVAILABLE TOOLS

What self-care tools, strategies or techniques have you used or are willing to explore to address these challenges?

3

SUPPORT NETWORK

Who can you reach out to (eg, friends, family, support groups) for emotional support, guidance or assistance when dealing with your mental health issues?

4

PROFESSIONAL ASSISTANCE

Have you considered seeking professional help, such as therapy or counseling, to address your mental health concerns?

5

GOALS AND NEXT STEPS

What are your immediate and long-term mental health goals and what steps do you plan to take to work toward achieving them?

It's essential to maintain open communication with your healthcare team and consider discussing your mental health concerns with them. They can provide guidance, support and resources to help you manage any mental health challenges you may be facing.

LONG-TERM MONITORING OF YOUR MENTAL HEALTH

If you do consult a mental health professional, they may suggest periodic follow-up appointments to track your progress, evaluate the impact of the interventions you've discussed and make any necessary modifications to your mental health plan. It's essential to work collaboratively with mental health professionals to determine the most suitable interventions based on individual needs and preferences.

On the next page you will find a short questionnaire, made up of 22 questions from the Impact of Event Scale - Revised (IES-R). You can use these questions to help you better understand your mental well-being.



IMPACT OF EVENT SCALE

The Impact of Event Scale-Revised (IES-R) is a self-report questionnaire designed to assess subjective distress caused by traumatic events. It is a useful tool for individuals confronting a traumatic event, such as a hospitalization for NMOSD.

The questions have been designed to help assess and gain insight into the impact of any traumatic event on your psychological well-being. It can be used for personal reflection or as a tool for self-awareness.

If you're dealing with significant trauma or emotional distress, it's recommended to consult a mental health professional. They can provide guidance, support, and help interpret the results in a more nuanced way.

On the right-hand side is a list of difficulties people may have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to (the event).

		Not at all	A little bit	Moderately	Quite a bit	Extremely
1	Any reminder brought back feelings about it	0	1	2	3	4
2	I had trouble staying asleep	0	1	2	3	4
3	Other things kept making me think about it	0	1	2	3	4
4	I felt irritable and angry	0	1	2	3	4
5	I avoided letting myself get upset when I thought about it or was reminded of it	0	1	2	3	4
6	I thought about it when I didn't mean to	0	1	2	3	4
7	I felt as if it hadn't happened or wasn't real	0	1	2	3	4
8	I stayed away from reminders about it	0	1	2	3	4
9	Pictures about it popped into my mind	0	1	2	3	4

		Not at all	A little bit	Moderately	Quite a bit	Extremely
10	I was jumpy and easily startled	0	1	2	3	4
11	I tried not to think about it	0	1	2	3	4
12	I was aware that I still had a lot of feelings about it, but I didn't deal with them	0	1	2	3	4
13	My feelings about it were kind of numb	0	1	2	3	4
14	I found myself acting or feeling as though I was back at that time	0	1	2	3	4
15	I had trouble falling asleep	0	1	2	3	4
16	I had waves of strong feelings about it	0	1	2	3	4
17	I tried to remove it from my memory	0	1	2	3	4
18	I had trouble concentrating	0	1	2	3	4

		Not at all	A little bit	Moderately	Quite a bit	Extremely
19	Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart	0	1	2	3	4
20	I had dreams about it	0	1	2	3	4
21	I felt watchful or on-guard	0	1	2	3	4
22	I tried not to talk about it	0	1	2	3	4
Totals						

Scores: To calculate the total score, you need to add up the scores of all 22 questions.

24 or more: Higher scores on the IES-R indicate higher levels of distress related to the traumatic event. If you scored 24 or more, you may want to discuss your scores with a mental healthcare professional.

It's important to note that while the IES-R provides a quantitative measure of distress it's not a diagnostic tool and the results should be interpreted in the context of an individual's overall well-being and circumstances. Remember, self-assessment tools are just one part of understanding your mental well-being and professional input can greatly enhance the accuracy and usefulness of the information gathered.

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