



# Addressing Advanced Care Needs of People with MS and Their Families:

## The Importance of Education, Prevention, Advocacy and Coordinated Comprehensive Care

### Summary

The advanced care needs of many individuals with multiple sclerosis (MS) and their families are not being adequately addressed. Too often, complex MS symptoms interfere with health, safety, independence and quality of life while co-existing health conditions and complications can increase disability and potentially shorten a person’s life. Family members often feel left to their own devices as they provide care for a loved one while trying to manage additional responsibilities at home and at work, and attend to their own health needs.

The National MS Society is working to increase access to high quality, comprehensive and coordinated care for everyone affected by MS, regardless of where they are in their MS journey. With this goal in mind, the Society convened a group of key stakeholders – including people with MS, support partners, Society staff and clinicians from the fields of neurology, primary care, rehabilitation medicine, psychology, nursing, physical therapy and speech pathology– to help inform the Society’s role in finding solutions for individuals and families who are facing advanced care needs.

The group made recommendations in the following areas:

- Information, education and support for individuals with advanced care needs and their families
- Engagement and education of healthcare professionals in relevant fields
- Advocacy issues

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## Introduction

Multiple sclerosis (MS) is a chronic, unpredictable disease for which we do not yet have a cure or treatments that are fully effective. The [available disease-modifying therapies](#) reduce disease activity and progression for many with relapsing forms of MS. However, individuals living with very active relapsing MS or progressive disease – including primary progressive and secondary progressive MS – may experience physical, cognitive and/or emotional changes that impact their ability to function safely and independently, participate fully in activities at home, work or in the community, and enjoy a satisfying quality of life. People with more advanced disease are also at risk for medical complications such as joint contractures from severe spasticity, pressure ulcers, bladder infections, compromised respiratory function, impaired speech and aspiration pneumonia resulting from impaired swallowing.

The National MS Society is working to increase access to high quality, comprehensive and coordinated care that promotes overall health and wellness, reduces complications and optimizes independence, safety, participation and engagement. We also want to assist family members and other support partners in their efforts to provide safe and optimal care for their loved ones while also attending to their own health and well-being.

With these goals in mind, the Society convened a group of key stakeholders – including clinicians from the disciplines of neurology, primary care, rehabilitation medicine (physiatry), psychology, nursing, physical therapy and speech pathology, people with MS and support partners, and Society staff – to help inform the Society’s role in addressing the needs of individuals and families who are facing these complex challenges. Participants from these diverse perspectives considered key issues related to the advanced care needs of people with MS in order to:

1. Determine the characteristics and scope of “advanced MS.”
2. Identify factors that can lead to greater disability, reduced quality of life and a shortened lifespan.
3. Understand the barriers – physical, cognitive, emotional, financial and social – to optimal care and identify strategies to reduce those barriers.
4. Consider the role and potential impact of: early and ongoing screening to reduce and manage complications and co-existing health conditions; optimal symptom management; effective integration of primary care and MS care; advocacy for local, national and systemic change; and personalized strategies and tools to optimize quality of life.
5. Suggest enhancements to the Society’s resources and programming for people affected by MS and healthcare professionals, which will promote and support collaborative, personalized care to address complex needs.
6. Identify priority research questions and make recommendations for the Society’s research agenda.

**“You know, my needs and my wants and my desires are of a human being. You can pretty much assume that whatever you might enjoy and you might want to do, so do I... just because I can't move most of my body, it doesn't mean that in my mind I don't want to do and enjoy the same sort of things as anybody else.”**

- person living with MS

## Definition of “Advanced MS”

Attendees were asked to define “advanced MS.” Responses varied widely depending on one’s personal experience or professional discipline. Some were more focused on the type or number of MS-related impairments; others related to the impact of impairments on a person’s ability to perform activities of daily living or engage in chosen activities at home or at work. Still others described advanced MS in terms of disability level as measured by the Expanded Disability Status Scale (EDSS) or stage of the disease when disease-modifying therapies are no longer effective.

