Treatment & Management of NMO


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PATIENT NAME
ADRESS

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Treatment & Management of NMO

OVERVIEW

Selecting a primary care physician, neurologist or related specialists, and other members of a clinical team is a personal decision that balances many factors unique to each patient and their caregivers. In addition, treatment regimens, lifestyle choices and other personal decisions such as pregnancy are for each individual patient to determine. The GJCF does not provide patient care or medical advice, and does not endorse any particular clinician, therapy or clinical trial. Rather, the following information offers resources that may be helpful in self-education and decision-making by NMO patients and their loved ones.

3.1 Finding an NMO Specialist

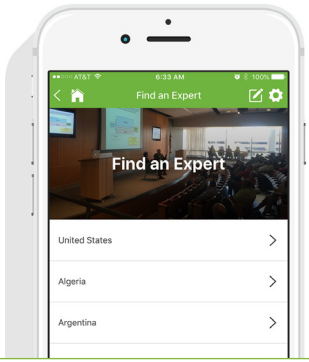
QUICK READ

Finding a clinician that you feel comfortable with and in whom you have confidence is an important personal decision.

There are several ways to locate NMO specialists. Physician referrals and word of mouth are two methods.

Another resource is **Connect the Docs**, an international directory of clinicians specializing in NMO diagnosis and/or treatment. Since 2008, the GJCF, along with the NMO patient community, has identified and collaborated with hundreds of clinicians around the world, mapping specialists including neurologists and neuro-ophthalmologists. **Connect the Docs** is available in this book and as an interactive, online directory.

To get started, refer to Chapter 7 or visit: guthyjacksonfoundation.org/connect-the-docs



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ANDROID APP ON Google play

3.2 Medical Treatment of NMO

QUICK READ

Treatment of NMO requires careful diagnosis and consideration by a clinical care team. Usually, this team consists of a neurology specialist focusing on NMO, along with a primary care doctor to manage routine medical care, as well as other specialists such as may be indicated. Depending on the unique factors of a given case, different approaches may be used to manage different patients. Medical approaches used to help treat NMO can include:

- steroids
- plasma exchange (PLEX)
- immunoglobulin therapy (IVIG)
- immune suppression with medications
- alternative therapies

At present there is no regulatory-approved treatment and no identified cure for NMO. The GJCF is doing everything it can to help find answers, together with scientists, clinicians, industry, and regulatory partners around the world. The term "standard of care" describes treatment regimens or procedures that, while not specifically approved for treating NMO by regulatory agencies, involve medicines or interventions that are approved for other conditions, and which are generally considered potentially helpful in NMO.

Treatment options currently being used to treat NMO are considered **"off-label,"** meaning they have been **approved to treat conditions and diseases other than NMO**, but are being used in NMO treatment without formal clinical evidence that they are effective. To obtain government approval, treatments must prove that they are safe and effective in carefully controlled and prospective clinical trials. **An utmost priority in the design of all clinical trials is patient safety.** A therapeutic candidate must undergo rigorous testing in a well-defined population of patients using a clinical trial protocol that is approved in advance by a regulatory agency. Such clinical trials must also prospectively define the effectiveness goals of the drug candidate as part of the criteria upon which effectiveness and potential approval will be evaluated.

A **key mission of the GJCF** is to catalyze the discovery or development of treatments that advance to be proven safe and effective in NMO through clinical trials. **While just a few years ago there were none, the good news is that there are multiple**

now clinical trials in progress testing therapies in NMO. There is great hope that these clinical trials will progress such that one or more drugs may soon be approved to treat NMO.

While effective treatment is a common goal of clinical care, the specific best treatment regimen may differ in different patients. There are many factors that contribute to NMO treatment decisions made by NMO clinicians, patients, and their caregivers, including:

- Specific diagnosis and disease subtype (e.g. NMO vs. NMOSD)
- Safety and tolerability of a treatment in a given patient
- Disease status (e.g. early vs. advanced; maintenance vs. relapse)

- Disease severity (e.g. mild, moderate or severe)
- Co-morbidities (simultaneous presence of two or more diseases) in a given patient
- Management of associated symptoms (e.g. pain, bowel / bladder function, etc.)
- Other factors that may benefit outcomes (e.g. nutrition, vaccination, etc.)

In some cases, the first sign of NMO may be eye pain or change in vision that comes on suddenly and worsens quickly.

Managing the First Episode of NMO

The first episode of NMO (termed the **"incident" episode**) can be a confusing and frightening experience. **Typically, this episode occurs completely by surprise**, with no known risk factors, warning signals, or prior history. Interestingly, recent research has suggested that some cases of **NMO may come after prolonged hiccups, nausea** or **vomiting**, or **other seemingly unrelated symptoms**. In some cases, **the first sign of NMO** may be **eye pain** or a **change in vision** (e.g. clarity, light perception, color)

that **comes on suddenly and worsens quickly.** In other cases, NMO **first appears as a loss of arm or leg strength or difficulty balancing**. In every case, **NMO can be a neurological emergency**, and quick actions offer best chances for good outcomes:

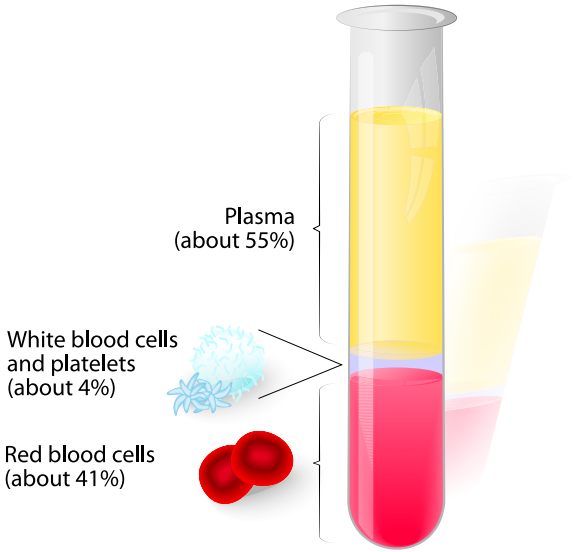
- Contact your doctor or neurologist immediately
- If necessary, seek care at the closest appropriate emergency room or urgent care center
- Remind the clinical staff to consider NMO as a possible cause of symptoms (called the ***differential diagnosis***)
- Be prepared for blood tests (e.g. NMO-IgG), imaging (e.g. MRI or CT scans), or perhaps a lumbar puncture (refer to section 1.7). These tests are generally extremely safe, and can be done relatively quickly.

Once the initial episode has passed and symptoms are under control, individuals begin their journeys living with NMO.

First episodes of NMO almost always come unexpectedly, and can be very serious. Managing this episode through calm, knowledge-based decisions may facilitate very positive outcomes in which recovery can be excellent.

If NMO or another inflammatory condition is detected in the optic nerves or central nervous system (CNS), **corticosteroids** (such as methyl-prednisolone) are normally one of the first medicines to be given. This medicine quickly reduces overall inflammation. For acute or severe cases, corticosteroids are administered through a vein (**intravenously or IV**). The neurologist may admit the patient into the hospital during an acute episode, to deliver IV medications, facilitate diagnostic tests, and provide close observation. Depending on results of blood or lumbar puncture tests, the clinical team may recommend other immediate treatment as well. For example, a process to remove harmful factors

such as autoantibodies from the blood may be used. This procedure is called **plasma exchange (PLEX)**, and involves the careful removal of plasma from the blood, with blood cells immediately returned to the patient bloodstream along with replacement fluid. In other cases, addition of potentially beneficial antibodies to the bloodstream may be used; such treatment involves **intravenous immunoglobulin (IVIG)**. The goals of



these strategies (described in more detail in the following pages) are to generally calm any acute inflammation that may be affecting the CNS, including the optic nerves, spinal cord or brain.

