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Yesterday, Today, Tomorrow: 40 Years of MS Focus National MS Education and Awareness Month®

Four Decades of Innovation in MS

Dear Readers,

As you read the 2026 NMSEAM toolkit, we want to take a moment and thank you. With your support, we are excited to celebrate this year's theme and a significant milestone, 40 years of MS Focus: the Multiple Sclerosis Foundation standing alongside the MS community. This anniversary offers all of us an opportunity to pause and reflect on the journey so far, but also look forward to the path ahead. Rather than focusing on a single aspect of MS, this year we explore the evolution of MS, how MS looked decades ago, what it has developed into today, and how individuals can visualize on the ongoing advancements.

When MS Focus began in 1986, the landscape of MS was vastly different. Diagnostic tools were limited, treatment options were few, and many people navigated their diagnosis with little guidance or community support. Yet even in those early years, resilience was at the heart of every story shared with us. Today, earlier diagnoses, increased treatment options, and growing public awareness have reshaped what it means to live with MS. People are entering their journeys with greater knowledge, better tools, and more connections than ever before.

This year's toolkit explores that evolution through three different lenses – personal, healthcare, and public.

As you read and work through this toolkit, we'd like you to think back to when you started on your own journey, where you have been, where you are now, and where you hope to go. The last 40 years have brought astonishing changes to our organization and to the MS community, but what remains unchanged is the strength and spirit of the people who live with MS and those who support them. Your stories, your voices, and your resilience continue to guide our mission.

We are honored to walk with you through yesterday, today, and tomorrow.

Sincerely,
The MS Focus Team

The experience of being diagnosed with MS has shifted significantly over the past four decades. What once was shaped by social stigmas, misunderstood, or mistaken as another diagnosis is now better recognized and supported by a growing body of scientific research. Hearing from individuals diagnosed in the 1980s and 1990s offers a fundamental contrast to the journeys of those diagnosed today, revealing how far the MS community has come and how earlier, clearer diagnoses can influence both emotional and physical outcomes.

The Diagnostic Experience in the Past

For individuals who received an MS diagnosis in earlier decades, the path was long and uncertain. MRI was not commonly utilized as a diagnostic tool until the 1990s. Before this breakthrough, diagnosis often depended on clinical observation, symptom history, and spinal fluid analysis – tools that frequently left individuals confused and scared without a definitive answer for years.

This long search for a diagnosis had a deep emotional effect on individuals and their loved ones. Many may recall feeling frustrated when their symptoms were dismissed or misunderstood. Some were told their problems were "all in their head," leading to feelings of doubt, isolation, or even embarrassment. Not knowing what was happening in their own bodies created constant worry and fear of the unknown, especially as symptoms changed or got worse without explanation.

The World Health Organization has long recognized that neurological conditions, especially those with fluctuating symptoms such as MS, were historically underdiagnosed because of limited access to specialized imaging and trained clinicians. This contributed to prolonged uncertainty, emotional distress, and a sense of invisibility for many individuals seeking answers.

When a diagnosis finally came, it could bring both relief and shock. On one hand, people finally had a name for what they had been experiencing. On the other hand, earlier decades offered very few treatment options, and the medical community had limited knowledge about how to support patients emotionally. As a result, many individuals faced their diagnosis with little guidance, unsure of what the future would hold.

To better understand how these diagnostic experiences feel on a personal level, we asked members of our Lived Experience Panel to reflect on their initial diagnosis and how MS has shaped their daily lives.

* **Didi Nguyen** said, "My diagnostic journey was very overwhelming at first. I had a flood of emotions, everything from fear, worry, determination, resilience, shock, and anxiety. But after my diagnosis, the one emotion that still stuck with me until this day was resilience."

* **Dawn Morgan** said, "It took some time for me to understand that just like seasons change, it is okay for my body to go through changes as well. I did take some time away and soul searching to accept this reality. MS has been the best teacher, and it allows me to be vulnerable in my daily life – which, in addition to being comfortable with this vulnerability, has taken me to a completely different space in my MS journey."

* **Nick Overton** said, “I went through the five stages of grief after my initial diagnosis. Reflecting on it now, I understand that my diagnosis had nothing to do with being a nurse or anything else I have done in my life, and now I focus on humanitarian work. With MS, I took the time to relearn my body and understand things I had to limit like walking or my daily chores. I have learned to not overdo it and listen to my body."

While these lived experiences reflect the emotional effect of diagnosis, they occurred at different points along the ongoing evolution of MS care and treatment.

Advances in healthcare by Dr. Ben Thrower

Time marches on. As a neurologist serving the MS community since 1992, I am amazed at the great advances we have seen in our ability to diagnose and manage MS. I say this with great humility and respect for those living with MS. With these advances comes the realization that we are not there yet. We do not have a cure yet. We do not have a way of restoring function and reversing disability yet. I fully believe we will though. What are some of the most significant changes that I’ve seen over my years of working with MS?

There has been a shift in how interested the medical community and society are in MS. While MS was once viewed as an obscure mystery that many had never heard of, we now see MS presented in television and cinema commonly. Young healthcare providers were sometimes discouraged from focusing their career on MS because of a sense of therapeutic nihilism. When I finished neurology training in 1992, there were no neuroimmunology fellowships. That first form of specialized training wouldn’t come along until 2005 at the Mayo Clinic. We currently have 69 fellowships in the United States that train bright young minds to help us defeat MS. With this exploding interest, we have seen new treatment options and more research. Of the published studies on MS, more than 50 percent have been in the past 10 years.

Optimism. Hopefulness. Frustration. I know the MS community experiences all these emotions when looking at the advances we’ve seen and those we anticipate on the horizon. I choose optimism and hopefulness.

Diagnosis Today

The advances made are not just historical milestones but rather, they directly influence how MS is diagnosed and managed in the present day. Today, advanced imaging technology and evolving diagnostic criteria allow many individuals to receive a diagnosis earlier in their symptom journey. (We will learn more about the latest updates to the diagnostic criteria in section two of this publication.) The FDA has highlighted the role of advanced MRI techniques and biomarker research in accelerating accurate neurological diagnoses. Earlier diagnosis means people can start lifestyle planning and receive treatment sooner, which has been shown to positively influence long-term wellness.

