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The information provided in this guide is intended as a source of general education to support patients 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.

CONNECT WITH FAMILY, FRIENDS AND CO-WORKERS BY BRINGING THEM UP TO SPEED



Explaining your NMOSD to others can be an incredibly challenging and emotionally taxing experience.

It's natural to feel overwhelmed by the weight of the news and to worry about how others will react.

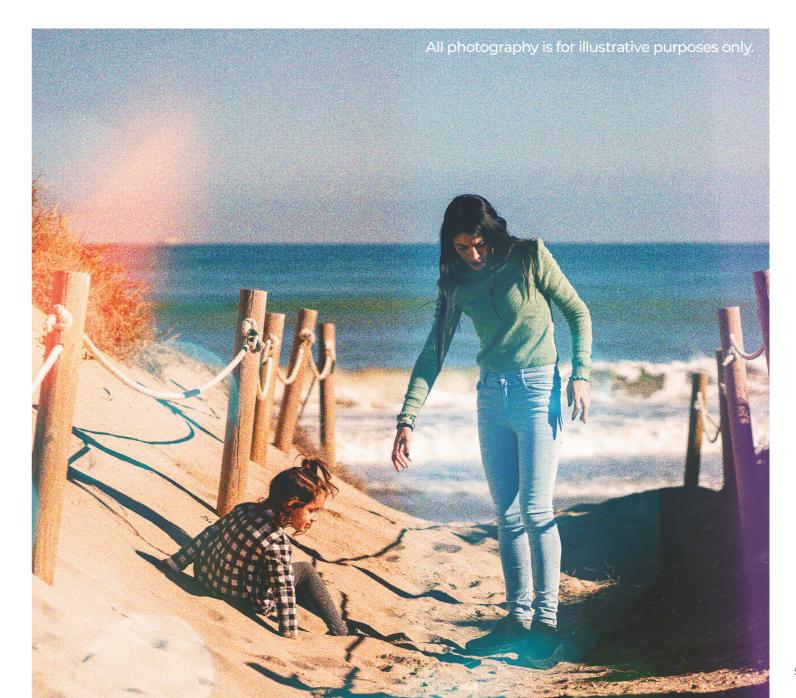
You may struggle with feelings of vulnerability, fear and a deep desire to protect others from the realities of your condition. The uncertainty of how your family, friends or your workplace will respond to the news can intensify these feelings, making it tempting to keep your diagnosis hidden from others.

If you received your diagnosis some time ago, you might still feel that your family, friends or co-workers cannot fully grasp the profound impact it has had on you. This lack of awareness can sometimes lead to misunderstandings or unintentional insensitivity.

This guide has been developed to offer you valuable tips on how to handle conversations with your family, friends and co-workers, whether you're newly diagnosed or not. Talking openly about your condition can be a daunting task, especially when it's something as complex and serious as NMOSD. It can take courage and practice to do so, but it's also a chance to increase awareness about NMOSD and help others better understand your condition.

Taking the courageous step to share information about your NMOSD with others can bring considerable relief. Knowing that you can open up about your NMOSD means you can create a strong support network that can be there for you to provide emotional or practical assistance.

The following pages offer useful guidance on what to consider when discussing your NMOSD with family, friends, your employer and co-workers.





DISCUSSIONS WITH FAMILY

The conversation you have with your family about NMOSD is likely to be one of the most important discussions you'll have following your diagnosis.

It's not just a routine conversation, it's a pivotal moment that establishes the foundation for the support, understanding and empathy that will be crucial as you face the challenges of NMOSD together.

It's essential to approach this conversation with compassion and empathy. Recognize that the news may be challenging for your family to absorb. It is also important to discuss how NMOSD might impact your family.

For example, will family members need to adapt their daily activities or work routine, will they need to accompany you to your medical appointments, will your home need adapting according to your physical abilities and will your family need to spend more time looking after you?

In addition to addressing the practical aspects of your NMOSD, it's also important to discuss the emotional challenges that may arise. Sharing your own fears and anxieties can help your family better understand your emotional state and allow them to provide the necessary emotional support.

Finally, reassurance is also key, emphasize that with medical support and treatment, NMOSD is a manageable condition.

Family members should be aware of what to do if you experience an attack or relapse, see page 17 for more information.



DISCUSSIONS WITH FRIENDS

As you navigate life with NMOSD, you may find it challenging to keep up with friends or engage in social events.

Frequent hospital visits and medical appointments can disrupt social plans and commitments, leading to last-minute cancellations or missed gatherings with friends.

Educating your friends about your condition, explaining your limitations or needs and seeking their understanding can help bridge the gap between managing NMOSD and maintaining fulfilling social interactions.

Having an open and honest conversation with friends is key to helping you find that balance. Sharing resources, such as the NMOSD Factsheet may help friends better understand your diagnosis.





DISCUSSIONS WITH YOUR EMPLOYER

The symptoms of NMOSD can potentially impact your ability to work so it is important to discuss your condition and your symptoms with your employer.