Ideally, a rapid response to symptoms of NMO may assist in the best outcome. Once the initial symptoms are under control, individuals begin their journeys living with NMO.

Managing Relapses in NMO

As in the first NMO episode, corticosteroids are often given as early as possible in the event of a relapse. Steroids work by generally suppressing the immune system and reducing inflammation in the central nervous system (CNS) and elsewhere in the body. Corticosteroids are usually given:

- Intravenously (through a vein; IV) for 3-5 days
- By IV followed by a course of oral steroids for several months or indefinitely as long-term therapy
- Steroid doses are initiated and adjusted in each individual patient based on disease status and severity, and/or side effects

What if corticosteroid treatment does not help?

Many episodes of NMO respond to corticosteroid therapy. However, **in some cases steroids do not provide clinical benefit**. When attacks progress or do not respond to this treatment, **other treatment options may be considered**. These include plasma exchange (PLEX), use of intravenous immunoglobulin therapy (IVIG), or other treatment regimens.

Plasma Exchange (PLEX) aims to remove harmful auto-antibodies (refer to sections 1.10 & 1.11) and other soluble inflammatory factors from the bloodstream. Using a specialized technique, blood is drawn out of the body

through an IV catheter, **cells are separated from the plasma and returned to the patient**, with the plasma being discarded and replaced. This procedure may be performed using catheters temporarily placed in arm veins, however some patients require a long-term catheter placement if PLEX is required on a regular basis.

Intravenous Immunoglobulins (IVIG) treatment is the administration of **a collection of antibodies** from a pool of thousands of healthy blood donations to the recipient patient. How IVIG therapy may work is not completely understood; it is believed to add beneficial antibodies and other factors from healthy individuals to act against any harmful antibodies or related factors within NMO patients. The result is that IVIG therapy may help to suppress inflammation overall, or interfere with disease-causing factors specific to NMO.

Long-Term Management of NMO

Long-term management of NMO **aims to reduce the frequency or severity, or prevent relapses** which can cause ongoing or worsening symptoms, and may lead to long-term or permanent damage. Individual neurologists use different agents and strategies for this goal, and the same neurologist may use different strategies in different NMO patients. Listed are a few of the common treatment options neurologists may consider on a case-by-case basis:

Low-Dose Steroids

In NMO, inflammation caused by the immune system leads to injury to the central nervous system (CNS) and disability in vision, limb use and other bodily functions. For this reason, medicines that broadly calm the immune system are often used to treat NMO. In this respect,

the term **"steroids"** is often heard in relation to NMO treatment. There are many kinds of steroids used in medical practice. In NMO, ***corticosteroids*** (also called glucocorticoids; often simply known as steroids in NMO treatment) are commonly used in treating acute NMO attacks and/or in long-term maintenance therapy. These steroids calm the immune system in a general way, or ***non-specifically***, by suppressing molecular and cellular effectors of inflammation. Initial or relapse episodes of diagnosed NMO are often treated with IV steroids. Once the episode is under control, steroid therapy is typically changed to oral administration, and continued until other ***maintenance treatments*** are in place (see the following pages). In some patients, relapses may occur after steroid treatment is gradually stopped. If so, use of low-dose steroids over a long period of time may be appropriate to help reduce the frequency or severity of relapses. Ideally, a

clinical care team may identify a low-dose steroid regimen alone or in combination with other therapy as best for a specific NMO patient. If so, long-term/low-dose steroid treatment is often referred to as a ***maintenance dose*** in hopes of reducing the number or severity of relapses.

Corticosteroids are powerful medicines that suppress the immune system overall.

It is important to note that steroids are powerful medicines that suppress the immune system overall, including the ability of the body to fight infection and promote wound healing. In addition, steroids can have other **adverse side effects**, such as **weakening of the bones**, predisposition to **kidney stones** or **cataracts**, and **changes in metabolism**, including fluid retention, increased blood pressure or weight gain.

Other **long-term side effects** of steroid treatment may also include:

- **Acne/skin conditions**
- **Indigestion**
- **Sleeplessness**
- **Diabetes**

In some cases, **antacids** and **tablets for bone protection** (biphosphonates, calcium supplements, and vitamin D) may be helpful to **reduce the long-term, bone-thinning side effects of corticosteroids**.

It is also essential to be aware of signs of tapering off of corticosteroids too quickly. These signs may include:

- **Nausea**
- **Vomiting**
- **Joint aches** (hands and feet especially)
- **Weakness**
- **Fatigue**
- **Low blood sugar**
- **Weight loss**
- **Lack of appetite**
- **Dizziness with standing**
- **Low blood pressure**

Patients experiencing any of these symptoms while on a steroid tapering or low-dose regimen should notify their physician immediately.

Other Immune-Modifying Agents

Aside from corticosteroids, several other medicines may also be considered in managing the acute and long-term course of NMO. Many of these agents are intended to reduce the need to take steroids, which can have adverse effects over the longer term. For this reason, such treatments are called ***steroid-sparing*** regimens, meaning they intend to spare the patient from the potential long-term risks of corticosteroids. Some of these regimens are considered briefly in the following pages. **These drugs can powerfully modify the immune system, often in ways that suppress inflammation.** As a result, they all have **side effects that can range from mild to serious**,

including increased risks of infection and cancer. Most of these risks are generally well understood, and measures can be taken to minimize them. However, any such drug would need to be explained and carefully considered by your clinical team. **As always, NMO patients should consult with their physicians or neurologists before taking any medicine, and report any adverse events immediately.**

First-Line Agents

Medicines that are generally accepted by clinical experts as a primary or usual treatment for a given type and severity of disease are called **"first-line" agents**. In NMO, there are several first-line regimens that

may be considered, depending on specific factors of each individual patient case. First-line agents that are commonly used in NMO are listed below, in alphabetical order:

Azathioprine (Imuran®): because it inhibits DNA synthesis in rapidly growing cells, such as immune system B and T cells, azathioprine is a strong and relatively non-specific **immunosuppressant**. It is believed to **calm the immune system by reducing the ability of these cells to promote inflammation** involved in NMO and other autoimmune diseases. Because it can significantly and generally suppress immunity, **risks of azathioprine treatment** include infection, cancer and related issues. Azathioprine is available in tablet form for oral administration.

Mycophenolate Mofetil (CellCept®): like other first-line agents, mycophenolate mofetil is an immunosuppressing drug that inhibits the number

Do You Know...

Only through formal clinical trials can new agents be approved as safe and effective for use in NMO.

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and function of immune system cells. Mycophenolate mofetil has a **more specific target** than azathioprine, namely **an enzyme that is enriched in T and B cells**. Because they have more of this enzyme target, mycophenolate preferentially inhibits these immune system cells. However, because of this action, mycophenolate mofetil also **reduces the ability** of the body to fight infections, and **increases the risk** of certain types of cancer especially if used at high-dose for many years. However, at low doses it may help prevent relapses and minimize long-term risks. Mycophenolate mofetil comes as a capsule, a tablet, a delayed-release tablet, and a suspension (liquid) to take by mouth. Some hospitals and physicians use another version of this drug (mycophenolate acid) called Myfortic®, which has the same activity against the immune system. Sometimes

this alternative version of mycophenolate is given to patients who experience gastrointestinal upset from the mycophenolate mofetil.