Evolving the Ways of Managing MS

The evolution of diagnosis has carried forward into the way people manage MS over time. Those diagnosed decades ago often relied on self-advocacy, support from loved ones, and trial-and-error coping strategies because of the limited therapeutic options. Today, the FDA has approved more than 20 DMTs, with continuous advancements in treatment options to fit individualized needs. This advancement empowers people with MS to make more personalized decisions about their care, considering factors such as financial effects, family planning, route of administration, and dosage timings.

During this time frame, the medical community has also shifted to a patient-centered model of care. Gone are the times when the doctor simply wrote a prescription for an MS medication, or dictated a plan of care with little to no input from the patient. Today, patients are involved in deciding which treatment is right for them. Thanks to reliable MS websites from health and advocacy organizations, newly diagnosed individuals can quickly learn about their options and what questions to ask their doctor when making such important decisions.

Technology, Inclusivity, and Social Awareness

MS diagnosis and symptom management in today's world are being transformed by technology in ways that may have seemed unimaginable decades ago. Telehealth, a health service recognized by the World Health Organization, serves as an essential tool for chronic disease management and allows access to specialists especially in rural or underserved regions. MRI and other advanced imaging methods have made an earlier and more accurate diagnosis possible. Aside from innovations in digital technology within the healthcare system, wearable devices and adaptive equipment have also seen advancements. Wearable devices such as a smartwatch or Fitbit can help individuals track mobility and heart rate; smartwatches can also track oxygen levels and serve as a phone in times of emergencies. Adaptative equipment such as kitchen tools, mobility aids, and visual aids may help individuals maintain a more independent lifestyle. Social media and online support groups connect people globally, reducing isolation and amplifying visibility.

Societal shifts toward inclusivity have further transformed the modern MS experience. Conversations and policies about disability rights, workplace accommodations, equitable healthcare access, and representation have become more mainstream. Individuals diagnosed today feel more validated in expressing their specific needs, seeking accommodations, and advocating for accessibility.

National Family Caregivers' Month Webinars:

Redefining What a Caregiver Is **- msfocus.us/110325 and**

Outside of Caregiving, Who Are You? **- msfocus.us/111725**

Sponsored by Novartis and Genentech

Technology Then and Now – Kasey Minnis, Executive Director

In the early days, when someone was diagnosed with MS, they didn't usually have anywhere to turn for guidance. They would find out about the Multiple Sclerosis Foundation by calling the telephone operator and asking, "can you give me a number for someone to talk to about multiple sclerosis?" They would reach our toll-free helpline and not even know what to ask. Our caseworkers would provide them information about MS and then use thick directories and massive binders full of resources to track down support in their area.

How different from today. These days, before we even connect with a client, they've likely been to our website, watched our educational programs on YouTube, or followed us on social media. Technology empowers people with MS right from the beginning of their journey.

Changes in Caregiving

Forty years ago, caregiving was mostly informal and provided by loved ones. Spouses shouldered most of the responsibility, often while balancing work, childcare, and daily household activities such as paying bills, cooking, etc. Extended families may have stepped in if permissible, but many caregivers navigated the emotional and physical demands with little guidance, few resources, and no formal recognition of their role. This could lead to significant stress, particularly for middle-aged individuals who were having to take care of their spouse, their children, and their aging parents. This stress and pressure are now identified as generation stress.

Today, caregiving has taken on a new identity. Caregivers are now more informed and have community support, though this does not take away from the demands of being a caregiver. More men are primary caregivers than in previous generations, reflecting both shifting cultural norms and increasing awareness of disability inclusion within families. Adult children can also provide caregiving from a distance by sharing digital calendars, health information through smartwatches, medication reminder apps, and many other technological advancements that have been created to provide support from afar. Remote caregiving has allowed for loved ones living in different states or countries to contribute to supporting individuals living with MS.

Aside from the shift in caregivers' role, the support and resources available have also expanded substantially in the last forty years. Caregivers are now offered:

- Training and education through hospitals, nonprofits, and community programs.
- Support groups, both in-person and virtual, where caregivers can share experiences and decrease the feeling of isolation.
- Paid caregiving services, which can supplement family care or provide relief.
- Case management and social work support, helping families navigate insurance, home-health assistance, or disability accommodations.

While these shifts may not have eliminated the daily challenges caregivers face, they have increased the tools available. Caregiving is increasingly recognized as a partnership between family, community programs, and healthcare professional rather than a responsibility one household must carry alone. As the MS community continues to grow, so does the understanding that caregivers, too, deserve support, education, and time to care for their own well-being.

Practical Ways to Share Caregiving Responsibilities

- Use shared apps to organize appointments and responsibilities.
- Divide tasks between family members and loved ones based on strengths and availability, if possible.
- Schedule routine breaks for self-check-ins.
- Ask your healthcare providers about home-health referrals or local support services.

Wellness and CAM

Complementary and alternative medicine, alongside other wellness practices, have become an integral part of how many people with MS manage their symptoms and support overall well-being. This inclusion represents a significant cultural shift in the way MS is now managed. Forty years ago, practices such as yoga, acupuncture, massage, meditation, and T'ai Chi were often viewed as "alternative," unverified, or outside the scope of traditional healthcare. Many individuals who benefited from these practices did so privately, without the encouragement or validation of their healthcare team or any support networks. This may have also led to these additional methods not being incorporated appropriately because of a lack of understanding or having a skilled instructor to help learn the proper methods.

Today, these same practices – and more such as art, dance, and music therapies – are widely recognized as valuable components of a holistic approach to MS care. Individuals frequently use them alongside traditional scientific-led treatments to support flexibility, balance, stress reduction, and emotional resilience in their daily lifestyle. Healthcare providers have also become increasingly open to discussing these tools, and many clinics now integrate CAM options into their wellness programs because of increased research supporting a holistic approach to manage MS symptoms.

MS Focus has played a role in normalizing and expanding access to complementary practices. Since our founding, we have provided education and resources for CAM therapies. Today, we also offer free virtual classes in adaptive chair yoga, art therapy, and T'ai Chi with the intention to support individuals with varying mobility levels and energy needs. These classes provide structure, community, and a sense of empowerment for participants who want to explore nonpharmacological ways to support their well-being.