The working definition of “advanced MS” became even more elusive over the course of the meeting. It became clear that people’s experiences, challenges and needs vary considerably, and

that our efforts to respond need to take this variability into account. With that in mind, the recommendation was made that we shift our thinking and our language toward “the advanced care needs of people with MS and their families,” in order to emphasize the integration of many types of specialized care that may be needed to help people with MS and their support partners maintain their health, safety, independence and quality of life.

**“Advanced MS is characterized by: moderate to severe MS symptoms (physical, cognitive, emotional), requiring on-going medical management (medications, rehabilitation, other interventions); dependence in activities of daily living, requiring personal assistance and/or assistive technology; diminished quality of life and unfavorable impact on life roles (family, occupational, social).”**

- healthcare professional

## Factors That Can Contribute to Greater Disability and Potentially Shorten Lifespan

Several factors – in addition to the gradual accumulation of damage in the central nervous system over time – have been shown to impact level of disability and lifespan in people with MS:

### **Active, aggressive disease**

A small proportion of people diagnosed with MS experience highly active disease and significant physical and/or cognitive impairments within a relatively short period of time. This highly aggressive disease process can compromise a person’s health and ability to function, occasionally leading to an early death.

### **Co-existing health conditions (co-morbidities)**

Life expectancy for people with MS has increased significantly over time. However, life expectancy in MS remains somewhat shorter than in the general population, with the expected lifespan varying from one study to another. In a recent, large-scale, population-based [study](#), people with MS lived, on average, seven years less than the general population – and people with MS who also had other health conditions (co-morbidities) were more likely to die at a younger age than people with MS alone.

People with MS have been found to have more co-morbidities than people in the general population. Some health conditions are particularly common in people with MS, including hypertension, diabetes, heart disease, fibromyalgia, depression, anxiety, bipolar disorder and chronic lung disease. Co-morbidities not only compromise a person's overall health, but have also been shown to impact a person's MS in a variety of ways. For example, co-morbidities are associated with a delay in the MS diagnosis, a delay in treatment with a disease-modifying therapy, a higher number of hospitalizations, more rapid disease progression and a [reduced quality of life](#). In [one study](#), people with MS who also had hypertension, diabetes, hyperlipidemia, or other vascular co-morbidity required assistance with walking sooner than people with MS who had no vascular co-morbidity. It is reasonable to expect that effectively treating vascular co-morbidities may slow MS disease progression, although this is not yet proven.

In the general population, co-morbidities increase with age. As people with MS live longer, the MS population as a whole is aging – this means that more individuals with MS are experiencing co-morbidities that impact their health and well-being. And women with MS have been found to have more co-morbid health conditions than men with MS.

### **Complications resulting from MS symptoms that are untreated or undertreated**

Physical symptoms that are not managed adequately can lead to additional health problems. For example, untreated [bladder problems](#) can lead to repeated infections, urosepsis (a life-threatening systemic reaction to a bacterial kidney infection that has spread to the bloodstream), permanent kidney damage and even death. Reduced mobility as well as bladder and bowel incontinence can lead to skin breakdown ([pressure ulcers](#)) that can have serious health consequences. [Swallowing problems](#) can result in aspiration of bacteria, saliva, food particles and liquids into the lungs, leading to aspiration pneumonia that can result in death. Problems with gait and balance can lead to serious falls and debilitating injuries. And [spasticity](#) (stiffness) that isn't adequately controlled can result in painful and debilitating contractures (frozen joints) that restrict movement and interfere with basic care.

**“If it never gets worse than this, we'll be OK....' I've seen my brother and our whole family continue to adapt to each benchmark of progression, even the past few years when we've wondered 'How can it get any worse?' So each level of awareness seems to redefine 'advanced'. My brother has been a quadriplegic for many years now, so I guess he's been advanced for a long time. But he used to be able to hold a conversation, and sip his water through a straw and eat food that wasn't cut so finely. In retrospect he wasn't so advanced.”**

–sister & caregiver

Significant problems with [mood](#) and/or [cognition](#) can also pose risks for people with MS. [Depression](#) that isn't adequately treated can interfere with self-care, reduce adherence to treatment and wellness promoting behavior such as healthy eating and exercise, and increase a person's risk of suicide. Problems with attention, memory, planning and problem-solving can impact self-care.