Rituximab (Rituxan®): rituximab is a **therapeutic monoclonal antibody**, and an example of the ***biologic*** (protein-based) class of drugs that may be considered in NMO treatment. It is an example of using an antibody to treat a disease. Rituximab works by targeting **B cells** (which make NMO-IgG) for removal from body by the immune system. This effect may help to prevent NMO relapses or increase the time between relapses. Rituximab is given through the bloodstream, usually as two intravenous (IV) infusions two weeks apart, followed by an approximate six-month break. In some cases, rituximab may be used alone or in combination with other methods to treat NMO cases that are refractory to corticosteroids, PLEX and/or IVIG therapy.

Second-Line Agents

If first-line agents such as those previously discussed do not control NMO or are not well-tolerated, a patient and their clinical team may consider different agents that may have more benefits in some patients. Medicines used when first-line agents fail or are contraindicated are called ***"second-line"*** agents. Such medications may be used alone or with other treatments. Each medication suppresses the immune system in a powerful way – and as with all such medicines – **the effects can come with unwanted side effects**.

Cyclophosphamide (Cytoxan®): this drug is another well-established agent that is known to generally suppress the immune system. When activated by the liver, cyclophosphamide calms the immune system by **preventing the function of DNA and RNA** needed in production of new immune system cells. This drug

When immune-suppressive agents are used to treat NMO, careful monitoring of the immune system is important to address potential risks.

is non-specific, and can have significant adverse effects. While there are **many known side effects** of this drug, there is little evidence supporting its use in NMO.

Methotrexate (Trexall®): Methotrexate inhibits the production of a vitamin-like factor called **folic acid**. Because immune system cells that cause inflammation reproduce quickly, they require high levels of folic acid for normal growth. For this reason, methotrexate is used to calm the immune system by inhibiting the generation of new immune system cells. This drug is non-specific, and like other immune-suppressive agents **can lead to increased risk of infection**, as well as metabolic and other side effects. Methotrexate is commonly used to treat many other autoimmune diseases, and in high doses it is used to treat cancer. In some cases, vitamin supplements rich in folic acid (vitamin B9) may be used to help minimize side effects of methotrexate. Any such supplement should be discussed with a clinical expert prior to use.

Mitoxantrone (Novantrone®): originally developed as an anti-cancer agent, mitoxantrone inhibits the generation and function of many types of immune system cells, including T and B cells, as well as other white blood cells involved in NMO, including ***macrophages*** and ***neutrophils***. This treatment reduces the activity of the immune system overall, thereby reducing inflammation. It is also commonly used in multiple sclerosis (MS) and other autoimmune diseases, and at high doses in cancer treatment. Mitoxantrone **side effects may include** increased risk of infection, hair loss, nausea and other symptoms.

Important Reminder: All treatments that reduce the activity of the immune system can have side effects, some of which can be serious or even life-threatening. If you and your clinical team choose to use such agents, **careful monitoring of the immune system is**

important to address these potential risks. For example, blood tests such as a **complete blood count (CBC)** and **white blood cell (WBC)** count may be performed routinely, with **kidney and liver function also routinely monitored in most cases**. Some patients require preventive vaccines against pneumonia, influenza, or other infections before using immune-suppressing drugs, and may also be prescribed preventive low doses of antibiotics for a period of time. Following some agents such as rituximab, previous vaccinations may be rendered ineffective. In any case, it is imperitive to ask your doctor what may be the best treatment and preventive plans in your particular case.
Also, if you develop any side effects, have fevers or other signs and symptoms of infection, it is important that you contact your medical care team immediately.

None of the agents previously described are regulatory-approved to treat NMO. One of the exciting recent **advances in NMO science and medicine** is the initiation of **several clinical trials** to evaluate specific new treatment candidates for safety and efficacy in NMO. Importantly, many of the drug candidates being tested are believed to have more specific cellular or molecular targets than the existing first- or second-line agents. Therefore, if proven safe and effective in clinical trials, **these new agents may have fewer risks or side effects than the general immunosuppressive agents currently used**.

To learn more about NMO clinical trials, refer to section 5.1.

3.3 Recovering from a Relapse

QUICK READ

Recurrent episodes of NMO attacks are called ***relapses***. It is not known what causes relapses in NMO, and they can come on suddenly and without warning. Relapses and recovery times vary from patient to patient. Likewise, recovery can depend on many factors, including the severity and duration of the attack, the time to confirmed relapse diagnosis and the effectiveness of therapy. Some relapse events can be long-lasting, while others more quickly resolve either partially or completely.

NMO Relapses Require Immediate Action

Regaining function after a relapse can vary greatly from patient to patient. After symptoms are evident, conditions may worsen over hours or days. **Because rapid diagnosis and treatment are crucial to enhance chances for best outcomes, it is important to notify your physician immediately if you sense a relapse.** Eventually, with appropriate treatment over time, many patients may regain some if not all the functions affected during the relapse. **Monitoring symptoms and staying in close communication with your team of clinicians is essential for treating relapses and ensuring a best chance for good outcomes in recovery from a relapse.**

Managing Symptoms of NMO

NMO is a disease that can have very different symptoms in each patient. Many symptoms may improve over time, **especially if treatment is received early**. However, the effects of relapses may be cumulative, and each attack may lead to additional injury to the nervous system. If nerve fibers have been permanently damaged, long-lasting changes in **strength, balance, vision, bowel or bladder, or other bodily functions may result**. The following discussion considers a few of the more common symptoms that NMO patients may experience:

- **Neuropathic (nerve) pain** in NMO results from acute injury or chronic damage to nerve fibers. While it often associates with peripheral sites in the body (abdomen, limbs, fingers and toes) nerve pain (also called **neuropathy**) can vary quite a bit from patient to patient. For example, **some patients experience numbness in affected areas**. For others, the pain is described as a **burning sensation**. It can be described as a **"sharpness"** or

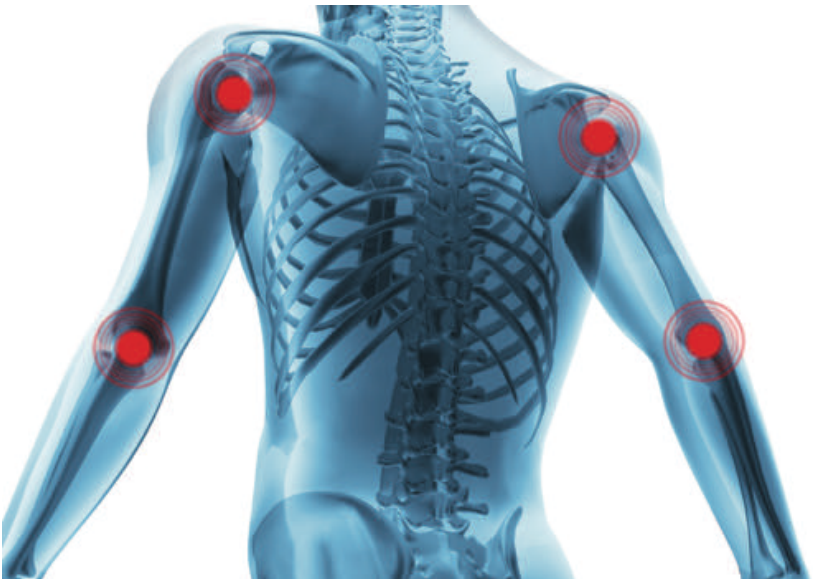
If nerve fibers have been permanently damaged, long-lasting changes in strength, balance, vision, bowel or bladder, or other functions may result.

a **brief "shooting" pain**, as well as a **"tingling," "crawling,"** and/or **"electrical" sensation**. Your clinical team may consider the many different medications that may effectively control neuropathic pain in order to recommend the treatment suited for you.

