Living with
NMO


HELPFUL
TIPS

4

Living with NMO

4.1 Fitness

QUICK READ

Exercise routines and preferences may vary from person to person depending on overall health, degree of symptoms, limitations of mobility, and basic fitness levels. A healthy lifestyle promotes a balanced immune system, reducing the risks of inflammation while defending the body against infection. Regular exercise and enough sufficient rest are two of the keys to a healthy lifestyle. Seek advice from your doctor or physical therapist before beginning any exercise program.

The benefits of exercise may include:

- Improved muscle tone and flexibility
- Increased mobility and endurance
- Better bladder and bowel function
- Reduced fatigue and depression
- Improved attitude and social engagement

Additional aspects of an exercise program to be discussed with your health care team include:

- **Appropriate exercises** vs. those that should be avoided
- **Ideal levels of exercise** intensity, frequency, and recovery
- **Duration of workout** and any physical limitations

- **Referrals to other professionals**, such as a physical therapist, who can help create a personal exercise program that meets your needs
- **Managing body temperature** as NMO pain symptoms may be more pronounced if the body is overheated. You will find a number of personal cooling devices on the market today. Your doctor may have recommendations for cooling measures and devices to best meet your needs.

Yoga may be a good choice of exercise to help NMO patients.

Yoga may be a good choice of exercise to help NMO patients. Yoga emphasizes relaxation, breathing, stretching, and deliberate movements. Physical benefits can include flexibility, strength, muscle tone, pain reduction, and improved breathing. Improvements in mood and well-being, restful sleep, and increased energy have also been reported in patients who regularly perform Yoga exercises. Locating a yoga class close to home may help you to attend regularly. If a stretch or pose does not feel right to you, listen to your body. Talk with your instructor to learn proper technique and more options to meet your needs.

There are many different types and varieties of yoga programs. Although they may differ in their philosophy and techniques, all yoga styles have a number of potentially beneficial qualities, including:

- **Breathing techniques** to focus the mind and body
- Individualized, non-competitive, and **customizable programs**
- Emphasis on bodily **alignment**, which benefits posture and balance
- **Muscle strengthening**, stretching, and conditioning
- **Tension release** that may allow the body to feel more energized
- **Relaxation techniques** to reduce stress

Most NMO patients are able to exercise in many different ways. Because no two people experience

Although they may differ in their philosophy and techniques, all yoga styles have a number of potentially beneficial qualities.

NMO in the same way, exercise programs should account for individual capabilities and limitations. The advice of a physical therapist or exercise specialist can help to identify goals and target programs that are safe and have good muscle, bone, and respiratory benefits. If changes in mobility occur, ask your specialist to recommend modifications.

Keeping a regular exercise routine is an important lifestyle strategy for managing complications and maintaining physical and mental strength in living with NMO.

QUICK READ

To help manage fatigue, pace yourself as you perform daily activities. Meal planning, use of handheld or other electronic devices, and setting a daily schedule can help to accomplish your daily goals. Accepting help from family and friends can benefit everyone.

4.2 Managing Fatigue

Varying types or severity of symptoms can affect fatigue and are common among patients with neurological conditions. Some patients report no fatigue, while others report experiencing extreme fatigue.

What is fatigue?

Fatigue is generally defined as a feeling of lack of energy and motivation that can be physical, mental, or both. The sensation of fatigue is associated with feeling tired, weary, exhausted, and weak. Try not to be discouraged. Nearly everyone struggles with fatigue or overwork from time to time.

Fatigue in NMO

Some people with NMO experience overwhelming exhaustion by simply carrying out their everyday activities. Fatigue can set in without warning, and accomplishing routine tasks may become a real challenge. This degree of tiredness can be difficult to understand, and may lead to frustration and feelings of guilt or inadequacy.

What causes fatigue?

It is difficult to determine a specific reason for fatigue, which is commonly found in people with chronic or neurological illnesses. Possible causes include:

- **An initial attack or relapse** that requires the body to compensate during recovery for the changes that have occurred. Over time, fatigue may improve or disappear completely.
- **Getting used to a new way of life.** Living with NMO can be physically and psychologically tiring.
- **Sleep disturbances** that can be due to pain or incontinence. After a period of time, a patient may feel the effects of sleep deprivation and exhaustion.
- **Low mood, depression, frustration, and anger**, all feelings that can be associated with changes in life.
- **Medications** that can lead to feelings of tiredness and lethargy.

After a period of time, many people with NMO are able to determine which activities or events are likely to cause, increase or decrease the chances of fatigue. While some patients report that physical activity increases their level of fatigue, others report a benefit from being active. Sometimes fatigue is caused by setting unrealistic goals and trying to accomplish too much too soon. **Remember to pace yourself.**

What is it like to live with fatigue?

Fatigue is subjective, hard to explain and difficult to measure. It can be difficult for others to appreciate and understand how debilitated a person may feel, even though they may appear fine. **Employers, friends and loved ones may all struggle to understand and empathize with fatigue, resulting in additional anxiety and stress for the patient living with NMO.** Clear and honest communication can help.