## **Tobacco use**

[Smoking](#), including exposure to secondary smoke, has been identified as a risk factor in the development and progression of MS. In addition, smokers may not get the full benefit of MS disease-modifying therapies. Smoking also contributes to co-morbidities such as heart disease, stroke and cancer that contribute to health issues and a shortened lifespan in people with MS. Stopping smoking has a protective effect by slowing disease progression and delaying the transition to secondary progressive MS.

## **Optimal Care for People with MS**

Optimal care for people with MS ideally begins with the onset of the first symptoms and continues throughout the lifespan. However, many steps can be taken to enhance each person's care at whatever point in the disease he or she may be.

### **Optimal integration of primary and neurologic care throughout the disease course**

People with MS need access to primary as well as neurological care. Neurologists primarily focus on MS care, including diagnosis, disease and symptom management. Most have neither the time nor the expertise to manage the co-morbidities and complications that can occur or to determine that a person with MS is attending to the recommended preventive care strategies for his or her age group. Having a primary care physician helps to ensure that co-morbidities are being identified and treated, complications are being addressed and recommended screenings and immunizations are being done. However several factors can interfere with the optimal integration of primary and neurologic care:

- Many people with MS rely on their neurologist for all of their care, incorrectly assuming that this physician will be attending to all of their healthcare needs.
- People with MS and their primary care providers may assume that reported symptoms are due to MS or that treatment for non-MS issues may interfere with MS treatments, with the result that co-morbid conditions are not adequately diagnosed and treated.
- When medical complications arise – for example, pressure ulcers, breathing problems, severe urinary tract infections – individuals with MS and their families may not know where to turn for care.
- People with advanced care needs, who may no longer be candidates for disease modifying therapies, may begin to feel hopeless and isolated. Thinking that there is nothing that be done to help them, they may become increasingly disenfranchised within the healthcare system or remove themselves from the system altogether.
- Those who look to the healthcare system may find that medical, dental and mental health offices are physically inaccessible.
- Accessible transportation may be challenging and potentially cost prohibitive.
- The costs of optimal care are beyond the reach of most families.

Integration of primary and neurologic care requires the following:

- The importance of both primary and neurological care for people with MS and their families must be reinforced and neurologists need to emphasize to their patients the importance of having ongoing care by an identified primary care provider.
- Neurologists and primary care providers need to communicate, collaborate and coordinate their care of a person with MS.
- Primary care providers need education about multiple sclerosis so that they can identify and treat common MS symptoms, make referrals when needed and have familiarity with MS disease-modifying therapies, including contraindications, side effects, risks, and medication interactions.
- Patient advocacy organizations need to provide information and resources to help people understand their care needs and identify primary and/or neurology care providers.
- People with MS and their families need to have the information and tools to self-advocate for integrated and coordinated care.
- People with MS and their families need information about advanced care directions.
- Access to healthcare services must not be restricted by physical or financial barriers.

### **Early and ongoing evaluation and management of symptoms**

Symptoms of MS can be visible – such as problems with walking, spasticity, tremor –or invisible – such as pain, mood or cognitive changes, urinary urgency, constipation, respiratory dysfunction, or disrupted sleep. The earlier symptoms are identified, the easier it is to manage them and prevent avoidable complications. Several factors interfere with early and ongoing attention to MS symptoms:

- Time is limited in the visit to one's neurologist, and all symptoms may not receive the attention needed for optimal long term management.
- Many symptoms of MS, including changes in pulmonary function, mood, cognition, sleep, among others, can begin very early in the disease without being readily apparent to either the person with MS or the physician.
- People with MS may not mention changes they are experiencing related to fatigue, mood, cognition, sexual function, pain or sleep because they do not know whether these symptoms related to their MS or because they may be too embarrassed to mention them.