- **Problems in muscle tone** are called **dystonia**, and can occur in NMO when communication between the brain and spinal cord is affected. Without normal transmission of signals from the brain or spinal cord, nerves can send incorrect signals causing muscles to relax or contract in an uncontrolled manner. Generally, **two basic types** of dystonia may occur: **hypertonic** and **hypotonic**.
  - In **hypertonic dystonia**, muscles become more tight or rigid due to spasms that may last minutes to hours. **Spasms** occur when there is too much nerve stimulation to muscle, causing excessive contraction.

- In **hypotonic dystonia**, muscles become more flimsy or flexible and limbs may seem weak. Muscle **weakness** occurs when there is too little nerve signal reaching the muscle.

Too much or too little muscle tone can reduce strength or endurance, and may be accompanied by pain or cramping. In addition, dystonia can contribute to **ataxia**, a condition in which muscular control is limited or poorly coordinated. Ataxia can make balancing or walking difficult. An exercise or stretching plan designed with your clinical team may help improve muscle tone and function.



- **Joint stiffness** is a symptom often caused by changes in muscle tone and/or inflammation. The result is reduced mobility of a joint, such as a knee, elbow, or shoulder. Oftentimes, joint stiffness may be

worse early in the morning or late in the evening. **Exercise** or **stretching** can help manage stiffness and pain. Sometimes **medication** or **external treatments** (heat or cold application, or physical therapy) may be needed. Your physician or physical therapist can help determine the best way for you to manage or treat joint stiffness.

- **Bladder symptoms** can occur in NMO, and may include **urgency**, **frequency**, **hesitancy** or **difficulty initiating urination**. Other symptoms such as ***nocturia*** (awakening at night because of the need to urinate) and ***retention*** (unable to pass urine) may occur due to spinal cord injury. In more difficult cases, catheterization may be required to relieve urinary retention. For conditions of urinary incontinence, medicines may be prescribed by your doctor.

- **Bowel symptoms** may also occur in NMO, and can include constipation and loss of bowel control. Urgency may also be experienced, due to changes in spinal cord and nerve function. **If recommended by your clinical team, a high-fiber diet, fluids, laxatives, stool softeners, and abdominal massage may be part of a care plan to help manage symptoms** (refer to section 4.4 for more).

- **Sexual dysfunction** in NMO may result from changes in nerve function, resulting in a lack of sensation or numbness. Men may experience difficulty in achieving erection, and women or men may have difficulty reaching orgasm. Managing symptoms

often varies from patient to patient. Medications or alternative therapies such as **biofeedback therapy may be helpful** if indicated and prescribed by your clinical team.

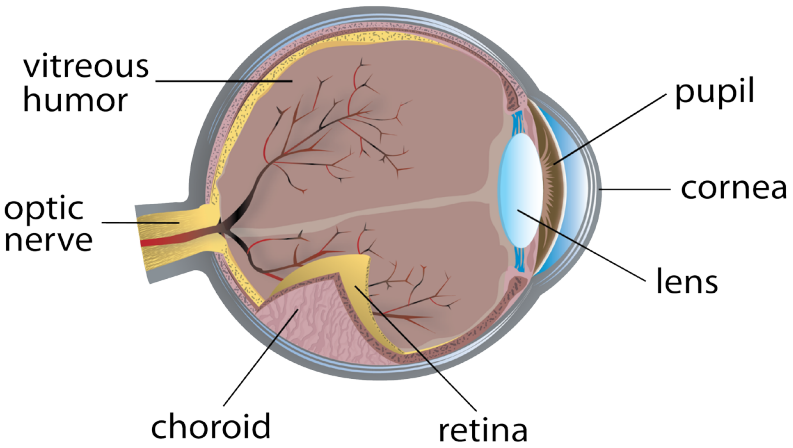
- **Osteoporosis** (brittle bones) may result from long-term use of steroid medication or lack of weight-bearing activities or exercise. If practical, **an exercise plan approved by your physician can be a natural way to strengthen bones**. Adding **vitamin D** or **calcium supplements** to your diet may also be important considerations to discuss with your doctor (refer to section 3.6). If appropriate, medicines to help strengthen bones or prevent bone loss may be useful in some patients.

- **Depression** can be a natural and normal symptom associated with NMO and other chronic diseases. Symptoms may occur for many reasons, such as **changes in quality of life, loss of vision,**

mobility or **sensation**, or **stress**. The causes, symptoms and effects of depression can be brief, intermittent or chronic. Treatment for depression often consists of **counseling**, **medication**, or both. It is important to discuss your feelings with your clinical team to consider the best ways to manage any emotional impact of NMO.

- **Visual symptoms** in NMO may include **eye pain** that is worsened by eye movement, **vision loss** over hours or days, changes in the field of view (such as loss of ***peripheral vision***) or perception of colors and depth. Such symptoms most commonly result from inflammation in the optic nerves (***optic neuritis***) that connect the ***retina*** of the eyes to the brain. With appropriate treatment, many NMO patients experience improved visual symptoms following a first attack or relapse, especially when treatment is started early.

Parts of the Human Eye



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E xperience
S tudy of NMO

Consider participating in the **CIRCLES** NMO Study.

To learn more, refer to Chapter 5.

Managing Long-Term Effects of NMO

Creating a Holistic Care Plan

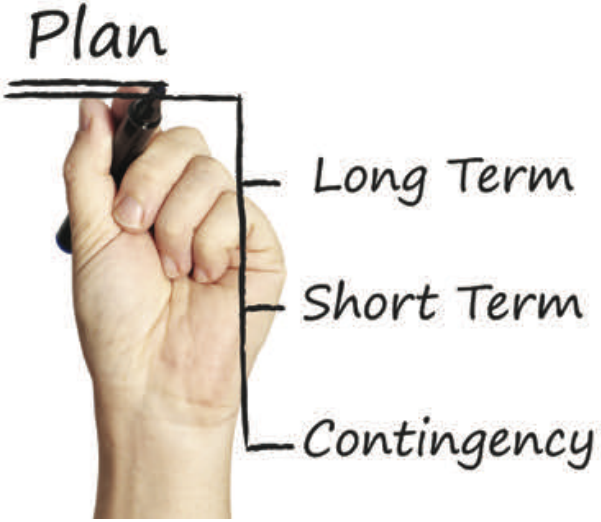
Symptoms experienced in NMO can persist over long periods of time, overlap with other symptoms, or have indirect effects on day-to-day functions and quality of life. For example, pain interferes with activities such as housework, employment or exercise. In turn, these effects can have negative impacts on self-esteem, mood, sleep, and personal or professional relationships. Although each problem may be addressed individually, many NMO patients find it helpful to manage their overall health through a multi-faceted approach, including ***holistic*** care.

