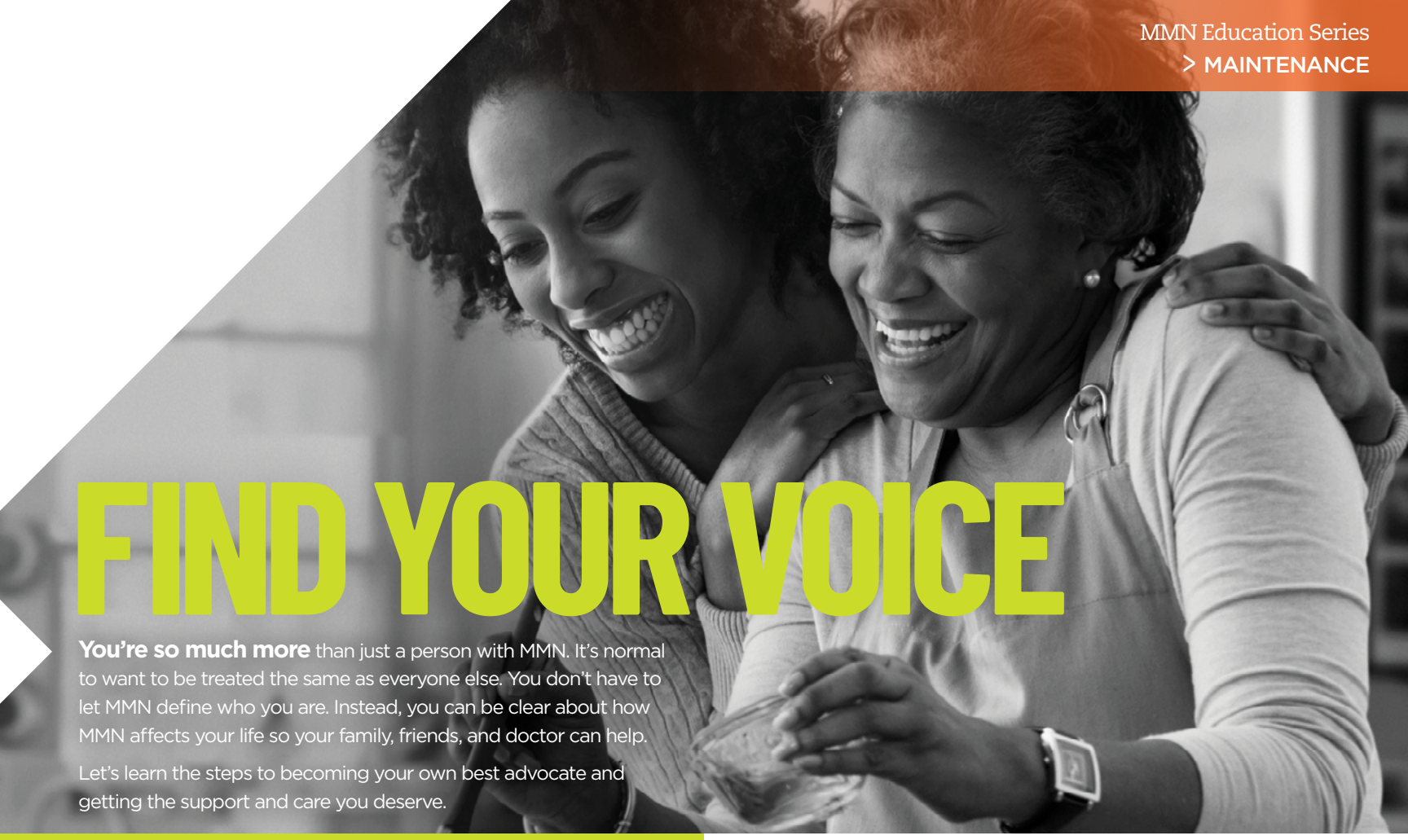
TAKING CHARGE OF MMN

MULTIFOCAL MOTOR NEUROPATHY

You can put MMN in its place.
You have what it takes.



FIND YOUR VOICE

You're so much more than just a person with MMN. It's normal to want to be treated the same as everyone else. You don't have to let MMN define who you are. Instead, you can be clear about how MMN affects your life so your family, friends, and doctor can help.

Let's learn the steps to becoming your own best advocate and getting the support and care you deserve.

You can control how people see MMN

Without your help, people won't always fully understand what you're going through. In those moments, remind yourself that MMN is very rare. Even some doctors don't know what it is. It makes sense that some people won't fully get it right away.

Some parts of MMN are easy to understand—like having trouble holding things or walking—while other parts are completely invisible to people. You can help others understand MMN by letting them know how you're feeling and what it is like being diagnosed with MMN and starting treatment. The more they know, the better they can support you.

4 points to help explain MMN

MMN causes weakness in the hands and feet

Be specific about where it affects you and how it impacts your life.

MMN is not just muscle weakness

Help your loved ones understand that things like fatigue can keep you from doing some activities.