Fatigue is a common symptom that can impact productivity at work. Vision problems such as visual loss, double vision and visual fatigue with reading can affect the ability to perform tasks, as can chronic pain. It's important to therefore let your employer know that your NMOSD symptoms may lead to unexpected sick days.

The treatment you are receiving may mean that you might have to take time off work to attend doctor or hospital appointments. You might consider exploring potential arrangements like remote work options or flexible hours to help minimize any disruptions.

Discussing your NMOSD with your employer can be helpful in gaining their support or understanding and facilitating the discussion around any adaptations that may be required for you to be able to continue doing your job.

Having your employer know about your NMOSD can also help you feel more secure in case you have a medical emergency at work or if you need to take time off work.

Your employer should be aware of what to do if you experience an attack or relapse, see page 17 for more information.



DISCUSSIONS WITH CO-WORKERS

Having a conversation with your co-workers about your NMOSD can also be a significant step towards feeling more in control of your NMOSD.

It's important to make them aware that NMOSD can sometimes lead to unexpected sick days. Explain that the symptoms of NMOSD and medical appointments may occasionally affect your ability to be at work.

Express your desire for a supportive work environment and that you appreciate their understanding during times of unexpected absence. You can also stress the need for confidentiality regarding your medical condition.

Discussing your NMOSD with co-workers can help foster a more empathetic and accommodating work environment.

Your co-workers should be aware of what to do if you experience an attack or relapse, see page 17 for more information.



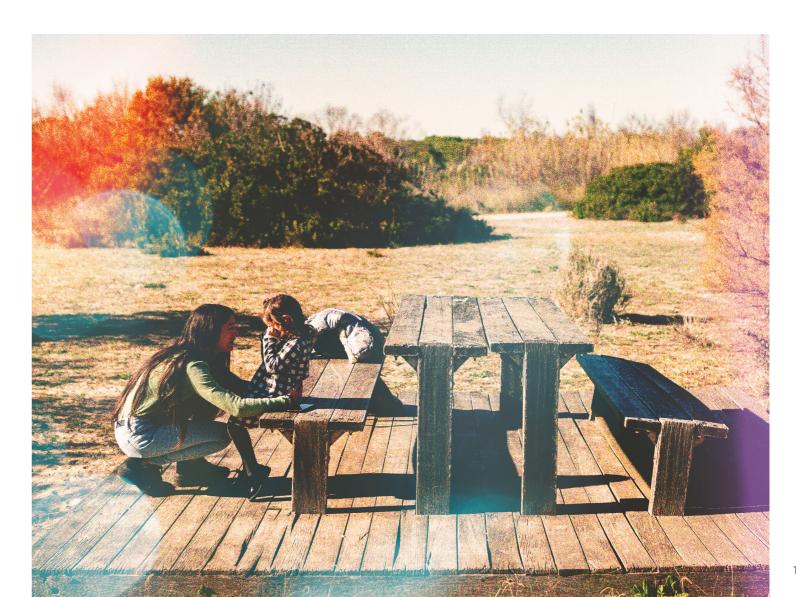
YOUR NMOSD DISCUSSION GUIDE



On the pages that follow, you will find some helpful tips on the topics you may want to cover when discussing your NMOSD with others.

The phrases highlighted in blue are suggestions that can help you have constructive conversations about your NMOSD.

Remember, there is no correct way of telling other people that you have NMOSD and you should always do what feels best for you.





INTRODUCE THE SUBJECT GRADUALLY

Find a quiet setting where you can have an uninterrupted conversation.

Make sure you have enough time to discuss the topic without feeling rushed.

You could start the conversation by saying something like:

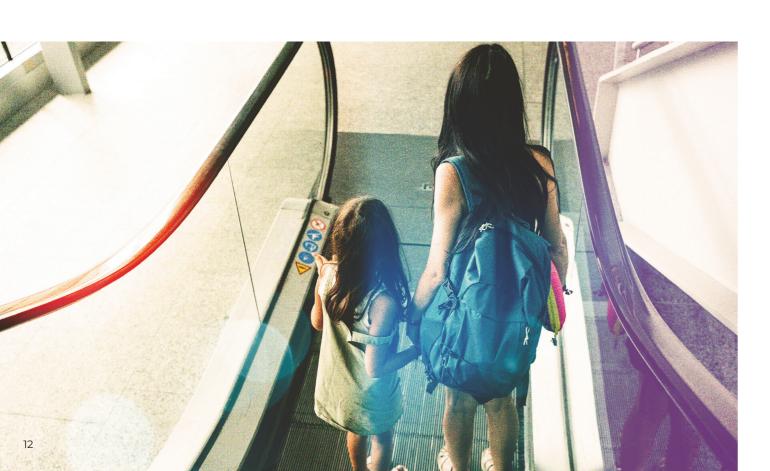
This is going to be difficult but I need to tell you something.

You could say:

I have had some bad news that I need to tell you about.

Or you could say:

I have been diagnosed with a serious illness and I need to tell you about it.





START WITH THE BASICS

It might be helpful to explain what NMOSD is first and then describe how it affects you.

Begin by introducing NMOSD in simple terms.

You might say something like:

I have been diagnosed with NMOSD, a rare autoimmune, inflammatory disease.