In an effective holistic care plan, honest and regular communication occurs among the patient, doctors, nurses, and team of health specialists including:

- Alternative medicine (e.g. meditation, acupuncture)
- Psychological support or counseling
- Social integration
- Physical therapy
- Spiritual health experts

Importantly, such a holistic medicine team creates a coordinated plan to manage the unique healthcare process of each NMO patient. In addition to regular clinical evaluations and treatment as appropriate, vision or mobility aids (e.g. **walkers** or customized **wheelchairs**), home health care (e.g. **visits by healthcare professionals to your home**), or **custom home remodeling** can be part of a multidisciplinary management plan and may improve quality of life.

As in many autoimmune diseases, NMO can cause a broad spectrum of symptoms that may vary widely, with every patient affected differently.



Can long-term symptoms improve significantly?

It is possible that long-term symptoms may improve or resolve over time. **Researchers are learning more about NMO every day, and clinical trials are in progress to find treatments that arrest or reverse the disease process.** However, based on current knowledge it is rare for symptoms that have existed for years to resolve quickly or entirely. It is for each of us to do our best with every day we have.

Modifications to patient residence, mobility aids (e.g. walking aids or wheelchairs), and lifestyle modifications (e.g. change of job, move to a single-story home) may best be planned in advance. This way, time and resources can be focused on improving quality of life, rather than trying unproven or potentially dangerous approaches, which can be very costly. Consulting with your clinical

team – including a qualified occupational therapist – as early as possible can be important to help guide your planning, and may be covered by medical insurance (refer to Chapter 4 for more information).

How severe can NMO be?

As in many autoimmune diseases, NMO can cause a broad spectrum of symptoms that may vary widely, with every patient affected differently. **Disease symptoms can range from mild** – such as only one relatively benign attack of optic neuritis with a near-complete recovery and no further relapses – **to severe** and can include lasting effects such as blindness and/or paralysis. Some of the more severe effects may include loss of vision in one or both eyes, a degree of paralysis in limbs due to damage of the spinal cord, breathing difficulties due to spinal cord or other neurological issues, and even premature death.

You can learn more about clinical trials on our website at:
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Although the factors that predict severity of disease are not yet known, research moves forward every day to help find these answers. And, with early diagnosis and effective treatment, many of the consequences of NMO can be managed, allowing people to better live their daily lives.

What about Alternative Therapies?

Alternative and complementary therapies can be used to **target a specific physical, mental, emotional or spiritual problem caused by NMO**. They can also be used as preventative measures or purely for relaxation, and may increase your feeling of well-being. Although this guide makes no recommendations for clinical care, reflexology, massage, Reiki or acupuncture may help sleep patterns, relieve pain, or reduce stress and tension. **Consult your physician and care team for more information or specific recommendations.**

Clinical research has yet to adequately study how effective any of these treatments may be. Therefore, **it is generally recommended that they not replace the medical treatments** that your neurologist, primary care physician or other healthcare professionals prescribe. However, alternative therapies may **complement the effects of traditional medicines when added to your overall care plan as appropriate**. For example, **stress reduction** methods have been reported in the scientific literature to help stabilize some autoimmune diseases, especially when part of a long-term medical treatment plan.

Physical therapy and rehabilitation medicine tend to be very customized to each specific patient case. The goal of these activities is to improve function and coordination of movement and strength, and reduce pain that may be associated with nerve inflammation. Specialized techniques and devices can be very helpful in this way, as part of an integrated treatment plan with your health care team.

Alternative and complementary therapies can be used to target a specific physical, mental, emotional or spiritual problem caused by NMO.

3.4 Pregnancy and Pediatrics

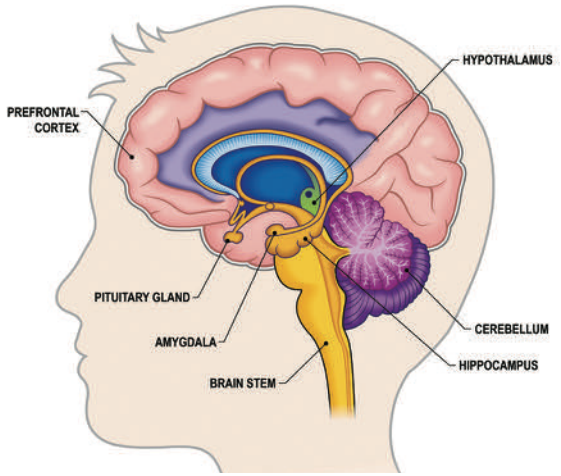
NMO and Pregnancy

The hormonal changes during pregnancy can affect disease course in several autoimmune conditions such as multiple sclerosis (MS), systemic lupus erythematosus, and Sjögren's disease. Similarly, **relapse rate may be influenced by pregnancy in neuromyelitis optica (NMO)**. Like MS, several studies from different geographic populations suggest NMO relapses increase in the months immediately following childbirth. In addition, there may be an **increased chance** for initial NMO symptoms to occur during the **post-partum period**. Some studies suggest that **relapses may increase during pregnancy** as well, signifying that pregnancy may not confer the same protective properties to disease course in NMO as in MS. However, every NMO case may be different with respect to the effects of pregnancy. Because of the potential severity

of relapses and the unique considerations of pregnancy, your clinician may advocate continuing treatment or changing to a different treatment during pregnancy. **This is an important discussion to initiate with your care team early in the process of considering pregnancy so that a plan can be made ahead of time.** Currently, there is no consensus on the most appropriate treatment options during pregnancy. It is known that some therapies may have higher risks on fetal development than others. Furthermore, there is greater acceptance for the need to monitor closely and if needed treat aggressively during the post-partum period because of a higher risk of relapse. Larger studies are needed to determine if the incidence of pregnancy-related complications, miscarriage, or infertility differ in NMO from the general population.

NMO in Children

The **pituitary** gland is called the "master gland." It is located in the center of the head, near the base of the brain and behind the eyes. The pituitary gland **governs many endocrine functions, including the thyroid gland, adrenal glands, ovaries and testes**. The pituitary gland also helps regulate the amount of salt and water in blood. **Growth hormone from the pituitary gland promotes growth and development in children**.



The pituitary gland is governed by a special region in the brain, called the **hypothalamus**. The hypothalamus connects to the pituitary by a thin stalk of vessels (known as the **infundibulum**) that **allows direct communication from the hypothalamus to the pituitary**. The hypothalamus is **rich in aquaporin-4** (AQP4; a key autoantigen in NMO), so **an NMO attack on the hypothalamus can disrupt pituitary function**.

Although most NMO cases are diagnosed in adults aged 30-40 years, NMO can emerge at any age. The development of the immune system is active during childhood, and is influenced by many different interactions with the environment. While the disease processes that lead to NMO may be similar in children as adults, the symptoms and treatments may be very different in children. Likewise, pediatricians may have special experience and insights into diagnosis and care for children facing NMO.