> After a period of time, many people with NMO are able to determine which activities or events are likely to cause, increase, or decrease the chances of fatigue.

NMO patients realize that each daily task uses up energy. It can be helpful to prioritize of the most important tasks of the day first, followed by optional tasks. In this way, energy can be focused on the most meaningful activities.

Ideas for managing fatigue

Here are suggestions that may help minimize the effects of fatigue:

- **Rest:** Don't be afraid to rest when your body says you should. One key to being able to accomplish critical daily activities is to rest before your energy level is depleted. If you can, take several rest breaks throughout the day.
- **Sleep:** Do your best to get a good night's sleep. If pain or incontinence issues interrupt sleep for more than one week, seek advice from your doctor. Keep caffeine intake at a healthy level and arrange for

One key to being able to accomplish critical daily activities is to rest before your energy level is depleted.

support in caring for children at night, if necessary. Try not to be hard on yourself if you have trouble sleeping. Meditation, music, and other tools may help improve sleep quality.

- **Daily Activities:** Plan your most important daily activities first and early in the day, and don't be afraid to explain your schedule. Talking with others about what you need may help you set realistic goals as you "talk them out." You never know, if you communicate more with others, help may come when you least expect it.
- **Cleaning:** Letting go of the responsibility of caring for your home can be difficult. In an effort to save energy, consider using lightweight equipment and carefully timing larger cleaning efforts. You may find a great benefit from accepting help with household chores or seek the help of a professional house cleaning service.
- **Laundry:** Try doing laundry one small load at a time throughout the week. This may help prevent doing multiple loads in one day, which can be exhausting.

- **Meal Preparation:** A well-balanced meal is a source of energy and health. Menu planning saves time, simplifies life, and makes meal time more enjoyable.

  Plan ahead: Planning your daily, weekly, or even monthly routine can help you prioritize your goals and prevent all the "little things" from piling up. For example, a weekly meal plan can help to feel more organized and in control. Select easy recipes that don't require a lot of prep work. Make weekly grocery lists from the meal plan to avoid multiple trips to the grocery store. Accept help from family or neighbors. A well-written grocery list can be easily followed by a caregiver.

Shopping: Consider shopping for food online and/or using home delivery services. Purchasing and storing pre-cut, washed vegetables, fruits, and frozen or canned foods may cost more but save steps in the end. Also, keep a good stock of "basics" which can be prepared as simple, nutritious meals.

Cooking: Pre-measure ingredients and arrange in the order they will be used to allow for interruptions. Use timers and reminder notes as needed. If practical, make more food than you need and save the extra for days when you don't have the energy or interest to cook. When boiling vegetables or other foods, consider placing wire mesh baskets in your cooking pans. They can be easily lifted out for serving, removing the immediate need for heavy draining of pans full of hot liquid. Consider using a slow cooker to enable having hot meals ready at the end of the day when you are feeling most tired. Remember to pace yourself: divide food preparation throughout the day and/or week. Soak dishes and pans in the sink if possible to make cleanup easier when you have more energy.

- **Work:** In your workday, carefully consider your roles, responsibilities, and activities. Frequent breaks may prove helpful in your work schedule and aid in managing your energy reserves. Take into account the effect of your travel time to and from work. **You may want to share this NMO guide to help your employer and colleagues better understand the effects of NMO.**

- **Electric appliances:** Small, simple kitchen appliances can save time and energy. It may be best to choose appliances that are simple to dismantle and clean.

- **Mobility:** Each person's ability to walk and move around can vary. Some NMO patients will have little-to-no restrictions, while others will use walking aids or a wheelchair. It is important to remain as active and mobile as is healthful, and remember that mobility can change at different times during the course of NMO. Combining different forms of transportation, walking, and using a wheelchair can help to reserve energy.

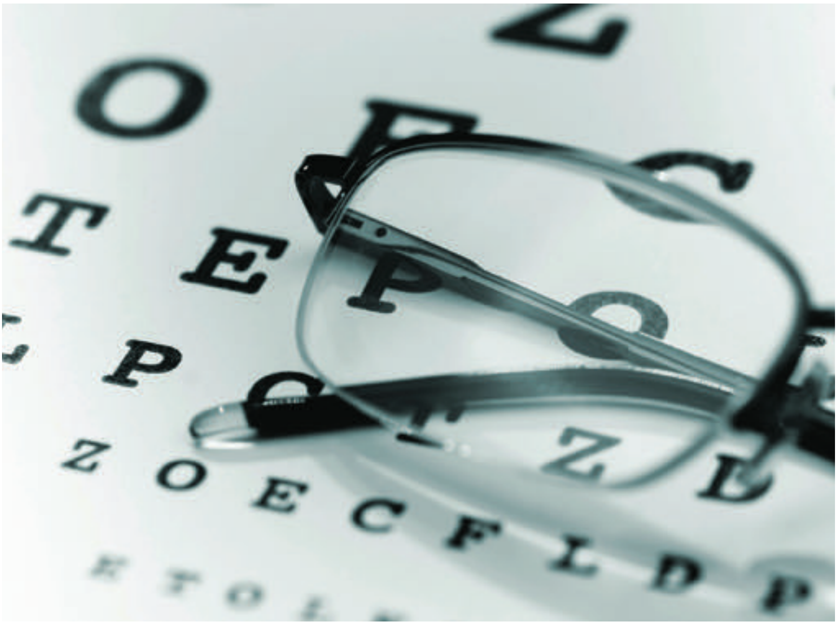
- **Leisure Activities:** It is widely recognized that a person's interests, hobbies, and leisure pursuits contribute to meaning, balance, and purpose in life. At the end of the day, you may find there is not enough energy left to try new activities or enjoy beloved pastimes. As stated above, prioritizing your interests, planning ahead, and managing energy may help you regain the ability to do the things you want to do.