To achieve optimal symptom management, the following are recommended:

- People with MS need to be aware of the [symptoms that can occur](#) in MS so that they can and self-advocate for early and ongoing assessment and management.
- Healthcare providers need to ask routinely about new symptoms or any changes that have occurred since the last visit.

- Routine screening is recommended in order to identify and address problems as quickly as possible:
  - Regular screening should be done to assess mood and cognitive function beginning at the time of diagnosis and routinely thereafter.
  - Regular screening for pressure ulcers is essential for any person who spends long periods of time in a wheelchair or bed. The skin check should be done frequently by a family member or by a healthcare provider if the individual lives alone.
  - The evidence also suggests that respiratory function can be affected very early in the disease course. Although more research is needed in this area, baseline screening of respiratory function, and periodic screening thereafter, could promote early identification and treatment of respiratory changes that increase fatigue and compromise health in people with MS.
- People who begin to experience changes in mobility, bladder and/or bowel function, respiratory function, speech, mood, cognition or other areas that are interfering with their health, comfort or ability to participate fully in everyday activities should receive appropriate, targeted care, including referral to medical, rehabilitation or mental health specialists as needed. The earlier these kinds of problems are addressed, the easier they are to treat.

### **Access to technology options that address specific needs**

Many forms of technology are available to help people stay active, independent and connected to the people and activities that are important to them.

- Devices such as ankle-foot orthoses (AFOs), functional electrical stimulators (FES), augmentative and alternative communication (AAC) devices and other basic technology options promote comfort, function and safety for many people.
- Complex Rehabilitation Technology (CRT) products are medically necessary, individually configured mobility devices that are designed to meet an individual’s medical, physical and functional needs. CRT includes manual wheelchair and power wheelchair systems, adaptive seating systems and other mobility devices – all of which enhance function, independence, safety and skin health.
  - Augmentative and Alternative Communication (AAC) systems allow a person with speech difficulties to communicate. A wide range of options are available to help a person with impaired speech be heard or understood or to provide an alternative form of communication for a person who is unable to speak.

Factors that reduce access to optimal technology options include:

- The view of many people with MS and some healthcare providers that assistive technology is a “failure of therapy” rather than a toolbox to enhance mobility, function, independence and quality of life
- Limited awareness among people with MS and healthcare professionals of the many technology options and funding sources
- The high cost and inadequate coverage of many types of equipment

- Medicare policies that limit access – for example, paying only for ‘in-the-home’ use of mobility devices
- Inconsistent follow-up by vendors/providers to repair or modify equipment as needed to accommodate disability progression or device malfunction

**“When I finally started using a wheelchair fourteen years after my first symptom, it was like spring after a housebound winter.”**

– health policy researcher who lives with MS

The use of assistive technology of all kinds increases when individuals, families and healthcare providers see it as a means to taking charge of MS symptoms rather than giving in to them. Greater access will be achieved through advocacy efforts for fair and reasonable insurance coverage, and referrals to rehabilitation

specialists, including physical and occupational therapists and speech/language pathologists, who can assess the person’s needs, recommend specific products and advocate with insurers.

### **Integration of lifestyle and wellness approaches**

Lifestyle and wellness strategies can have a significant impact on a person’s MS and overall health and well-being. A healthy, balanced diet, an exercise program geared to one’s abilities, management of mood issues, and smoking cessation are among the strategies that have been shown to have a significant impact. For example, these lifestyle interventions are needed for the prevention and treatment of the vascular comorbidities (hypertension, heart disease, diabetes, elevated cholesterol) mentioned above that are common in people with MS. In addition, lifestyle interventions have been found to help manage MS symptoms and improve overall quality of life. It is never too early or too late in the disease course to focus on wellness strategies. However, it is important for people affected by MS to be educated consumers and to discuss their priorities and goals with their healthcare provider. The Society’s [Wellness Discussion Guide](#) can facilitate these conversations.