MMN is a long-term, daily experience

Explain that there may be good days and bad days. Even on good days or when you don't want to talk about it, it still hasn't gone away.

MMN is personal

Talk about specific times when MMN affected you. It may be hard, but people understand stories better than symptoms and examples will let loved ones know how and when they can help.

Embracing your support network

Once those close to you learn about MMN, some will ask how they can help. Others will wonder but won't know how to ask. Don't be afraid to ask your friends and family to help you while you figure out your new routine. It will let them feel helpful and allow you to spend quality time together.

There are plenty of ways loved ones can help out

- Running errands
- Cooking or doing housework
- Driving to and from appointments
- Providing emotional support

CHART YOUR OWN COURSE

There is no set formula for MMN management. Over time, your doctor may want to adjust your approach based on your symptoms. Your doctor will only know how well your current plan is working if you tell them. That's why it's so important that you continue to partner with your doctor to make sure you're on the best path forward.

Track your experience for your doctor

At each appointment, you should share with your doctor how you are feeling. It can be hard to remember in the moment what has changed since you last saw your doctor. Using a weekly journal can help you notice trends and communicate any changes.

Sample experience tracker

Date / /							
This week, I:	Completely disagree ←						→ Completely agree
Was able to get dressed without issues	1	2	3	4	5	6	7
Was able to walk without issues	1	2	3	4	5	6	7
Was able to do the things I wanted to do	1	2	3	4	5	6	7
Had enough energy	1	2	3	4	5	6	7
Felt frustrated or limited by MMN	1	2	3	4	5	6	7
Was independent	1	2	3	4	5	6	7

Notes: _____

_____

_____

Seeking out knowledge

Being an advocate for your own care means finding new perspectives and keeping up-to-date with MMN news. Fortunately, there are many organizations that can help you do just that.

The GBS/CIDP Foundation International

- Lists 30 "Centers of Excellence" in the United States
- Hosts forums, chapter meetings, and other events

Neuropathy Action Foundation (NAF)

- Posts brochures, news, and quarterly newsletters
- Provides information on how to fight insurance denials

National Organization for Rare Disorders (NORD)

- Posts information about ongoing clinical trials
- Provides links to associated organizations

The Foundation for Peripheral Neuropathy

- Lists foundation-recommended neurologists
- Organizes support groups

REMEMBER THAT YOU CAN ALWAYS TALK TO YOUR DOCTOR ABOUT HOW YOUR MANAGEMENT PLAN IS WORKING AND WHETHER YOU COULD BENEFIT FROM ANY ADJUSTMENTS.

STAY ON TRACK

Your doctor, specialty pharmacy, and insurance company all have critical roles to play in your ongoing MMN management. Your doctor should be the only person to determine when you start or stop treatment. By understanding the process, you can be better prepared to help keep your plan on track.

Working with specialty pharmacies

If you are going to receive treatment at home, your specialty pharmacy will play a critical role in your access to care. They will be the ones sending you medication, administering medication, monitoring your progress, and keeping comprehensive medical records. They can also often help you manage insurance and financial issues.

Whenever possible, try to arrange for a single point of contact—a person at the specialty pharmacy who knows your history and situation. Keep this person up to date on any issues you may have, changes to your insurance, or any other adjustments to your treatment that you've discussed with your doctor.

NAVIGATING INSURANCE

Consistent insurance coverage is critical for long-term care. Here are some key actions you can take to help prevent lapses in coverage.

Know your policy

Read through your insurance policy carefully and understand what is and isn't covered. If there's any part of your coverage you don't understand, call your insurance company and have them explain it to you.

Discuss with your healthcare team

Make sure your doctor's office has reviewed your insurance information, particularly when making a change to your treatment. If you need a prior authorization for a change, make sure your doctor gives you one before the change.

Take detailed notes

With insurance, it's all about the details. Take notes of all conversations you have with your doctor, specialty pharmacy, and insurance company. Maintain all records in a single folder so you have everything you need.

If you are denied

1. Review your policy, records, and notes. Have them on hand
2. Call your insurance company and find out whether this is an error or an authorized denial of coverage
3. If it's not an error, request a formal review. Follow their review procedure to file your request as quickly as possible
4. If needed, get your doctor involved. They can often help to resolve the issue directly

REMEMBER, MMN TREATMENT SHOULD NOT STOP UNLESS YOU AND YOUR DOCTOR DECIDE IT SHOULD.

KEEP MOVING FORWARD

You're now more prepared to take charge of your future and manage MMN. As you continue down your path, don't forget that your loved ones and healthcare team are there to help.

3 things to remember

> Your support network is there to help

> Keep a dialogue going with your healthcare team

> You have a right to continued care

BE YOUR OWN ADVOCATE TO STAY ON TRACK WITH YOUR MMN MANAGEMENT

Additional brochures in this series

> Diagnosis of MMN

> Management of MMN

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