Further sources of information on fatigue

The National Multiple Sclerosis Society (NMSS) website features comments and thoughts from people living with fatigue, anecdotes, and advice.

www.nationalmssociety.org

4.3 Coping with Loss of Vision



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The use of visual enhancements and technology can help NMO patients maintain more independence.

Vision problems can be common in NMO patients who have experienced inflammation of the optic nerve. The optic nerve transmits signals from the light-sensitive, inner layer at the back of the eye (called the **retina**) to the vision area of the brain.

Sight loss takes many forms. Visual impairment is a deeply personal experience and no two cases are exactly the same. Some patients can't see well in the dark; others are affected by bright sunlight. Some have a restricted field of vision (**peripheral vision**) and others experience a loss of contrast or color. Everyone experiences some days where we may see better than other days.

How is visual impairment measured?

Partial sight can be hard to judge. If you cannot read normal newsprint while wearing glasses or contact lenses, then you could be considered partially sighted. Blindness and partial sight are formally defined terms which relate to the quality of vision, but **blindness does not necessarily mean the absence of light.**

Sources of support and services

Dealing with the emotional and practical impact of changes to your sight can be overwhelming, especially if there has been a sudden and unexpected deterioration as can be the case in NMO.

It is important to remember that you are not alone and that information, support and services are available to help you live your life as independently as possible.

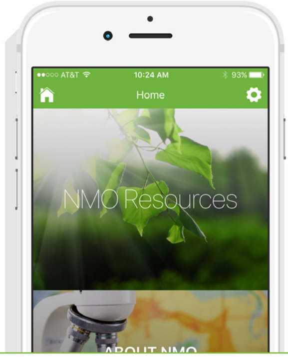
Everyday equipment exists to make life easier.
A wide range of tools and gadgets are available to help daily activities. A few examples include:

- Devices that alert you when a pot of liquid begins to boil.

- Tools that make a sound when a cup you are pouring water into is nearly full.
- Knives with an adjustable guide to help you cut even slices.
- Tactile watches and alarm clocks.

Accessible technology and telephones can aid communication. Computer products and telephone systems that can be useful include:

- Mobile phones with tactile, well-spaced buttons and the ability to read text messages aloud.
- Telephones with large, color-contrasting keypads.
- Computer screen readers.
- Magnification software.
- Voice-activated software and writing programs.



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4.4 Managing Bowel and Bladder Problems

QUICK READ

Bowel issues are not uncommon. Evaluate your diet, research a bowel plan with your clinician, look into bowel-specific products, and carry back-up supplies when you travel.

In some patients, NMO can cause spinal cord lesions (known as **transverse myelitis**), which can cause disruption of bowel and bladder functions. This is termed **neurogenic bladder** or **neurogenic bowel**. If you experience neurogenic bladder or bowel issues that lead to loss of bladder and/or bowel control, **there are two important things to know:**

- **You are not alone.**
- **You have options.**

You Are Not Alone

According to the International Foundation for Functional Gastrointestinal Disorders, "bowel incontinence is very common. It occurs in **6 percent of women** younger than 40 and increases to **15 percent** of women aged 40 and older. **Between 6 percent and 10 percent of men** experience fecal incontinence, with a slight increase with age. Individuals with incontinence are often reluctant to report their symptoms; therefore, **the condition is believed to be widely under-diagnosed and hidden in our society**."

Bowel and bladder accidents can happen, and it is not your fault.

The Urology Care Foundation states, "A quarter to a third of men and women in the U.S. suffer from urinary incontinence. **That means millions of Americans**."

Incontinence can have a significant emotional and psychological impact on those who suffer from the symptoms. It can be embarrassing and distressing, and can have a negative impact on social and work situations, sexual intimacy, and relationships.

It is not unusual for NMO patients to have bowel or bladder issues. Sometimes the bowel or bladder is overactive, and some patients may have issues with constipation or urine retention. **Bowel and bladder accidents can happen, and it is not your fault.** If you are having bladder issues, your physician might request a urodynamics study. There are also self-help measures that can be useful to some patients. It is important to maintain an honest dialogue with your doctor and caregivers.