### **Effective service and care management**

Managing the challenges of MS can feel daunting, particularly if a person begins to have increasingly complex care needs. Self-advocacy, finding and coordinating the right healthcare providers, identifying helpful community resources and tools, and learning what one’s entitlements might be can be challenging and exhausting under the best of circumstances. Add the challenges of physical impairments, mood and/or cognitive changes and the task can feel impossible. The Society’s MS Navigators are available nationwide at 1-800-344-4867 to assist individuals living with MS and family members with all of these efforts. Navigators provide:

- Information and referral
- Emotional support
- Connections to local programs and services
- Case management for more complex needs related to housing, accessing treatments, benefits and entitlements, employment, crises related to domestic violence, neglect, suicide, homelessness)



- Access to short-term care management services for those without a support system who need additional assistance coordinating their care, dealing with a crisis, or accessing resources

### **Adequate support for the individual and family**

Individuals and [families](#) who are living with the challenges and demands of advanced symptoms and complex care needs often feel isolated. Several factors may prevent people affected by MS getting the support they need:

- Individuals and families may withdraw from their friends or feel that their friends are withdrawing from them.
- The demands on their time and energy may leave them feeling too busy and too tired to think about getting out, socializing, attending religious services or engaging in community activities.
- Getting out of the house may require so much planning and problem-solving that the required effort becomes too much.
- The activities that they used to enjoy may no longer be physically accessible to them, including stores, restaurants, friends' houses, movie theatres, sporting events – ultimately leading to a loss of important social connections and supports.
- Family members (including children) who are providing hands-on care for a loved one with advanced care needs often feel under-prepared, overwhelmed and exhausted, but have no idea where to turn for help or how to ask for it.
- The healthcare system tends to overlook the health and well-being of caregivers, with the result that many are living with significant medical and mental health challenges of their own.

**“Having advanced MS means that I have lost the opportunity to be spontaneous....I am forced to plan every second of every day down to the minutest detail, which can result (if I allow) in exhausting and unhappy experiences even where fun and relaxation might be expected....Doing laundry, taking a bath or shower, cooking a meal, preparing to go to work or to attend an event, and even things that are supposed to be simple – like buying gas or parking the car – every moment of the experience must be plotted out in terms of mobility, access, potential dangers, and the availability of assistance should something go wrong.”**

–person living with MS

To ensure greater support for individuals and families:

- Healthcare providers need to recognize that MS affects the whole family and treat the family as a unit, while acknowledging that every individual and family affected by MS is unique – with different values and priorities.
- Families can connect with the National MS Society for information, support, connection opportunities to reduce isolation, referrals to community services and crisis intervention.

- Families can learn effective ways to communicate with extended family and friends about the kinds of help they need and the kinds of adaptations that would make it possible for continued social interaction.
- Individuals and families can work with physical, occupational and speech therapists to identify tools, strategies and home modifications that would make life easier, safer, less fatiguing and more satisfying for everyone in the household. The optimal use of tools and home modifications can also reduce barriers to shared activities and decrease isolation in- and outside the home.
- Individuals can benefit from adult day programs of various types that offer support and connections with others, education, wellness-oriented activities, monitoring of a person's physical and emotional well-being and cognitive stimulation. In addition, families can benefit from the support and respite they receive from these types of day programs for their loved ones.

## Common Barriers to Comprehensive, Coordinated Care for People with Complex Needs

- The emphasis on early treatment and the initiation and management of disease-modifying therapies leaves little time in the neurologist's office to adequately address symptom management, rehabilitation needs, or quality of life issues.
- The focus on MS care often results in inadequate attention to general health and wellness.
- People with MS experience inadequate care coordination between MS care and primary care, potentially resulting in inattention to and/or lack of treatment for complex problems.
- Healthcare professionals may make inaccurate assumptions about what people with advanced care needs want from the healthcare system.
- Healthcare providers have little understanding of what daily life is actually like for an individual living with significant impairments.

- Many people with complex care needs and their families believe that the healthcare community has nothing to offer them, particularly as disease-modifying therapies may not be indicated for many people with progressive forms of MS.