Many people note their personal journey with wellness has evolved over time. Someone who once relied only on medication might later incorporate slow, intentional movement or stretching into their daily routine. Another might discover acupuncture or breathwork as a meaningful way to manage stress. Some become advocates, sharing what has helped them with support groups or online communities. Maggie Courier, an active volunteer of MS Focus, has shared numerous words of wisdom on the benefits of CAM and continues to be an advocate of a holistic approach to MS management. “Mind and body can be treated using CAM.”

What was once considered unconventional is now widely perceived as practical and accessible. Wellness and CAM practices offer individuals new ways to participate actively in their care, not as replacements for medical treatment, but as additional tools that support daily functioning, emotional steadiness, and self-connection. As more people share their experiences, these practices continue to gain visibility and acceptance, shaping a more holistic and personalized MS journey for those diagnosed today.

Benefits People Commonly Report

While individual experiences vary, many people share that CAM practices help them.

- Build routine and structure
- Reduce stress and tension
- Improve mood and emotional balance
- Increase body awareness
- Enhance flexibility or mobility within personal limits
- Feel part of a supportive community

CAM isn’t a replacement for medical treatment; it’s an empowering complement. Before introducing a new approach of therapy into your lifestyle, discuss your options and desired outcomes with your healthcare team.

Looking at the Long-Term: Expectations Then Versus Now

When individuals were diagnosed decades ago, their expectations for the future often felt uncertain or limiting. Many believed their lives would become increasingly restricted, with few options for maintaining independence or long-term stability. The future felt defined by the lack of research and understanding of MS. But over the past forty years, the way MS is diagnosed and managed has altered.

While the paths differ greatly between those diagnosed decades ago versus today, a shared theme emerges across all stories: growth and perseverance.

Take a moment to reflect on how your MS diagnosis has affected your outlook on your independence with the following prompts:

What was your diagnostic journey like, and what emotions stand out when you look back on that time?

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How has living with MS changed the way you see yourself or your day-to-day life?

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What do you wish more people understood about MS and what it’s really like to live with it?

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What advice or message would you share with someone who has just been diagnosed?

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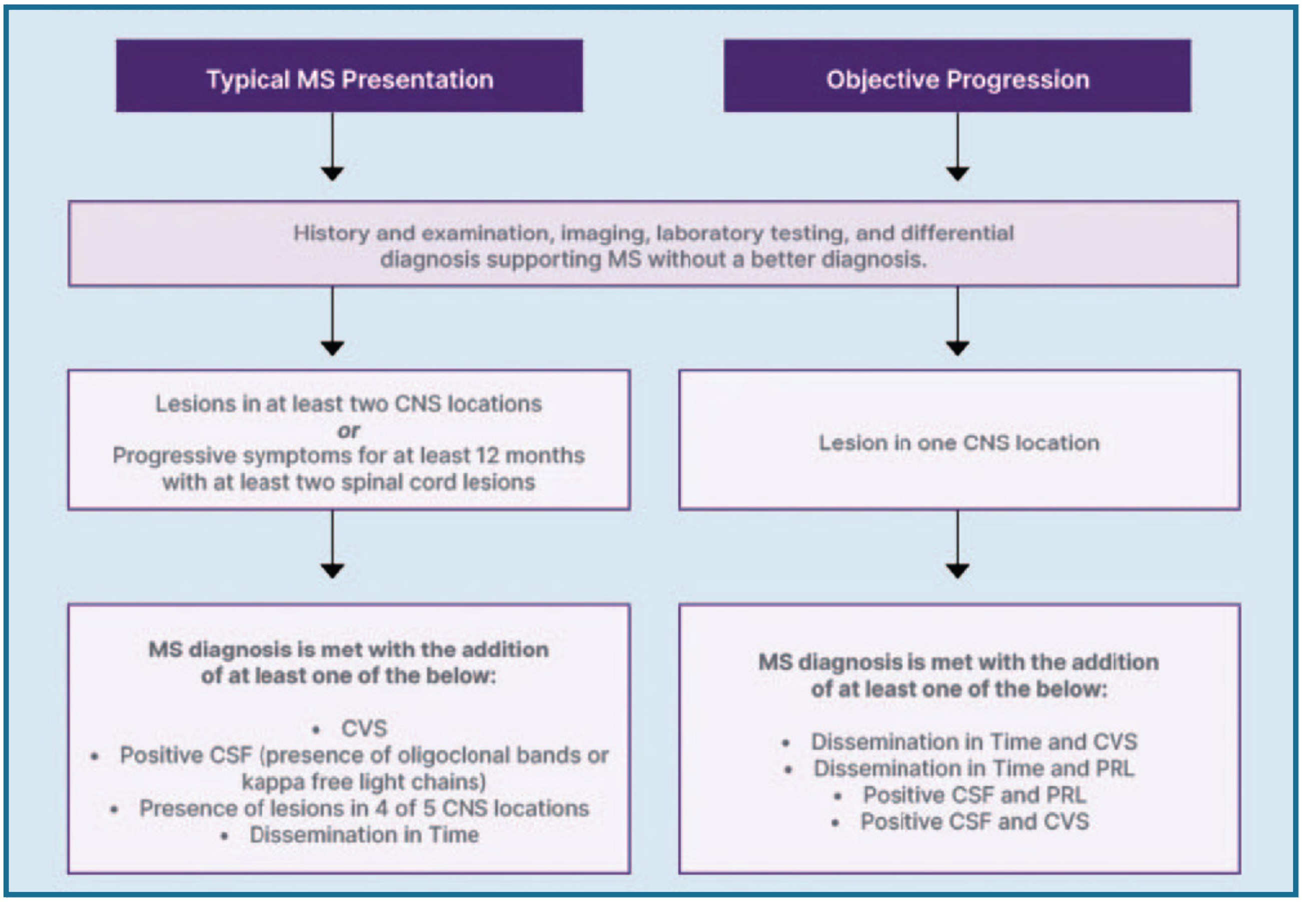
Healthcare

Diagnostic Tools: Then and Now

Before the medical and scientific advancements in MS were made, receiving a diagnosis was a long and stressful process. Without advanced imaging tools, people often went from physician to physician searching for answers. Symptoms that would appear and then disappear made the condition only more difficult to identify. Many individuals spent months, or even years, wondering what was happening to their bodies. This curiosity mixed with fear led to self-doubt, internalizing their emotions, and left individuals questioning if there was any answer awaiting them. Over time, this prolonged uncertainty urged important changes in diagnosing MS leading to the McDonald's criteria, which is now used by physicians to make an accurate and timely diagnosis.