You Have Options

Help is available to begin to regain control of your bladder and bowel. The first steps are to:

- Understand the functions of the bowel and bladder.
- Understand how NMO can disrupt bowel and bladder functions.
- Work with healthcare professionals to identify the types of challenges that are presented and explore possible rehabilitation and/or management options.

Avoiding caffeine and acidic foods can aid bladder control.

Sometimes diet can exacerbate bladder or bowel symptoms. Avoiding caffeine and acidic foods can aid bladder control. **Many patients keep a daily diary of fluid intake and output to accurately monitor their bladder habits.** Likewise, dietary fiber can stabilize bowel function, and keeping track of frequency of bowel movements can help plan activities best for time intervals of bowel or bladder functions.

Function of the Bladder and Bowel

The functions of the bowel and bladder are **to store waste and release it at appropriate times with intentional control**. Each has a muscular storage area: the bladder or the rectum. Each has an outlet, or a valve (called a sphincter) that operates under both voluntary and involuntary control. NMO may change the ability to control one or both sphincters.

How NMO can Disrupt Bowel and Bladder Functions

Spinal cord lesions that result from NMO can interrupt communication between the nerves in the spinal cord that regulate bladder and bowel functionality and the brain. In this way, NMO can lead to incontinence, or the inability to control urine or stool expulsion. **Incontinence can occur in two ways:**

- Involuntary release of urine or stool.
- Involuntary retention of urine or stool.

In addition, NMO lesions in the CNS can disrupt the sensation of having to urinate or have a bowel movement.

There are **two different types of incontinence mechanisms** that result from CNS lesions caused by NMO:

- **"Spastic" bladder or bowel** in which the sphincters or muscles of these organs that control release of urine or stool do not open normally, resulting in retention or constipation.
- **"Flaccid" bladder or bowel** in which the sphincters or muscles that control retention of urine or stool do not close normally, resulting in unexpected accidents.

You can learn more about NMO clinical trials on our website at:

guthyjacksonfoundation.org/clinical-trials

Cases in which bladder or bowel dysfunction are caused by neurologic issues are called **neurogenic bladder** or **neurogenic bowel**.

Communicating with your healthcare team about bladder or bowel dysfunction is the best way to regain control and confidence. Even if it may feel embarrassing at first, clearly and honestly expressing your experiences and concerns is the best way to find solutions.

Working with Healthcare Professionals

A **bladder and bowel plan** is a specific schedule, diet, exercise and in some cases, medical routine to best manage bladder and bowel dysfunction. These plans are customized by each person based on many factors, respecting daily activity and personal preference. Typically, bladder and bowel plans are developed under the guidance of a healthcare specialist.

One method for effective communication with your healthcare specialist is to first state your bladder or bowel concern, then introduce NMO as a potential cause. This approach allows healthcare professional the best chance of assessing all potential causes of the condition in your case. In turn, understanding the specific causes yields the best specific management plan or treatment. Healthcare providers with expertise in caring for patients with neurogenic bladder or bowel issues are knowledgeable and experienced in helping patients with these conditions.

Overview of Bladder and Bowel Management

Healthcare professionals target **three overall goals** to help patients manage their bladder and bowel:

- Prevention of incontinence and accidents
- Achieve consistent and predictable release periods
- Maintain general health and prevent complications such as impaction or constipation.

These goals can also help prevent:

- Developing a thick, inelastic spastic bladder.
- Frequent urinary tract infections.
- Kidney damage, which can result if the bladder is not well managed.

To help manage your bladder and bowel dysfunction, healthcare professionals encourage healthy lifestyle habits, such as being as active as possible, eating a well-balanced diet (refer to section 3.6), and drinking an appropriate amount of fluids. **Healthcare professionals offer these general guidelines to help optimize your bladder and bowel management:**

- Fluid intake should be spread out throughout an entire day, rather than consuming large amounts of fluid at one time.
- Fiber or a fiber supplement can be a good source to help achieve proper stool consistency.
- Exercise and/or an active lifestyle can help with **gastrointestinal (GI) motility.**
- Proper hygiene can help reduce the risk of infection.
- Establishing and following your bladder and bowel program.

The goal is to achieve independence, only relying on assistance when necessary. Being able to execute your own bladder and bowel routine without assistance helps you to regain confidence and helps to support your hygiene as well as the hygiene of your caregivers.

> To help manage your bladder and bowel dysfunction, healthcare professionals encourage healthy lifestyle habits.

Bladder Management

People who suffer from **neurogenic bladder** might experience frequent and urgent urination or the inability to control urine retention. Options for management include:

- **Medications to relax the bladder**

  Many types of medications exist that might help an overactive bladder hold more urine. Consult your healthcare professional to determine which type of medication might be best for you.

- **Intermittent catheterization**

  A catheter is inserted into the bladder to empty urine and is removed when finished. Occurrence is approximately every 4 hours, generally 5 times per day.

People who have a **flaccid bladder** might experience constant leakage, or leakage during coughing, sneezing, or other activities. Medications have not been proven to be effective for flaccidity. However, options for effective management include:

- **Establishing and following a good periodization routine**

  Train the body to empty the bladder every 2 – 3 hours.