Epidemiology of Pediatric NMO

Current data suggest that approximately 3 percent of all NMO patients experience their first symptoms in childhood or adolescence. **Patients as young as 16 months have been reported with NMO.** The average age for NMO diagnosis in children is 10 years

old. **Both boys and girls can be affected, but as in adults, there is a propensity for females to be more commonly affected than males, at a ratio of 5:1 or higher.**

Symptoms of Pediatric NMO

Children diagnosed having NMO usually present with acute, new neurological symptoms appearing within **a few hours or days**. These attacks can include symptoms of back, neck, or eye pain, blurred vision, or loss of vision in one eye or both eyes. Some children may experience other possible symptoms including:

- Weakness or numbness (tingling/itching) of the arms or legs
- Confusion or extreme lethargy at their attacks
- Stomach pain, nausea, vomiting, or hiccups
- Fever or seizures
- Muscle spasms / backaches
- Headaches

Some special features and effects of NMO in children may be considered:

- **Puberty may come early or be delayed** in pediatric NMO patients. Some girls with previously regular menstrual cycles will develop irregular periods. Even if NMO occurs during puberty, males with NMO can father children and females with NMO can become pregnant and have healthy babies with proper medical care.
- Some children may have **abnormal sodium levels** in their blood during an attack.
- The **effects of relapses** in pediatric NMO patients may be greater than those in MS patients, including impact on blood pressure, heart rate, and other bodily functions.
- **Some children with pediatric NMO may be shorter in stature** as they develop to teenagers and adults, because of prolonged steroid use or impact of NMO on pituitary activity such as growth hormone.

As in adult NMO, **keeping relapses to a minimum,** and **rapid diagnosis** and **therapeutic intervention** if they do occur, **are the keys to avoiding long-term disability, managing day-to-day symptoms** and **improving overall quality of life.**

Diagnosis of Pediatric NMO

Similar to adults, NMO diagnosis in children is usually made by a combination of **laboratory and clinical**

Diagnosis is usually made by a combination of clinical features, appearance of lesions or "spots" on the optic nerves, spinal cord or brain using MRI.

features, appearance of lesions or "spots" on the optic nerves, spinal cord or brain using MRI. Approximately **two-thirds of children** with NMO can also have **autoantibody to aquaporin-4** in their blood or spinal fluid. However, this **antibody may not be present at the onset of the disease**, and may only appear years later. Pediatric NMO often differs from childhood MS in the **distribution of MRI lesions**, as well as laboratory results such as oligoclonal bands (in MS) or the presence of the **aquaporin-4 autoantibody** (in NMO).

Treatment of Pediatric NMO

As in adult NMO, there are **no regulatory approved treatments** for children with NMO. Clinical specialists such as pediatric neurologists usually recommend **immunomodulatory treatment regimens** similar to those used in adults, except that the dosages and duration of therapy vary. For example, **corticosteroids**

such as prednisone and procedures such as **plasma exchange (PLEX)** are often used in pediatric NMO. Attacks or relapses are typically treated with a short course (usually up to a week) of IV corticosteroids, or IVIG or plasmapheresis. As in adults, it is important to prevent new attacks in children with NMO, and treatment with mycophenolate mofetil, azathioprine or rituximab is often considered for this reason.

Research in Pediatric NMO

There is ongoing research to understand the causes of pediatric NMO including possible genetic predisposition, environmental associations, or dysfunctions in key

immune system checkpoints. As well, the 2015 IPND diagnostic criteria are helping to improve the speed and accuracy of NMO diagnosis. The effects of age, immune function and endocrine development are also being carefully studied in basic science and clinical research to better understand NMO. In addition, imaging methods are advancing to improve recognition of the effects of NMO on the CNS, and help refine prognosis. Importantly, **clinical trials are now ongoing to evaluate treatments for NMO in children when appropriate**, as well as adults.

You're invited to join...

- NMO Parental Support Group for parents with children who have NMO
- Pregnancy NMO Support Group for expecting NMO mothers
- Many more...

Find details on the NMO Resources app or on our website at:

guthyjacksonfoundation.org/support-groups

Advocates Specializing in Pediatric NMO

There are several centers across the U.S. and the world that have special experience in the diagnosis, treatment and management of NMO in children and adolescents. Care includes neurological expertise, family support, psychological therapists, social workers, occupational therapists and caregivers with special expertise in supportive and healthcare needs. Care is often co-managed by a specialist team as well as a patient's local neurologist or pediatrician.

3.5 Creating a Healthcare Team

QUICK READ

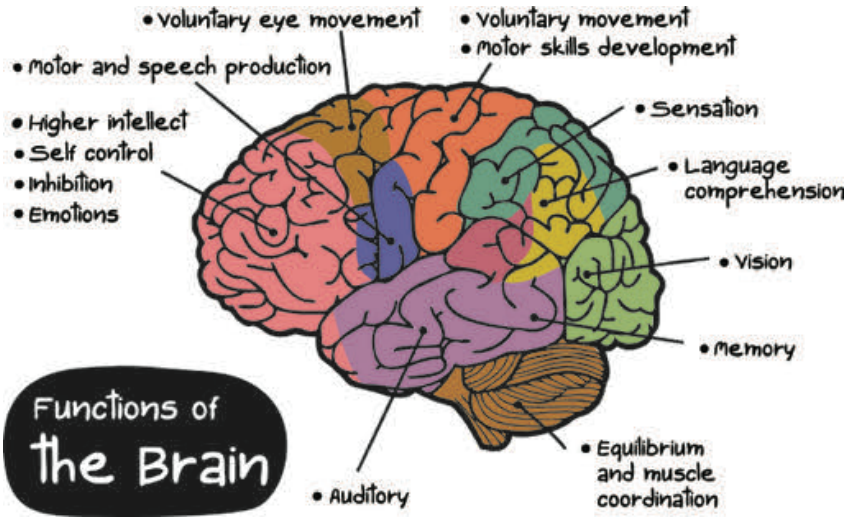
Healthcare professionals working together as a team may offer the most effective way to manage NMO. Start with the list below when considering a healthcare team:

- Primary Care Physician
- Neurologist (central nervous system specialist)
- NMO Neurology Expert
- Pediatric Neurologist
- NMO Nurse Specialist
- Ophthalmologist (eye doctor)
- Neuro-Ophthalmologist (NMO eye doctor)
- Neurology Fellow
- Physical Therapist
- Urologist (bladder and sexual functions)
- Gastroenterologist (bowel functions)
- Continence Advisor
- Occupational Therapist
- Clinical Psychologist
- Dietician / Nutritionist

NMO is a complex disease, and many patients benefit from a team of healthcare professionals having diverse expertise to help manage their health. This section describes some of these different roles.

Primary Care Physician (PCP)

The primary care physician (PCP) is responsible for providing routine health care to individuals seeking medical care. With his or her team, this doctor arranges day-to-day care, such as prescribing medications, arranging basic laboratory tests and monitoring results. When NMO is a potential diagnosis, a key role of the PCP is to rapidly engage the expertise of a neurologist with expertise and experience in NMO. The NMO neurologist works closely with the PCP and clinical care team to ensure that all aspects of diagnosis and treatment are implemented and monitored as necessary.



General Neurologist

A general neurologist focuses on diagnosing and treating diseases or medical conditions of the nervous system. This neurologist uses their expertise and knowledge to recognize and treat symptoms, and may refer a patient

to sub-specialists, such as an NMO neurologist, neuro-ophthalmologist, or other expert for further advice on diagnosis and management.

The general neurologist will be closely involved in the care of the patient alongside the team of providers. The neurologist may be seen for regular follow-ups or perhaps if needed, to admit the patient to a hospital at the time of a relapse.

NMO Neurologist

The NMO neurologist has special training, experience, and expertise in field of NMO and related neurological diseases. The NMO neurologist is responsible for ensuring the correct diagnosis is made as quickly as possible, and determines the most appropriate treatment for patients with a diagnosis or suspected diagnosis of NMO.

In addition, the NMO neurologist often leads the NMO clinical care team, and works closely with the specialist nurses and other members of the caregiver team to ensure the best possible care is delivered.