Typical MS Presentation

Objective Progression

History and examination, imaging, laboratory testing, and differential diagnosis supporting MS without a better diagnosis.

Lesions in at least two CNS locations
or
Progressive symptoms for at least 12 months with at least two spinal cord lesions

Lesion in one CNS location

MS diagnosis is met with the addition of at least one of the below:

- CVS
- Positive CSF (presence of oligoclonal bands or kappa free light chains)
- Presence of lesions in 4 of 5 CNS locations
- Dissemination in Time

MS diagnosis is met with the addition of at least one of the below:

- Dissemination in Time and CVS
- Dissemination in Time and PRL
- Positive CSF and PRL
- Positive CSF and CVS

2017 versus 2024 McDonald Criteria
What Changed What Stayed the Same

Both the 2017 and 2024 McDonald Criteria aim to:

- Help doctors diagnose MS as early and accurately as possible.
- Use MRI, symptoms, and spinal fluid findings to show MS activity in different parts of the central nervous system.
- Reduce the time people wait for a clear, confirmative diagnosis.

What's New in the 2024 Update?

1. Expanded Areas for Diagnosis

2017: Brain and spinal cord lesions were counted, but the optic nerve could not be used as a separate area.

2024: The optic nerve is now officially the fifth anatomical location doctors cause for diagnosis. This helps because many early symptoms of MS may affect vision.

2. New Supportive Biomarkers

2017: Physicians relied mainly on traditional MRI findings and oligoclonal bands in spinal fluid and had no use of advanced MRI features.

2024: The criteria introduced new tools that help confirm MS and allow physicians to rule out other conditions which may present with similar symptoms.

- **Central vein sign:** a small vein in the middle of certain brain lesions that may be visible in certain MRIs.
- **Paramagnetic rim lesions:** a specific active lesion which can be identified on MRIs and suggests unresolved chronic inflammation
- **Kappa free light chains in spinal fluid**: a biomarker which measures inflammation within the central nervous system, also known as intrathecal inflammation.

3. More Flexibility for Early Diagnosis

2017: Required clearer symptom attacks or specific MRI changes before diagnosing MS.
2024: Allows MS to be diagnosed earlier in certain cases, including radiologically isolated syndrome.

4. Guidance for Older Adults

2017: Offered little direction for diagnosing MS in people older than 50.
2024: Provides specific guidelines to help physicians tell MS apart from aging, strokes, or other common conditions in older adults.

5. A Unified Approach Across All Ages

2017: Criteria mainly focused on adults and typical MS presentations.
2024: Revised to include children, adults, and older adults, making diagnosis more consistent across the lifespanwith new research.

Alongside the updates made to the McDonald criteria, other areas of MS have also seen further advancements because of the consistent efforts in researching how the disease begins, progresses, and can be managed. MS was classified into four main types based on its progression within the body: relapsing-remitting MS, primary progressive MS, secondary progressive MS, and progressive relapsing MS. For quite some time, it was thought that MS followed a specific path in the body from relapsing-remitting to secondary progressive MS. This thinking has now been evolved with new research.

Rethinking Progression

MS may be a two-process, rather than a two-stage, disease.

For many years, relapsing MS has been considered a two-stage disease. A person was first diagnosed with relapsing-remitting MS, and it was expected that later they would probably stop having relapses and transition to a stage called "secondary progressive MS." The following definitions reflect the traditional understanding of the two-stage thinking:

- Relapsing-remitting MS – clearly identifiable attacks lasting days or weeks, with periods between relapses being stable and absent of disease progression. After an attack, many people experience a full recovery, but some will experience residual loss in mental or physical function upon recovery.

- Secondary-progressive begins with an RRMS classification that becomes consistently progressive and includes more frequent relapses with minor remission. Loss of physical and mental function accumulates without recovery between attacks

In this paradigm, disease progression was generally thought not to occur in people with MS unless it was linked to relapse, or to occur slowly and sporadically. Then, as relapses decreased over time, the progression increased.

New research indicates this thinking may be incorrect. The medical community is shifting its view of MS from a two-stage disease to a two-process disease, where relapse and progression are two processes that occur simultaneously.

Today, the diagnosis process looks very different because of the advanced MRI technology and the cumulative efforts made by scientists and other individuals in the healthcare sector to provide an early and accurate diagnosis.

Evolution of Treatment

During the last four decades, the approach physicians took to treat MS has dramatically shifted. In the 1980s and early 1990s, treatment options were limited. Healthcare providers mainly used high-dose corticosteroids to shorten acute relapses and provided treatments to manage common symptoms such as pain, spasticity, and bladder problems. There were few, if any, therapies that slowed the underlying disease process itself.

That shift in treatments to slow the disease process occured in 1993, when the first disease-modifying therapy, Betaseron, an interferon-B-1b, was approved. Since then, the list of FDA-approved therapeutic treatments has expanded from a handful of symptomatic measures and short-term relapse treatments to more than twenty DMTs which aim to reduce relapse rates, limit new inflammation visible on MRI, and delay the accumulation of disability.

The types of treatments available today are far more varied than the early injectable interferons. Modern DMTs include self-injected drugs (interferons, glatiramer acetate), oral medications (fingolimod, dimethyl fumarate, teriflunomide, etc.), and intravenous or subcutaneous monoclonal antibodies (natalizumab, ocrelizumab, ofatumumab, alemtuzumab, and others). Each class works differently, some broadly modulate the immune system, others target specific immune cells such as B cells, and this diversity allows doctors to choose therapies based on a person's disease activity, lifestyle needs, and risk tolerance.