**“All persons with MS have their own preferences, values and expectations about their lives. These personal qualities and the social and physical environments in which people live affect how different people approach their MS – and what they seek out of life – at all stages of the disease.**

**No way is ‘right’ and another ‘wrong.’”**

-health policy researcher who lives with MS

- Families often feel they are expected to provide complex, round-the-clock care of their loved one – without adequate information, tools, training or support.
- Many individuals with MS, family members and healthcare professionals share a discomfort in talking about complex needs, personal priorities and end of life concerns.

- Long term services and supports that would benefit people with advanced MS care needs (e.g. meal delivery, day programs, assisted living, skilled nursing facilities) are often unaffordable or age-restricted for the elderly population.

## The Society's Role in Addressing Barriers

Meeting participants made recommendations in three critical areas: information, education and support for individuals with advanced care needs and their families and advocacy priorities.

- Recommendations regarding information, education and support for individuals with advanced care needs and their families:
  - Revise the language on our website and in our materials to be more descriptive and inclusive so that any person living with MS – regardless where he or she falls on the disease spectrum – and every family member feels welcomed, recognized and supported by the National MS Society.
 

**“Unless you come into our homes, you have no idea what our lives are like.”**  
-health policy researcher who lives with MS
  - Ensure that our messaging acknowledges the significant challenges faced by people with advanced care needs and their families while continuing to support people’s efforts to live their best lives, maintain hope and access the care and support they need.
  - Promote early and ongoing management of co-morbid health conditions that can hasten disease progression and shorten life.
  - Promote the importance of healthy living strategies for members of the family – to optimize health and reduce co-morbidities, including weight management, exercise, preventive healthcare, stopping smoking, attention to emotional well-being.
  - Educate people with MS and their healthcare providers about the importance of integrating primary and neurologic care and screening early and often for physical, emotional and cognitive changes that could compromise health, self-care and quality of life.
  - Educate people with MS, family members and healthcare providers about available assistive technology options.
  - Increase opportunities for people affected by MS – at all points in the disease course – to share solutions with one another.
  - Ensure that all people affected by MS and their healthcare providers are aware of the full scope of our services.
- Recommendations regarding engagement and education of healthcare professionals in relevant disciplines:
  - To achieve the desired impact for people affected by MS, the Society must promote comprehensive, coordinated care that addresses MS holistically, prevents unnecessary complications and equips individuals and families with the training and tools they need to manage complex challenges.

- Partner with other organizations including the Consortium of Multiple Sclerosis Centers, American Academy of Neurology, AMDA (the American Medical Directors' Association/Society for Post-Acute Acute and Long-Term Care Medicine) and primary care organizations to develop, promote and deliver education programs to health care professionals.
  - Develop and deliver two tiers of medical education programs for primary care clinicians: 1) a basic continuing education program to ensure that every healthcare professional and professional-in-training has access to up-to-date information about advanced care needs in MS; and 2) an in-depth mini-fellowship targeted to select primary care clinicians who elect to develop a mini subspecialty in multiple sclerosis.
  - Ensure that professional education programs include information on: MS management (including symptom and relapse management); the impact of medical and emotional comorbidities; Complex Rehabilitation Technology; and health behaviors that have a specific impact on MS (including smoking cessation, weight management and stress management).
  - Professional educational strategies should include online CE programs, CE articles in professional journals, presentations at professional meetings, tools to promote doctor-patient communication about advanced care needs, information sheets/checklists embedded in the medical record for physicians to use during office visits.
- Recommendations regarding advocacy activities:
    - Focus our efforts on issues that will have the greatest impact and collaborate with other organization whenever possible.
    - Community based care advocacy priorities:
      - Eliminate Medicare's 'in-home' provision regarding mobility equipment
      - Eliminate the requirement for hospitalization prior to receiving in-home care
    - Access to care advocacy priorities:
      - Revised coding for primary care physicians and neurologists to allow for longer office visits to address complex care needs
      - Telehealth options for care (currently included in the 2017 state policy agenda)
      - PACE/Duals comprehensive care programs for individuals under age 55
      - Adequate coverage for maintenance and wellness interventions
      - Adequate funding for assistive technology, including Complex Rehabilitation Technology devices
      - Adequate Medicaid reimbursement for long-term care services
      - Revised age restrictions for services primarily geared to the elderly
    - Family respite care and support for caregivers