Pediatric Neurologist

Pediatric neurologists specialize in neurological care for patients 18 years old or younger. For children and adolescents with NMO, all care is managed by their pediatric neurologist, who works closely with the overall NMO clinical team. This doctor will ensure appropriate diagnosis, treatment, and continuity of care is in place for pediatric patients. It is important to have a pediatric neurologist closely involved in the daily management of all pediatric NMO cases since drug dosing and side effects can vary more so in children than adults.

NMO Nurse Specialist

Some, but not all medical neurology groups have an NMO nurse specialist, who can be a first point of contact for any day-to-day concerns of NMO patients. The NMO nurse specialist will take time to discuss the diagnosis, treatment plan, specific problems the patient may encounter and answer any basic questions the patient may have. The NMO nurse specialist may help provide:

- Information on the **condition**, **symptoms**, **medications** and other **therapies** available to increase educational understanding
- A rapid link to the NMO neurologist should there be concerns of **new or worsening symptoms** or indications of relapse
- **Support** with **relapse issues and care**
- **Facilitation** for working effectively with **healthcare professionals** such as neurologists, physicians and occupational therapists as well as nutritionists and other medical professionals
- **Education for other healthcare professionals** who might encounter NMO patients
- A link to transmit **clinical information** to the PCP, pediatric neurologist, and NMO clinical care team

Ophthalmologist

The ophthalmologist is an **expert in the assessment of visual problems** such as optic neuritis (ON). This doctor may also arrange scans and other tests to assess vision. He or she discusses findings with the NMO neurologist and connects patients with visual problems to appropriate local support services for visually impaired people.

Neuro-Ophthalmologist

A neuro-ophthalmologist is a specialist doctor trained in ophthalmology who specializes in eye diseases associated with neurological conditions. Thus, this physician has an **expertise in both neurology and ophthalmology** and generally practices and studies central nervous system (CNS) diseases that affect vision.

Some NMO patients see a neurologist who is also a neuro-ophthalmologist and who manages all aspects of patient care. In other cases, a neurologist may refer patients for consultation with a neuro-ophthalmologist for help with diagnosis, treatment, and clinical follow-up related to their vision.

NMO patients are encouraged to take an active role in their health care to help minimize the impact of disease, optimize treatment benefit, and enrich quality of life.

Neurology Fellow

A neurology Fellow is a **neurologist-in-training** who is early in their career and **gaining experience** in a specific area of interest. In addition, the neurology Fellow often conducts clinical research, and may assist patients in considering and enrolling in clinical trials. A patient may meet a neurology Fellow during a visit to the NMO clinic or while being admitted to the hospital for care.

Physical Therapist (PT)

As prescribed by neurologists or other physicians, physical therapists work to **enhance movement, coordination, and strength of the body**. A physical therapist will assess physical problems such as poor balance, limb weakness, stiffness and spasms. They will advise the neurologist on range of motion, level of activity and pain, and implement exercise or physical care programs, prevention, rehabilitation treatment plans.

NMO patients are encouraged to take an active role in their health care to help minimize the impact of disease, optimize treatment benefit, and enrich quality of life. Refer to local services for information or provision of aids such as walking sticks, hand supports, and wheelchairs.

Urologist

Patients may experience bladder and sexual dysfunction as a result of neurological damage due to NMO. The urologist is an **expert in urinary and sexual function**, and can perform bladder function tests. Specific medications are available and may be appropriate to manage urinary issues or sexual dysfunction in NMO patients.

Gastroenterologist

Similar to bladder issues, NMO may cause abnormal bowel function or control. Because the nervous system regulates normal bowel activity, **changes in neurologic function that lead to bowel dysfunction are not uncommon in NMO**. In addition, NMO may cause symptoms of prolonged nausea or hiccups. These issues are typically referred to a gastroenterologist for evaluation and management, including the use of specific medicines or dietary changes.

Continence Advisor

NMO patients may experience symptoms related to bowel and bladder function. Bladder and bowel problems can restrict daily activities and lead to embarrassment

and isolation, affecting both physical and mental health. Continence advisors **assess bladder and bowel problems, review medication regimens, suggest exercises to improve urinary and fecal incontinence, and provide advice regarding best practices for healthy living**.

Occupational Therapist (OT)

The role of the occupational therapist is to help patients **maintain independence in day-to-day activities**. This goal includes addressing activities related to personal care, domestic tasks, hobbies and employment that may be challenging due to fatigue or loss of functions such as vision, mobility or strength. Occupational therapists work to find different ways of doing routine tasks to help patients maintain their self-sufficiency and well-being.

Clinical Psychologist

Clinical psychologists **support patients and their families with the emotional adjustment of living with NMO**. By looking at emotional issues in context of NMO as a manageable aspect of one's life, psychologists can help individuals find solace and meaning on their NMO journey through coping strategies. They can also access cognitive problems (memory, thinking, focus) and make recommendations for beneficial exercises. Psychologists may also assist in behavioral modification, such as stopping smoking (which can worsen outcomes in NMO). **Psychologists are different from psychiatrists in that psychologists may not diagnose mental health diseases or prescribe medications.**

Dietitian / Nutritionist

The role of the dietitian or nutritionist is to **advise patients on nutrition, health, and dietary-related topics** to minimize impact of disease and enhance quality of life. For NMO patients, recommendations may be provided for weight management (weight gain or loss) or optimizing diets for nutrition, and for customizing special diets that may reduce bowel inflammation (e.g. acids, glutens, caffeine, alcohol), help manage weight issues and all nutritional concerns. Dietitians and nutritionists may also provide advice regarding supplements that may be helpful in NMO, such as vitamin D, calcium, or other nutrients if approved by the physician. For more information on diet and nutrition, refer to section 3.6.

Pain Management Team

The neurologic effects of NMO can cause pain in specific areas or more generally throughout the body. Beyond its discomfort, suffering from chronic pain can negatively affect daily living, create challenges in work, exercise or recreational activity, impair sleep, and have adverse impacts on meaningful relationships with others. Because the causes and effects of pain in NMO can be complex, pain management teams are often available to NMO patients. **The pain management team may consist of pain physicians, nurses, physiotherapists, occupational therapists, and psychologists, and function in a collective way**. This holistic approach ensures better pain management and coordination of care so that treatment goals are met.

3.6 Managing Diet and Nutrition

QUICK READ

Many medical caregivers and patients view dietary strategies as an important component of their treatment plans. Optimizing diet and nutrition may contribute to control or slow down NMO effects on the body, and help maintain overall good health.

To help people with NMO make informed decisions about diet and dietary supplements, the following text provides information about approaches that are not

absolutely proven, but are low risk and may benefit the underlying disease process in NMO.

Many people with NMO and related conditions may wish to use dietary approaches to help control the disease. The goal is to slow down the disease process in a safe and natural way. Paying close attention to diet and nutrition may provide a sense of control, hope and empowerment. **Medical caregivers generally agree that healthy diets are an important part of the overall care plan for their NMO patients.**

For those interested in using dietary strategies for NMO, it is extremely important to be well informed. High-quality information allows one to identify and use approaches that are low risk and potentially beneficial, and avoid those that are possibly harmful or ineffective. Due to the complexity of NMO and NMO medications, it may be difficult to obtain high-quality, unbiased NMO-specific dietary information. **Some dietary information may have financial incentives, biases, or limitations in evidence of benefit that lead to inaccurate and sometimes potentially dangerous information.**

When considering diet or nutrition changes, several key points should be kept in mind:

- Before trying specific dietary approaches (or any other unconventional therapies), the **risks and benefits** of these approaches should be discussed with your healthcare provider.