To learn more about MS treatments, watch the webinar with Dr. Ben Thrower. *Can I Ever Stop My MS Therapy?* msfocus.us/081225

So why does the evolution of treatment options since the 1980s matter? Unlike steroids, which treat only short episodes, DMTs target the processes that cause repeated inflammation and nerve damage. A study authored by Dr. Daniel S. Reich, in the *New England Journal of Medicine,* showed that many DMTs reduce relapse frequency, reduce new MRI lesions, and can slow disability progression when used appropriately. During the past two decades, evidence has accumulated that earlier use of DMTs is linked to better long-term outcomes, fewer relapses, and a lower chance of disability later in life.

The shift from “watchful waiting” to “early intervention” is one of the most significant changes in MS care. In the past, some physicians took a conservative approach – they monitored patients and delayed long-term therapy until disease activity was apparent. That approach reflected both a lack of DMTs options and concern about the long-term safety of immunotherapies. As new DMTs proved their efficacy and their safety profiles became better understood by physicians and patients, healthcare providers began to recommend early and ongoing treatment for most people with relapsing forms of MS. Clinical studies have shown that early initiation of an appropriate DMT can reduce relapses, limit the buildup of MRI damage, and help delay or prevent long-term disability.

A couple factors allowed healthcare providers to modify their approach of early treatment in MS. First, MRI technology became widely available and sensitive enough to detect subclinical disease activity (brain lesions that occur without obvious symptoms). This made it possible to identify the disease earlier, sometimes at the stage of clinically isolated syndrome, and provided reasonable justification for initiating a DMT before significant, irreversible damage accumulates.

Second, the growing variety of DMTs allowed personalization. Healthcare providers could match drug potency and risk profile to how aggressive a patient’s disease appeared to be. Patients could decide what type of treatment they wanted based on their lifestyle, finances, and family or friends’ support.

That said, early intervention is not a one-size-fits-all requirement. Choosing when to start and which DMT to use requires shared decision-making. Discussions may need to occur with your healthcare team, your loved ones, and most importantly with yourself. You have to decide what type of DMT best suits your individual needs. Risks such as infection, rare serious adverse events, or monitoring burdens must be weighed against the expected benefits. Preferences such as family planning, tolerance for monitoring efficacy of dosage, and financial costs are also important to consider. The clinical guidelines from the American Academy of Neurology emphasize personalization and careful risk management rather than automatic use of the most potent drug for every patient.

Below is a quick questionnaire to help you start the conversation on the best DMT for you. This questionnaire is not meant to be used as the sole decision-maker but rather a tool to start the conversation on what DMT is suited for you when discussing options with your healthcare team and loved ones.

Finding the Right MS Disease-Modifying Therapy (DMT)

1. How active is my MS right now?

☐ I have had frequent relapses or new MRI lesions
☐ I have had few or no recent relapses
☐ I am not sure and need to review my MRI and history with my doctor

2. How do I feel about medication risks and monitoring?

☐ I'm comfortable with regular blood tests or infusions if the treatment is effective
☐ I prefer treatments with fewer side effects and less monitoring
☐ I want to balance effectiveness and safety

3. Which treatment method fits my lifestyle best?

☐ Pills taken by mouth
☐ Injections at home
☐ Infusions given at a clinic
☐ I am open to any option

4. Are there personal factors that affect my treatment choice?

☐ Pregnancy or family planning
☐ Other medical conditions
☐ Financial planning
☐ Travel, work schedule, or access to infusion centers
☐ None of the above

5. What are my long-term goals for managing MS?

☐ Prevent future relapses as much as possible
☐ Maintain independence and daily function
☐ Minimize side effects
☐ All of the above

Continuing Innovation in MS: CAR-T and Stem Cell Therapies

As our understanding of MS advances, new and emerging therapies challenge the traditional disease-modifying treatments. Two major areas of research are CAR-T cell therapy and stem cell-based treatments. These treatments aim to specifically target the underlying immune dysfunction in MS and, in some cases, "reset" the immune system itself.

CAR-T Cell Therapy

Chimeric antigen receptor T-cell therapy, also known as CAR-T, was first developed for certain blood cancers and works by genetically modifying a patient's own T cells to recognize and destroy specific targets. In the world of MS, CAR-T therapies are being engineered to target immune cells that are driving the autoimmune response, specifically autoreactive B cells, which contribute to the ongoing inflammation in the central nervous system. Early and small clinical studies suggest CAR-T cells can reach the CNS and exhaust the pathogenic immune cells.

A small Phase 1 study presented at the American Academy of Neurology annual meeting showed a CAR-T cell candidate was safe and showed early signs of biological activity in people with progressive forms of MS. Case reports have also noted CAR-T cell presence in cerebrospinal fluid and the spinal cord showing antibody production, suggesting meaningful biologic effects.

Myelin oligodendrocyte glycoprotein is a protein found on myelin, the protective layer covering nerve cells. Research on a MOG-specific CAR-Treg cells, regulatory T cells, is also occurring with the aim to halt the immune system from attacking myelin, while leaving the rest of the immune system working normally. This mechanism of treatment is still in the very early stages of being studied.

Though it looks promising, CAR-T therapy for MS remains in early stages. Larger clinical trials are being conducted to better understand the long-term benefits and risks, and whether these therapies could eventually offer long-lasting disease control with potentially fewer ongoing medications.

Stem Cell Therapies: Resetting the Immune System

Stem cell-based treatments for MS are focused primarily on hematopoietic stem cell transplantation, where a person's immune system cells are first removed and then rebuilt using their own hematopoietic (creation of blood cells) stem cells. This process is designed to eliminate autoreactive immune cells and replace them with a newly "reset" immune system that no longer attacks the nervous system.

HSCT has been studied for more than two decades as a treatment for highly aggressive, relapsing MS in individuals who have not responded to a standard DMT. Systematic review of clinical studies show many patients experience significantly reduced relapse rates, lower MRI activity, and high rates of no evidence of disease activity after HSCT.

Despite its efficacy in select cases, HSCT is not appropriate for everyone. The procedure involves extensive immunosuppression, high risk of infection, and requires specialized care. This treatment option should be discussed in length with your healthcare team prior to starting treatment.