  Attempt to use abdominal muscles to help empty the bladder.

- **Intermittent catheterization**

  If frequent urinary tract infections exist, intermittent catheterization might help continence maintenance.

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Tip: Drinking cranberry juice is believed to help prevent and/or treat urinary tract infections. If consuming large amounts of cranberry juice is not feasible, supplements in the form of cranberry powder or tablets may be helpful alternatives.

Want to know more about these options? Access the bowel and bladder videos on NMO TV, on our website at: **guthyjacksonfoundation.org/nmotv**

Maintaining Confidence and Independence

There are many products available that are used to avoid embarrassing bladder or bowel accidents. There are absorbent pads and adult pull-ups that cannot be seen under clothing. Many patients carry emergency supplies with them that include disposable moisturized wipes, spare undergarments, antibacterial soft soaps, and zip lock bags.

NMO patients are strongly encouraged to discuss incontinence with their doctors who can provide a viable program for better management and referral advice as needed. **With advice from physicians and diligent attention to bladder and bowel habits, most patients are able to carry out everyday routines without incontinence issues negatively impacting their lives.**

QUICK READ

Tip: There are many ways to get more **fiber** into your diet. Things like **chia** or **flax seeds** or **pharmaceutical products** are available. Consult your healthcare professional to discussion your options.

Want to know more about bladder and bowel management? Access more videos on NMO TV, on our website at:

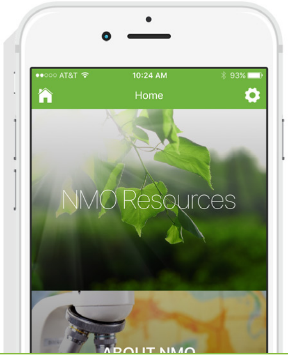
guthyjacksonfoundation.org/nmotv

4.5 Occupational & Physical Therapy

Occupational and physical therapy are important options to help address physical effects of NMO. These approaches include **specific exercise programs**, **activities to enhance mobility, dexterity and balance**, and **maintaining physical fitness**. Together these programs often **greatly benefit NMO patients** in maintaining daily independence and capabilities, and **may aid in recovery from acute NMO episodes** (first attacks and/or relapses). Occupational and physical therapy are typically provided in specialized centers with specific expertise in these treatment strategies. **Your neurologist can help you find a center with the staff equipped to best address your specific therapeutic plan.**

Occupational and physical therapists are healthcare professionals who work with people who have temporary or long-term physical disabilities caused by diseases such as NMO, or other medical conditions. These experts also help people who have communication or learning challenges. They help people who have difficulties with everyday tasks such as preparing a meal, taking a bath, lifting their legs into bed or using a computer keyboard. **The aim of occupational and physical therapy is to enable you to live as independently as possible at home, work, school and during leisure time.** These specialists can help you adapt to changes in your life and overcome practical problems by:

- Looking at ways an everyday task can be done differently to maintain your **independence** or **reduce** the effects of **pain** and **fatigue**
- **Offering advice on daily living equipment** that may help you to maintain your independence with a specific task or activity
- Recommending alterations or **changes to your home** to make it more accessible or safer for you
- Helping to address **education or work issues**



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Physical and occupational therapy often includes developing a maintenance routine consisting of **stretching**, **conditioning**, **and/or using adaptive equipment**. Centers will instruct patients on frequency and proper form in these activities over the course of a series of appointments. Once a patient achieves maximum benefit at the center, they **continue recommended activities on their own, in their own home or exercise venue.** Periodic reassessments might be scheduled if necessary.

4.6 Support with Daily Life

QUICK READ

Balancing the many roles each of us play in our lives and the lives of others can be complicated. NMO can make these roles more challenging. Identifying essential needs can help NMO patients determine what they can accomplish independently and when they may need help.

Coping with difficulty in carrying out your daily activities may present unique challenges. These difficulties can be experienced for a variety of reasons including fatigue, pain, and weakness due to the NMO itself, and/or the psychological impact it can produce.

Sometimes solutions to challenging tasks can have simple solutions by asking yourself, "Is there a way of doing this differently or more efficiently?"

Identify your most important roles and activities

It may be helpful for you to make a list of your activities in a 24-hour period. Begin with the moment you wake up in the morning until you go to sleep at night. Include any activities during the night if you awaken. Next to each activity record if you need help or note an "OK" if you can do it on your own.

It may be surprising just how complex our daily lives are in meeting basic needs from washing and dressing to household chores, shopping, cooking, employment, leisure activities, and socializing.

Why are roles important?

Our particular roles in life make us who we are; they contribute to our identity . These roles are many and varied including parent, child, caregiver, lover, friend, homemaker, cook, shopper, cleaner, volunteer, employee, student, DIY expert or animal caretaker, among others. It is natural for NMO to impair performing one or more of these roles. **Remember, NMO is not your fault.** With the many recent advances in NMO medical care, in the majority of cases these **setbacks are temporary**. Is important to try to resume those things that have meaning in your life. Where possible, find ways around the difficulties so you can continue to play an important part in the role. Having family, friends, and caregivers participate in creative solutions can also promote positive experiences and **strong bonds that endure difficult times**.