## Research Priorities Concerning the Care and Support of People with Advanced Care Needs and Their Families

Meeting participants identified a large number of questions that need to be answered in order to enhance health, wellness and care of people living with advanced care needs. The group then refined the list of questions to arrive at a key priority in each of eight areas:

- **Assistive Technology:** What are the unmet needs and barriers among people with MS regarding wheeled mobility?
- **Co-Morbidities and Primary Care:** How does the treatment of co-morbidities affect MS symptoms, progression and lifespan?
- **Health Care System Issues:** How can telehealth be used to monitor symptoms, complications and co-morbidities?
- **Long-Term Care:** What are the benefits and costs of community-based comprehensive care compared to residential care?
- **Other MS Symptoms and Complications:** What are the early indicators of progressive MS, especially advanced MS?
- **Skin Care:** What is the effectiveness of patient education programs to prevent pressure sores, falls, and other adverse events?
- **Speech, Swallowing, and Respiratory Function:** What are effective interventions to improve respiratory function?
- **Wellness and Lifestyle:** What are the long-term benefits of wellness interventions on MS, e.g., weight management, increased physical activity?

## Summary and Next Steps

The advanced care needs of many individuals with MS and their families are not being adequately addressed. Too often, complex MS symptoms interfere with health, safety, independence and quality of life while co-morbid health conditions and complications can increase disability and potentially shorten a person's life. Family members often feel left to their own devices as they provide care for a loved one while trying to manage additional responsibilities at home and at work and attend to their own health needs.

The National MS Society is working to increase access to high quality, comprehensive and coordinated care for everyone affected by MS, regardless of where they are in their MS journey. The

Society also wants to support family members in their efforts to provide safe and optimal care for their loved one while also attending to their own health and well-being.

With these goals in mind, the Society convened a group of key stakeholders – including people with MS, support partners, Society staff and clinicians from the fields of neurology, primary care, rehabilitation medicine, psychology, nursing, physical therapy and speech pathology– to help inform the Society’s role in finding solutions for individuals and families who are facing advanced care needs.

**“We need to get to a place where no one ever hears ‘There’s nothing more we can do for you’.”**

-healthcare professional

The group focused on several key questions

- *What does it mean to have advanced MS?*
- *What are the factors that contribute to greater disability and potentially shorten a person’s lifespan?*
- *What are the key components of optimal care and what are the barriers to that care?*
- *What role can the National MS Society play in addressing those barriers?*
- *What are the key research priorities?*

and made recommendations in the following areas:

- *Information, education and support for individuals with advanced care needs and their families*
- *Engagement and education of healthcare professionals in relevant fields*
- *Advocacy issues*
- *Research priorities*

All of these recommendations will be carefully considered and prioritized to ensure that we have the greatest possible impact for individuals living with advanced care needs. In the meantime, individuals and families nationwide may contact the Society’s MS Navigator® program via the Society’s toll-free help line 1-800-344-4867 or via email at [contactusNMSS@nmss.org](mailto:contactusNMSS@nmss.org). The MS Navigator Program is the gateway to service and care management, connecting people to resources in the community and nationwide, and helping people access optimal healthcare, understand benefits such as health insurance, face financial challenges, plan for the future and find support when MS progresses.

Right now, MS activists are advancing home modification tax credit legislation in their state legislatures, to provide financial assistance for home modifications for people with MS advanced care needs. [Take action now](#)

The National MS Society provides support to people living with advanced MS, including guides for families, a guide to financial planning, and information on advanced directives. [Read more](#)

The Society also provides support for healthcare professionals who are seeking to help people with MS obtain care at home, in nursing homes, assisted living facilities, or adult day homes. [Read more](#)

## Meeting Participants

**Jeremy Barewin** – Vice President, Marketing & Community Engagement, Greater Illinois Chapter

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