Why Do These Innovations Matter

The development of CAR-T cell and stem cell therapies embodies a paradigm shift in MS treatment. Rather than managing relapses or slowing down disease progression, these approaches aim to target the cells driving autoimmune inflammation more precisely through engineered immune therapies or resetting the immune system entirely. By targeting the immune system at its core level, these next-generation techniques could transform long-term outcomes and quality of life for people with MS, especially those with an aggressive or treatment-resistant form of MS.

MS therapy has advanced from limited, short-term measures to a broad, evidence-based set of disease-modifying options. This expansion in therapies, combined with improved diagnostics, clinical trial evidence, and guideline recommendations, is what drove the shift from "watchful waiting" to early, individualized intervention aimed at preventing damage before it becomes permanent.

Along with the evolution of treatment options, there also came a shift in the outlook of how MS was treated with a more holistic approach. Neurologists are the first stop for MS treatment in diagnosed individuals, but they are not the last.

The Transformation of Comprehensive Care

MS care is no longer focused only on controlling relapses or slowing disease progression. Now, treatment emphasizes a whole-person, long-term approach that addresses the physical function, mental health, lifestyle factors, and shared decision-making between patients and their healthcare team. This comprehensive mindset mirrors a deeper understanding of how MS affects every single aspect of an individual's life.

One major change is the larger role of rehabilitative and supportive care, including physical and occupational therapy, nutrition counseling, and mental health support. PT is now commonly used to help individuals maintain their strength, balance, and mobility. Rather than waiting for disability to appear, PT is often used to prevent falls, reduce fatigue, and improve quality of life. Similarly, OT focuses on helping patients adapt to their daily activities, conserve energy when needed, and use assistive tools that support independence at home and their place of occupation.

Nutritionists are being referred to more often by neurologists or primary care physicians because of the link diet and MS have. It's important to note that while no single diet cures MS, growing evidence suggests nutrition, weight management, vitamin D levels, and cardiovascular health can influence fatigue, inflammation, and overall well-being. Many MS clinics now include dietitians or nutritionists who help patients make realistic, healthy changes that support long-term health alongside medical treatment.

Another major shift in MS treatment is the recognition of mental health as a core component of care. Anxiety, depression, and cognitive changes are common in people with MS and may significantly affect disease management and quality of life. Today, mental health screening, counseling, and stress management are increasingly viewed as essential parts of comprehensive MS care. Addressing emotional health can improve treatment adherence, coping skills, and overall outcomes.

To learn more about the role mental health plays in your MS, watch our free quarterly Mental Health Matters webinars hosted by Tiffany Malone MSW, MSCS on our YouTube channel: youtube.com/@MultipleSclerosis Foundation.

Specialist	Baseline	When to request a referral evaluation
Neuropsychologist	Yes	When cognitive problems are suspected or apparent, including issues with memory, concentration, information processing speed, etc.
Speech Language Pathologist	Yes	Often subtle changes in cognition, speech, and voice occur early in MS that are effectively treated with a home exercise program. If changes in swallowing occur, early intervention can prevent worsening.
Physical Therapist	Yes	As early as possible to initiate a home exercise program. Reinitiate if relapses/progression create mobility, dexterity, strength, or balance issues. Also, when assistive technology, orthotics, or mobility devices are needed for proper selection and customization/fitting.

Specialist	When to request a referral evaluation
Occupational Therapist	When MS symptoms begin to interfere with one's job or activities job or activities of daily life, including work, driving, household chores, and selfcare tasks. For fatigue management or cognitive rehabilitation.
Psychologist	If changes in mood or behavior begin to regularly occur, worsen over time, or are noticed repeatedly by friends and family. These can include symptoms of depression (feelings of sadness or irritability; difficulty concentrating or sleeping; or a desire to be left alone or loss of interest in activities), anxiety (restlessness or feeling 'keyed up,' difficulty concentrating, irritability, muscle tension, sleep disturbances, or more serious symptoms such as sweaty palms, chest tightness, or shortness of breath), or pseudobulbar affect (uncontrollable or inappropriat bouts of laughing or crying).
Urologist	When changes in frequency of urination (frequency or retention) or repeated urinary tract infections occur, or for erectile dysfunction in men with MS.

Aside from the whole-body approach that is now being utilized by healthcare providers in diagnosed individuals, the patient–physician relationship has also evolved. In the past, MS treatment decisions were often physician-directed with limited patient input. Today, care is more collaborative, emphasizing shared decision-making and focused on empowering the patient. Individuals are encouraged to ask questions, express concerns, and participate actively in choosing treatments. This approach recognizes that people with MS are experts in their own experiences and that treatment success depends on aligning medical decisions with patient values, goals, and lifestyles.

This collaborative model is especially important given the growing number of treatment options. Choosing a DMT often involves balancing effectiveness, safety, side effects, monitoring requirements, and personal life considerations such as family planning, work schedules, and finances. A strong patient–physician relationship helps to ensure that treatment decisions are informed, realistic, and sustainable over time.

Your Personalized Treatment

MS care has transitioned towards personalized treatment. Advances in imaging, biomarkers, and clinical research allow providers to better assess disease activity and tailor therapy to an individual's unique needs. Rather than using the same treatment approach for all patients, physicians now consider factors such as disease severity, MRI findings, response to prior treatments, and personal risk tolerance. This personalized approach aims to treat MS earlier and more effectively while minimizing unnecessary risks.

Use the section below and fill out the information best to your knowledge. This goal of this activity is to help you reflect on what is needed to build a stronger and more collaborative relationship with your neurologist. You may also use these same questions for other specialties including your nutritionist, physical therapist, etc.

1. I feel most comfortable talking to my neurologist about:

   ____

2. One thing I find hard to talk about with my neurologist is:

   ____

3. The way my neurologist explains my condition or treatments makes me feel:

   ____

4. I feel involved in decisions about my MS treatment when:

   ____

5. A decision I wish I had more input on was:

   ____

6. One question I want to bring to my next appointment is:

   ____

7. One goal I want to achieve with my neurologist in the next six months is:

   ____

Public

Community, Access, Awareness, and Advocacy in MS Care

Helen Keller said, "Alone, we can do so little; together, we can do so much." While medical advances and personal experiences with MS have transformed over the decades, the evolution of the MS community has also seen a drastic transformation.