- **Unfortunately, no dietary approach has ever been systematically studied in NMO.** For those who are only interested in absolutely proven therapies, there is no dietary regimen that can be formally recommended as of yet.

Vitamin D

Recent studies have significantly changed our understanding of the role of vitamin D in health and disease. In the past, it was believed that most people have adequate vitamin D level from exposure to sunlight or intake of dairy products, and that the effects of vitamin D are restricted to regulating calcium absorption and maintaining bone health. However, much has been learned about production and function of vitamin D in recent years. **It is now recognized that vitamin D deficiency may exist among peoples of all countries.** In part, this phenomenon may be related to the beneficial effects of sunscreen in preventing

skin cancer. In addition to its effects on bones and calcium, **vitamin D exerts important actions on many other body systems, including the immune system**. Vitamin D has not been rigorously studied in NMO, but studies in other autoimmune conditions suggest **there may be some benefit to maintaining appropriate vitamin D levels consistently**.

Fatty Acids and Fats

Fatty acids are complex molecules that can have important actions on multiple body systems, including the immune system. There are two types of fats that can render fatty acids in the process of digestion. **Saturated fats** are typically solid at room temperature, and are what we generally think of as "fat." White fat on or in red meat is an example of a saturated fat. The other major type of fat is **unsaturated fat**, which is typically liquid at room temperature, and is

commonly referred to as "oil." Saturated and unsaturated fats may contain **monounsaturated fatty acids** (e.g. present in olive oil) or **polyunsaturated fatty acids**. The two main forms of polyunsaturated fatty acids are **omega-six fatty acids**, which are found in healthy oils such as sunflower and safflower seed oils, and **omega-three fatty acids**, which are enriched in fish oil.

Fatty acids can affect immune system function. **Immune system suppression, which could be beneficial for NMO, may result from omega-class fatty acids, and especially by omega-three fatty acids.** This effect on the immune system may involve T cells, B cells, or other regulatory effectors of the immune system. Although omega-three and omega-six fatty acids have not been studied specifically in NMO, they have been studied in other immune diseases.

Sodium and Inflammation

Beyond its role in other conditions such as heart disease or kidney failure, too much salt in the diet may adversely affect NMO patients. Emerging clinical evidence suggests that **excess dietary sodium may promote inflammation and could worsen NMO**.

For example, the protein encoded by a gene called **SGK-1** governs sodium transport by sensing salt. Importantly, sodium causes this system to induce pro-inflammatory molecules such as **interleukin-17A (IL-17A)**, **which is known to contribute to NMO disease**.

Possible Harmful Dietary Supplements

Like medications, dietary supplements contain chemical compounds that may produce beneficial as well as harmful effects. **Certain supplements may actually activate the immune system and promote inflammation.** For this reason, NMO patients should

avoid dietary supplements that have potential harmful effects and lack any known beneficial effects for NMO. For NMO patients, there are three main types of possibly harmful supplements:

"Immune-Stimulants"

Some supplements, such as **Echinacea**, appear to activate various components of the immune system. Through this process, these supplements could actually **worsen NMO disease mechanisms, and/or counteract the therapeutic effects of NMO medications**. The potential risks of such supplements are based on scientific studies in the laboratory or as correlated with disease, and thus are theoretical. Nonetheless, immune-stimulating supplements should be approached with caution, and certainly should not be used in high doses, over extended periods of time, or without physician approval.

Do You Know...

Some supplements, such as Echinacea, appear to activate various components of the immune system and could be harmful in NMO.

Toxic Supplements

Many dietary supplements are well tolerated. However, some **may produce side effects that range in severity** from mild, such as sedation, to severe, such as liver or kidney toxicity, or death. Such toxic effects can be caused by the supplement material itself, or by contaminants contained in the supplement as a result of manufacturing. Unfortunately, the production of supplements is not typically monitored by regulatory agencies, and quality can vary widely from manufacturer to manufacturer.

Supplements that Affect Medications

Some dietary or nutritional supplements can have negative effects on medications used to manage or treat NMO or its attacks. For example, certain supplements may directly and negatively interact with medicines, including NMO medications (such as steroids and immune-modifying medications). Alternatively, certain supplements may stimulate the functions of the liver or other organs, and affect how NMO medicines are metabolized, distributed, or cleared from the body.

Diet & Nutrition on NMO TV

For information about diet and nutrition regarding autoimmunity and NMO, please visit our video library on our website at:

guthyjacksonfoundation.org/nmotv

A Three-Step Approach to Healthy Nutrition

STEP ONE: Eat a Well-Balanced Diet

To be certain that a diet has an adequate intake of a variety of nutrients, the following general guidelines should be followed:

- Consume a variety of nutrient-dense foods and beverages
- Limit the intake of saturated and trans-fats, cholesterol, added sugars, salt, and alcohol
- Consume adequate amounts of fruits and vegetables
- Eat a variety of vegetables and fruits each day
- Unless advised otherwise, consume three or more ounces of whole-grain products daily

- Consume less than 10 percent of calories from saturated fats
- Maintain total fat intake to between 20 and 35 percent of calories
- Consume fiber-rich foods
- Limit sodium intake

More specific information may be found at: choosemyplate.gov

STEP TWO: Consider Diets and Supplements that May Balance the Immune System

NMO patients may want to consider strategies that aid in healthy immune system function and balance. Here are a few possible considerations toward that goal:

- Under the advice of your physician, take supplements of vitamin D if the blood level of vitamin D is low. Vitamin D levels may be determined with a simple blood test known as "25-hydroxyvitamin D."
- Increase intake of omega-three fatty acids
  - Fatty fish (such as salmon)
  - Healthy oils (olive, safflower)
  - Specific supplements (fish oil, omega-class fatty acids)
  - Maintain or modestly increase intake of omega-six fatty acids
  - Decrease dietary sources of saturated fat
  - Supplement with vitamin E if omega-three or omega-six fatty acid intake is increased

STEP THREE: Avoid Adverse Supplements

NMO patients should avoid or use caution with supplements that may trigger immune system reactivity, cause significant side effects, or interact with medications. As with any dietary or nutritional supplement, consult your physician, dietician or nutritionist before beginning use of any supplements.

Expanding Perspective

There are many different types of unconventional therapies that may be used in NMO. The five main types of alternative and complementary therapy, along with representative examples, are:

- Organic based therapies: diets, dietary supplements
- Mind-body medicine: meditation, hypnosis, biofeedback
- Manipulative and body-based systems: massage, chiropractic medicine

- Alternative medical systems: traditional Chinese medicine, Ayurveda
- Energy therapies: magnets, therapeutic touch

Access the entire article free of charge on the GJCF website at:
guthyjacksonfoundation.org/diet-nmo

It is imperative that you talk with your doctor about dietary, nutritional, supplement or alternative medicine strategies if you are considering them as components of your treatment plan. Some clinics have an on-site nutritionist, while others have a recommended reading list for those interested in monitoring their nutrition as an attempt to control symptoms of NMO.

Do you know?

NMO clinical trials are essential to achieve regulatory approval for NMO therapy. Read more about clinical trials in section 5.1 or on our website at: guthyjacksonfoundation.org/clinical-trials