If more context is needed:

NMOSD affects the central nervous system, particularly the nerves to the eyes (optic nerves) and the spinal cord.

You could also explain that:

Most people with NMOSD have attacks or relapses resulting in damage to the nerves that may cause a range of symptoms, such as vision loss and limb weakness.



If more detail is needed:

Attacks or relapses can be unpredictable, and can make someone with NMOSD very weak and may lead to permanent disability, such as blindness or paralysis.



PROVIDE ADDITIONAL INFORMATION

Share additional information about NMOSD, including its causes, symptoms and possible complications.

Use plain language to make it easier for your family, friends or co-workers to understand.

CAUSES

NMOSD is usually not inherited, but some people with NMOSD may have a history of autoimmune conditions in the family.

Most NMOSD patients have autoantibodies against the waterchannel protein aquaporin-4 (AQP4) in their blood.

Autoantibodies are proteins produced in patients with an autoimmune disease. These proteins target the body's own tissues and can thus be harmful.

If more context is needed:

AQP4-autoantibodies bind to AQP4 on specific cells of the central nervous system thereby activating the complement system, a part of the immune system.

In NMOSD, this unwanted complement activation leads to damage to the central nervous system, particularly to the optic nerves and the spinal cord.

SYMPTOMS

Talk about the symptoms of NMOSD, explain that:



SPINAL CORD

NMOSD can cause chronic pain, limb weakness, inability to move, burning or prickling sensation, spasms and loss of bladder and bowel control.



FATIGUE

NMOSD can cause fatigue, feeling weak all over, feeling tired or listless.



EYES

NMOSD can cause loss of vision (or blindness), blurred vision, loss of color vision or pain with eye movement.



BRAIN

NMOSD can cause hiccups, nausea, vomiting and dizziness.



POSSIBLE COMPLICATIONS

Explain that the symptoms of NMOSD can occur suddenly and may indicate an attack or relapse. If your family, friends or co-workers notice a deterioration in your condition, they should seek urgent medical assistance for you.

The symptoms of NMOSD are usually experienced as unpredictable and recurrent attacks or relapses.

The relapses or attacks in NMOSD can have serious consequences, such as vision loss or partial paralysis.

IN AN EMERGENCY

It is important that your family, friends, work colleagues and your employer know that most people with NMOSD experience attacks or relapses that can be sudden and potentially life-threatening.

They should be aware of any of the signs of an NMOSD attack, so that they can seek immediate medical care for you as quickly as possible.

Prompt treatment of attacks is crucial to prevent the physical impairment in NMOSD that accumulates with each relapse.

They should know that:

NMOSD attacks or relapses are defined as the onset of new symptoms, or the worsening of original symptoms, lasting more than 24 hours, in the absence of other recognized causes such as fever and infection.

OTHER INSIGHTS

NMOSD IS DIVERSE

NMOSD is associated with a wide range of symptoms and therefore affects people differently.

NMOSD CAN BE UNPREDICTABLE

The symptoms of NMOSD can be experienced as unpredictable attacks or relapses.

NMOSD CAN BE LIFE-THREATENING

The consequences of an NMOSD attack or relapse can be both permanent and devastating.

NMOSD MAY NOT ALWAYS BE VISIBLE TO OTHERS

The mental health burden in rare diseases is well documented, so it's also important to understand that the impact of NMOSD may not always be visible to others.



DISCUSS HOW NMOSD AFFECTS YOU PERSONALLY

Talk to your family, friends or co-workers about your own specific symptoms, and how they affect you personally. Because NMOSD is associated with a wide range of symptoms, only you know how NMOSD affects you.

It is also important to explain how NMOSD impacts your daily life. Describe the symptoms you experience and it affects your daily routine. Discuss your treatment and how it affects you and any lifestyle changes you may have to make in order to manage your NMOSD.



2 SHARE YOUR EMOTIONAL EXPERIENCE

Talk about the emotional challenges you face. Describe your feelings, fears and concerns. Let them know that their support is crucial in helping you cope.

3 EXPRESS YOUR NEEDS

Let your family and friends know how they can help and support you. Whether it's accompanying you to medical appointments, helping with household tasks, or simply being there to listen.

Tell them they might need to have patience and understanding when your symptoms are severe and you are unable to do the things you want to.





Offer to share informative resources about NMOSD, such as the NMOSD Factsheet, so your family, friends or co-workers can learn more on their own.

Offer updates on your condition and treatment progress, especially if there are significant changes. Regular updates can help your family, friends or co-workers feel more involved in your journey.

Remember that patience is key when explaining NMOSD to family, friends or co-workers. It may take time for them to fully grasp the complexities of a condition like NMOSD.



Invite your family, friends or co-workers to ask questions and encourage discussion. It is likely that they will have needs and concerns that they will want to share with you.

Be patient and open to their inquiries or concerns, no matter how simple or complex. Answer to the best of your ability or offer to find additional resources if needed.

Remember that sharing your experiences and feelings is your personal decision. Talking about health is a sensitive matter and you should always only do what feels right for you.

NOTES