As MS care has progressed, so has the recognition of the role a community plays in an individual's daily lifestyle. Beyond clinical treatment, community building, public awareness, research support, and advocacy help shape access to care, support networks, and long-term resources for people living with MS. While significant achievements have been made, challenges such as healthcare disparities and underrepresentation in research remain urgent public health priorities.

Healthcare Access and Disparities

One of the persistent challenges in MS care is unequal access to healthcare resources, particularly in rural and underserved areas. Neurologists and MS specialists are concentrated in urban centers, meaning people in rural communities may face longer travel distances, limited appointment availability, or difficulty accessing specialist care. This physician shortage can delay early diagnosis, timely treatment decisions, and ongoing monitoring, potentially contributing to poorer outcomes over time.

Access to healthcare is a critical part of managing MS, but not all communities have equal access to the services they need. One of the most insistent challenges is the shortage of physicians, especially specialists such as neurologists who are needed to diagnose and treat MS. This shortage is felt mostly in rural and underserved areas.

The Effect on Rural Communities

Rural areas across the U.S. are experiencing significant shortages of healthcare providers. According to federal workforce data, a substantial portion of designated "Health Professional Shortage Areas" are in rural regions, and many rural counties have far fewer primary care physicians than needed, with some having five or fewer, and others none. Projections suggest that by 2037, rural areas will only meet about 68 percent of the demand for primary care physicians compared with higher numbers in urban areas. This will leave significant gaps in critical primary care services.

Studies show that access to neurologists, and therefore specialized MS care, is substantially lower in rural areas. In one analysis of U.S. census tracts, rural communities had roughly 80 percent less access to a neurologist within a 60-mile radius than urban counterparts. Areas with higher percentages of certain vulnerable populations (e.g., uninsured residents or people with mobility challenges) had even more limited access, highlighting how geographic and socioeconomic factors intersect to create disparities in specialized care. This imbalance means that people with MS living in rural areas often rely on their primary care physician or are forced to travel long distances to see an MS specialist. This can result in delays in diagnosis, treatment planning, and ongoing follow-ups, all of which are essential for managing MS effectively. In some cases, rural patients report dissatisfaction with the quality or comprehensiveness of care when compared to what might be available in urban specialty centers.

Telehealth May be an Option

To help address these gaps and disparities, telehealth has become a fundamental tool in expanding access to care. Telemedicine allows patients to consult with neurologists and other specialists from their homes without the need for long travel. This is particularly useful for the rural patient population who might otherwise face several hours of driving, extra financial costs, and possible dangers to exposure of pathogens for a single appointment.

Telehealth services can provide routine check-ins, treatment discussions, symptom monitoring, and medication management. However, telehealth alone cannot be used for all physician appointments. Some limitations that may occur include:

- Internet access in some rural communities may not be strong enough to keep the connection during visits possible, which can prevent reliable video visits.
- Licensing and reimbursement challenges, since regulations and insurance coverage policies for telehealth continue to evolve across states and private payers.
- Inability to perform full neurological exams remotely, meaning certain assessments still require in-person visits.

Despite these challenges, telehealth remains a vital and expanding part of MS care. It offers flexibility, improves continuity for patients who might otherwise go long periods without specialist contact, and enhances access to specialists that rural patients might otherwise never reach.

By making small changes, such as using adaptive furniture, controlling air temperature, and eliminating sensory overload, you can create a healthier, more functional living space for yourself.

Taking Action

Telehealth has proven to help connect healthcare providers with patients, but it also provided individuals a way to see that connections can be made over the Internet. Progress in MS care has never occurred in seclusion. Advances in research, access to treatment, and patient support have been driven in large part by public action, including grassroots fundraising, advocacy, and policy engagement. As MS care continues to evolve, continued community involvement remains critical to ensure that progress is unbiased, well-funded, and resilient to the ever-changing political and economic conditions.

Policy Advocacy

Policy advocacy is crucial, especially in today’s world. Public funding decisions directly influence the pace of MS research, access to healthcare services, and the strength of safety-net programs that support individuals with chronic illness and disability.

Advocacy for healthcare policies may include:

- Contacting local elected officials to support increased funding for neurological research and public health agencies.
- Advocating for protections for people with autoimmune disorders.

- Supporting policies that maintain or expand access to disability benefits
- Participating in organized advocacy days or letter-writing campaign.

Sharing your personal experiences, whether as someone living with MS, a caregiver, or a supporter, can be powerful in shaping policy discussions and humanizing the decisions being made.

MS research depends heavily on a combination of federal funding, nonprofit support, and private philanthropy. Safety-net programs are government-funded initiatives that provide essential support such as housing, food, and healthcare, to individuals and families facing economic hardship, unemployment, disability, or old age. These programs require continued advocacy to ensure their availability remains responsive to the evolving needs of the MS population.

Fundraising, advocacy, and public engagement are not separate from the medical evolution that has occurred over the past four decades, but rather, they are essential drivers of it. By remaining informed and involved, communities can help share these advancements to those who need them most, now and in the future.

Teen Advocacy

Often when we think of advocacy, adults are the population that may come to mind. But advocacy isn't just for adults, teens and young people living with MS have unique needs and contributions too. Over time, teen advocacy has transformed into youth programs, educational events, peer mentorship networks, and platforms that empower teens to share their voices. These programs help young people navigate school such as the transition from high school to college, social challenges including navigating friendships and romantic relationships, mental health issues, and transition from pediatric to adult care, while also engaging them in advocacy and community outreach.

MS Focus offers pediatric booklets and works with Oscar the MS Monkey to provide information for the pediatric population. We also provide free educational webinars to provide more insight on MS in the pediatric population.

To learn more about the pediatric population, watch *High School Graduation & Transition to College with MS* at: msfocus.us/webinar-May2023.

Building the Community Through Support Groups

Around the time MS Focus was founded, discussions of MS did not occur. And if they did, they were infrequent or done behind closed doors. Individuals did not have answers regarding their diagnosis, physicians did not have much information to provide their patients because of the lack of research, and everything we know now did not exist.