Adapting to Change

Whether caused by NMO or not, everyone is affected by change. One key to making the most of change is to adapt to it as best you can. **Accentuate the positive.** From the list of daily activities recorded in the previous section, you could prioritize those that are essential, most useful or desirable, and those that are not essential or have the least benefit or enjoyment in your daily routine. **This exercise can help to focus energies on what is most important.**

Our daily schedules, roles and routines are very different. Some may live alone, while others live with and/or care for others. Our situations are unique and bring with them their own challenges and solutions. **Your list can help provide you with a clear picture of those roles and activities that are essential and desirable in your life.** It may also help to find ways to best fulfill these roles and goals in the most meaningful ways possible.

Finding New Solutions

Overcoming challenges and achieving goals may be found through many different approaches. For some, adapting to change may come in the form of changing the timing of an activity, or receiving support from a family member, friend, colleague, or caregiver. For example, a solution may require you to use your left hand for activities rather than your preferred right hand. For others, special equipment or routines may offer new ways to perform daily tasks. **Trial and error can be a valuable tool in finding solutions.** A wide range of products designed for people affected by neuromuscular illnesses are available as possible aids. Questions regarding performance of particular activities should be discussed with your doctor.

NMO Support Groups

More and more NMO support groups are being created to offer support for those affected by NMO. These groups are often led by NMO Advocate volunteers who may themselves be facing the challenges of NMO, and know what it can feel like. Other groups may be facilitated by relatives or caregivers of NMO patients who want to help the broader NMO community. Support groups exist in the forms of in-person groups, telephone conferences, and online groups. Types of support groups that have been created are:

- NMO Caregivers
- Pregnancy
- NMO Parents for pediatric cases
- Facebook groups (both private and public)
- Mens Group

- Local support groups
- more!

Join one of the many NMO support groups or create your own. Get NMOtion for NMO and visit our website at:
guthyjacksonfoundation.org/support-groups

Living with an "Invisible" Disability

In many cases of NMO, symptoms may not be visible to others. At times, NMO might not appear to affect an NMO patient physically, and therefore a patient might not appear to be disabled, or display signs of illness. In addition to NMO, many other types of medical conditions fall into this category. These conditions are sometimes referred to as **"invisible disabilities"** or **"invisible illnesses."** Generally, people consider only those with outward signs of medical disabilities to "qualify" as being ill or impaired, and who need disability care and access. However, **awareness of invisible illnesses and disabilities is growing**. There are many online resources dedicated to these challenges, including "Invisible Illness Awareness Week." Learn more online.

4.7 Daily Living Equipment

QUICK READ

Daily living equipment and technology can help NMO patients regain independence.

The effects of NMO can sometimes make previously simple, everyday tasks more difficult. **Equipment is available that can help to lessen these effects and regain greater independence.** This equipment is called **Daily Living Equipment**. Examples may include small gadgets such as electric can openers or self-leveling spoons to help at meal time. Likewise, voice-activated or virtual assistants can make computer use or internet access simpler. A stairlift is an example of a larger device that can help overcome difficulties in climbing stairs due to weakness or pain.

Daily living equipment and technologies such as these can also help with routine activities including bathing, dressing, doing laundry, cooking, getting out of bed, traveling, exercising and more. These activities all help patients to preserve or regain independence at home, work, and during leisure time.

Wheelchairs and Scooters

NMO patients can experience a decrease in mobility due to vision impairment, weakness, imbalance, or other reasons. Many people experience a reduction in their strength that may necessitate the use of a walking aid such as a cane or crutches. Others may experience a more extensive reduction in activity that results in inability or difficulty standing and walking.

In these cases, modern wheelchairs and personal scooters can be highly useful means for patients to remain mobile. These can be light in weight, agile and portable, enabling mobility in the home and while traveling. For many, the use of a wheelchair can greatly aid in living life as normally as possible. **Many NMO patients improve over time with treatment and rehabilitation to such a degree that use of a these devices is no longer needed.**

Types of Wheelchairs and Scooters

There are hundreds of styles of modern wheelchairs and personal scooters for differing needs and abilities. They fall into three main categories:

- **Self-Propelled:** these devices are propelled by the patient themselves.
- **Attendant-Propelled:** these devices are operated by someone who assists on behalf of a patient.
- **Electrical-Powered:** these devices run on batteries and enable the user to move easily and quickly with little or no physical effort. Batteries are re-charged overnight or when not in use.

Wheelchairs and scooters may be used in conjunction with an appropriate pressure cushion for greater comfort and support, and to avoid pressure points that can otherwise irritate skin and produce pressure sores.

Many home healthcare stores carry a variety of wheelchair and scooter styles, which are available in many different sizes and dimensions to provide best comfort and support. Some tilt to create different seating angles, and others can be raised or lowered in height to aid a user to reach something high up or communicate with others more easily at eye level. In many cases, modern wheelchairs and scooters are prescribed by a physician and **may be covered by medical insurance**.

Other Assistive Devices

Many types of devices are available that can assist individuals to regain independence for everyday living. Other examples of tools and devices that are available include:

- Assistive grip jar openers.
- Electric and/or V-shaped can openers.
- Easy-to-grip utensils.
- Automatic soap dispensers.

Do You Know...
You can learn more about NMO clinical trials on our website at:

guthyjacksonfoundation.org/clinical-trials

- Buttonhooks to help fasten clothes.
- Clothes with elastic waistbands or magnetic clasps.
- Velcro bras.
- Electric toothbrushes with wide handles for easier grip.
- Fanny pack to help carry supplies.
- Self-leveling spoons.
- Telephone headsets or headphones.

These are just a few examples of the many options that can help you keep or regain your independence.

4.8 Modifying Your Home

QUICK READ

Grab rails, shower chairs, and banisters installed in a residence can be relatively simple ways to help NMO patients have mobile independence.

Some of the effects of NMO such as reduced mobility, pain, or vision loss can result in difficulty getting around your home. The layout of your home may provide you with full independence and ease of access. Yet some newly-diagnosed NMO patients find that movement and access in their home are limited, especially in areas containing stairs or outdoor areas.

Solutions vary. They may come in the forms of a simple grab rail secured to the wall in your shower to help with stability, a second banister on the stairs to hold for balance, carefully positioned lighting to enhance vision, or additions such as a stairlift or permanent ramp to your front door. **A well-designed and accessible home can make a world of difference to your independence and ease of living.** There are hundreds of ideas and solutions available. It is most important to find solutions that are best suited for your specific needs.

Each person's home may have different options that allow for changes in lifestyle. If a home cannot accommodate the necessary changes, moving to a more suitable home may help some gain greater independence. **However, time is often needed to come to terms with such changes if they are needed.**

> A well-designed and accessible home can make a world of difference to your independence and ease of living.

4.9 Driving and Transportation

QUICK READ

A careful assessment by an NMO patient and their healthcare team is key to determine the level of driving capability. Skills to assess include:

- Vision
- Physical ability
- Fatigue
- Cognitive changes

Along with the skills and capabilities of a patient, it is important to consider other factors that may affect driving safety. These include climate and road conditions, as well as vehicle maintenance.

Without question, driving is one of the most important means of independence for many people. It is a primary activity that enables connections to work and socializing outside of the home. Driving is often a necessity and a convenience, and represents personal freedom. In contrast, the prospect of losing one's ability to drive may trigger fears of becoming isolated, lonely, and dependent. When NMO affects driving skills, discussing the ability to drive can make a patient feel defensive and protective.

A careful assessment by each patient's healthcare team should be made to determine the level of ability to operate a moving vehicle. **Many NMO patients may continue driving as advised by their doctor.** However, the demands of driving on the human body cannot be underestimated, and certain medications can impair decision making, energy, and stamina needed for safe driving. For these and related reasons, special care must be taken to ensure safety for those patients who continue to drive, and that of other drivers.

Vision: Unimpaired vision and peripheral vision are crucial to safe driving. Assessing **visual acuity** (clearness of vision) is important to determine any necessary adaptations such as vision correction that may be needed to fulfill driving regulations.

Physical/motor changes: For people with physical impairments, driving assessments include evaluation of motor involvement (muscle weakness), range-of-motion limitations, coordination, and sensory deficits in arms and legs. Limitations in these areas can restrict the ability to operate a vehicle. **A wide range of adaptive controls may be considered for driving.** These controls generally require skilled professionals to assess, inform, and install.

Fatigue: Planning ahead is key to preventing fatigue from impacting driving. Knowing and anticipating signs of fatigue and scheduling outings accordingly can go a long way toward preventing or minimizing the effects of fatigue on driving.

Heat and Cold: Temperature extremes **may cause symptoms to worsen**, so plan ahead by scheduling outings during the part of the day that offers the most comfortable conditions. Park in areas that are protective from sun or wind if possible. Also, consider remote car ignitions to enable starting a car without getting inside. Heating or cooling a vehicle prior to driving can help reduce temperature-induced discomfort.

Cognitive Changes: Taking inventory of NMO symptoms as they relate to the ability to absorb, process, and apply important information to make quick decisions is crucial to safe driving.

Regular checkups with your doctor will help to diagnose any cognitive effects that may jeopardize driving safety. Together you can determine your ability to operate a motorized vehicle safely in the best interests of all concerned.

Public Transportation Services: Many cities have vehicles that have special equipment such as ramps, lifts, and designated seating that is specifically intended to assist persons with special needs. These services vary from city to city, but are often posted on community service websites and available from the city services department. It is important to become familiar with the public transportation services of your specific location to better plan your activities as needed.