All this left people newly diagnosed and even those who had received a prior diagnosis to be confused and isolated. Today, this is not the case. Support groups and community organizations are the key to fostering connection and emotional support for people living or have loved ones with MS. The purpose of a support group is to provide a lending ear and discuss shared experiences. These groups can be local or virtual. According to a study, participation in community groups has been shown to improve coping, reduce isolation, and build social support networks.

Below are some ways to connect and build your community:

- MS Focus' support groups and programs, including online and in-person meetings, peer support, and educational events.
- Local nonprofit groups may have regional chapters that host meetings, educational sessions, and awareness events.
- Online communities and virtual meetups that allow people to connect across distances and ages, building supportive networks through social media, apps, or dedicated platforms.

By participating in support groups, whether in your area or online, people with MS can share their experiences, resources they may use, and empower one another. These social interactions not only provide emotional support but can also incentivize grassroots advocacy and fundraising efforts that strengthen the broader MS community.

Third-Party Fundraising

Third party fundraising events and initiatives organized by individuals, schools, workplaces, or community groups has long been a cornerstone of MS advocacy. These efforts have historically supported organizations such as MS Focus: the Multiple Sclerosis Foundation and other nonprofits, providing critical funding for scientific research, patient programs, and educational resources.

Beyond the financial effect, third-party fundraising has played a powerful role in raising public awareness and reducing stigma. Community events bring MS into public conversation, helping people better understand the disease and the daily realities faced by those living with it. Over time, these initiatives have helped build a visible, engaged MS community that extends beyond clinical settings. There have been many instances in which someone heard about MS from a friend of a friend, or from some event they volunteered at.

Realistic Ways to Fundraise

Individuals and communities can participate in meaningful fundraising efforts in a variety of accessible ways. Below are some examples:

- Organizing local events, such as walks, fitness challenges, or bake sales.
- Participating in existing campaigns hosted by nonprofit organizations, including virtual fundraisers and awareness months such as NMSEAM.
- Using social media platforms to share personal stories, promote fundraising pages, and reach a larger audience.
- Engaging workplaces or schools through matching gift programs, awareness days, or team-based fundraising efforts.

Fundraising not require large-scale events. Small, consistent efforts, especially those rooted in something that holds a personal significance to you, can collectively have a significant effect.

If you are looking for ways to fundraise, reach out to events@msfocus.org for additional help.

Research and The NARCOMS Registry

Research is the backbone of medical advancements. Without clinical trials, new pharmaceutical treatments to slow down MS progression would not exist. According to North American Research Committee on Multiple Sclerosis Registry, participation in clinical trials and registries improves scientific knowledge, diversifies the research data, and accelerates progress toward better therapies.

Clinical trials and observational studies help develop new treatments, improve existing therapies, and better understand how MS affects different populations. People with MS can participate in research through clinical trials, patient registries, surveys, and long-term observational studies, often gaining closer monitoring and contributing directly to future care improvements.

Unfortunately, access to research and clinical trial participation is not equal. Studies have shown that MS clinical trials frequently lack racial, ethnic, and socioeconomic diversity. Black, Hispanic, and other underrepresented groups are often enrolled at lower rates than their representation in the MS population. Barriers may include limited access to research centers, transportation challenges, time constraints, lack of awareness, and historical mistrust of medical research. As a result, trial findings may not fully reflect real-world patient populations, limiting how well treatment options apply across diverse groups.

To address these gaps, researchers and advocacy organizations are increasingly prioritizing inclusive trial design. Strategies include creating a broader eligibility criterion, utilize community-based recruitment, foster partnerships with advocacy groups, and reduce logistical burdens such as travel and time commitments. Improving diversity strengthens both the scientific quality and fairness of MS research.

Fundraising plays a critical role in supporting research. Federal agencies such as the NIH provide major funding, but nonprofit organizations and community-led fundraising efforts can provide additional support for early-stage studies, innovative projects, and patient registries. Public fundraising also indicates a strong community demand for continued investment in MS research.

NARCOMS has been one of the most important voluntary registries in MS research. It collects real-world, patient-reported data on disease course, treatments, and outcomes from tens of thousands of participants. Contributions to the registry help researchers study long-term trends, inform clinical practice, and identify new research questions. The data collected continues to inform scientific work and help advance the understanding of the MS disease process.

To learn more about NARCOMS, visit narcoms.org. or visit the webinar with MS Focus: msfocus.us/NARCOMS.

Moving Forward Together

As we close this year's National Multiple Sclerosisi Education Month, we invite you to pause to thank yourself. Your resilience and adaptability are what inspire grassroots organizations like MS Focus: The Multiple Sclerosis Foundation to continue providing free programs and services to the MS community. Whether it has been decades, months, or even days since you received your MS diagnosis; take a moment to fill out the activity below and reflect on your perseverance.

The future of MS care continues to evolve with advancing research, earlier diagnoses, a variety treatment options, and a growing community of advocates, clinicians, and researchers committed to progress.

At MS Focus: The Multiple Sclerosis Foundation, our commitment remains steady. We will continue providing access to free programs and services supporting education, and standing alongside you at every stage of your journey.

Because progress is not just measured in research breakthroughs, but in the strength of the community that moves forward together.

Part 1: At the Time of Diagnosis

- The year I was diagnosed with MS: ____________________.
- The biggest feeling I remember at that time was:

☐ Fear ☐ Confusion ☐ Relief ☐ Anger ☐ Uncertainty ☐ Other: _______________

- The main information source I relied on then was:

☐ Doctor ☐ Internet ☐ Family/Friends ☐ Support group ☐ Other: _____________

Part 2: How Things Have Changed

Fill in what feels true now:

Today, my understanding of MS is:

____

____

- My approach to managing MS has changed by:

☐ Starting or changing treatment
☐ Adding lifestyle supports (PT, nutrition, mental health, etc.)
☐ Becoming more involved in my care decisions
☐ Connecting with others who have MS
☐ Other: __________________________

- One thing I know now that I didn't know then:

____

____

Part 3: Looking Forward

- Right now, my biggest hope for my MS journey is:

____

____

- One message I would share with someone newly diagnosed is:

____

____.

- My MS story continues to evolve, and today I see it as:

____

____