4.10 Social Security Disability Benefits in the United States

NMO and its relapses can complicate day-to-day schedules and necessitate frequent medical visits. For these reasons, NMO can create challenges to routine employment and career choices. As a result, NMO patients may choose to seek financial assistance through government programs. For example, in certain cases, the **United States Social Security Disability (SSD)** program may offer benefits to help alleviate the financial costs of NMO by offering a monthly payment for medical care. **Understanding the Social Security Disability application process** is the first step toward determining if financial aid may be appropriate in your case.

The **Social Security Administration (SSA)** operates two disability programs including **Social Security Disability Insurance (SSDI)** and **Supplemental Security Income (SSI).** To qualify for either program

Understanding the Social Security Disability application process is the first step toward determining if receiving the financial aid may be appropriate in your case.

you must meet the specific medical criteria, and the financial qualifications of the respective program to which you are applying.

Generally, to **qualify for SSDI benefits** you must have **earned enough work credits through previous employment**. The amount of earnings needed for credits may change slightly from year to year as average earnings levels change. The credits you earn remain on your Social Security record even if you change jobs or have no earnings for a period of time.

Unlike the SSDI program, the **SSI** program is not based on prior work activity. Instead, the SSI program is a **needs-based program**, where income and assets largley determine eligibility.

Considering the SSA Medical Criteria

When you apply for Social Security Disability benefits the SSA compares your condition to a listing of conditions in a reference known as the "Blue Book." This publication contains all of the conditions that could potentially qualify an individual for SSDI or SSI benefits, along with the criteria that must be met for assistance in each condition. **While NMO is not included in the SSA Blue Book, you may still be approved for Social Security Disability benefits through a vocational medical allowance.** To achieve this specific aid, a patient must be able to prove to the SSA that their condition prevents them from working.

Preparing for the Social Security

While NMO is not included in the SSA "Blue Book," you may still be approved for Social Security Disability.

Disability Application Process

As **NMO is not included in the SSA Blue Book**, patients may find that careful preparation for the application process offers the best chance for positive outcomes. **Key in this regard is documenting that your disability prevents you from performing work.** Obtaining documentation of the following information may be invaluable in this respect:

- Clinical histories
- Hospital records
- Lab results
- Treatment histories
- Written statements from treating physicians

By providing as much evidence as possible with your application, it will be easier for the SSA to understand how your condition qualifies you for benefits.

Applying for Social Security Disability Benefits

When you apply for disability benefits you will be asked to fill out a number of forms. Be sure to **fill out each form in its entirety and provide as much detail as possible in your answers**. Some individuals may choose to engage legal advocates to assist in form completion and submission. You will receive a decision regarding your claim approximately **two to four months** from the date

of your application. If you are awarded benefits, you will be notified as to what benefits you will receive, how much you will be receiving each month and when benefits will begin.

Appealing a Denial of Benefits

If you are denied benefits, you have **60 days** from the date of the notice to appeal the SSA decision. If you choose to appeal a denial of benefits, you may want to consider retaining the services of legal counsel. These professionals can help you determine why your initial claim was denied and assist you in gathering the evidence needed to strengthen and support your claim. A disability attorney can also represent you before the administrative law judge at your disability hearing.

Sources of Information

The United States Social Security Administration:
www.ssa.gov

Social Security Disability Help:
www.disability-benefits-help.org

4.11 Support for Caregivers

QUICK READ

Caregivers also need support to maintain healthy and balanced lives.

Caring for a relative, loved one or child with NMO can be a rewarding and fulfilling experience.

Caregivers include anyone who cares for an NMO patient on a day-to-day basis. Oftentimes, caregivers include parents, children, other relatives, or friends. It is important to remember the needs of caregivers. Many people who act as caregivers for NMO patients find it to be a rewarding and fulfilling experience. However, without the right support it may also be difficult at times. Some caregivers live with the person they are supporting, while others do not. Caregivers are people of all ages, even children who provide care for a parent. **Caregivers often have a need for information, financial and other support, and time away to connect with people who have similar needs.** It is perfectly normal to have complex feelings in a role as a caregiver. It may be challenging to cope with the life

Join or create an NMO Support Group.
Refer to section 6.5 for more.

changes that occur when the role is assumed, and a loved one is suffering from a chronic illness. **Support comes in many forms and may provide a tremendous help to a caregiver.**

Regular breaks from daily responsibilities, eating well and exercising regularly, and sufficient amounts of sleep are necessary to maintain good emotional and physical health. **It may be a good idea to accept help from a trusted friend or family member to allow time for a primary caregiver to run errands or visit friends.**

A caring role is not a conventional job. There is no need for a caregiver to feel guilty about wanting a break or needing time off. In the long term, personal time can help avoid feeling isolated and depressed, and may improve coping with the demands of being a caregiver.

NMO Support Group Telecon

If you are an NMO caregiver, you are invited to join the NMO Support Group telecon. This group meets monthly by participants dialing a conference call line. If you would like to learn more or join this telephone support group, please visit our website for details: **guthyjacksonfoundation.org/support-groups**

Become an NMO Advocate

Anyone can be an NMO Advocate, and signing up is easy! See Section 6.2 to find out how.