



National  
Multiple Sclerosis  
Society

## **Depression in Multiple Sclerosis: What We Know, What We Need To Learn, and What We Can Do Today**

### **Summary**

People living with MS want to know how to manage mood changes – particularly depression – and develop strategies to achieve emotional wellness. They want to know what they can do to feel and function at their best and they want the support of knowledgeable healthcare professionals to help them achieve their goals. To better address these needs, the National MS Society brought together people with MS, healthcare professionals, researchers and Society staff to discuss key issues related to depression in MS, highlight the work that needs to be done in the areas of screening, diagnosis, treatment and suicide prevention, and develop a prioritized list of research recommendations. In addition, the group made specific recommendations regarding the information, programs and services individuals and families need in order to recognize and manage depression, and outlined next steps to move this important priority forward.

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## Introduction

The National MS Society is committed to identifying solutions to the challenges of living with MS through research initiatives and focused efforts to improve access to high-quality MS healthcare. In keeping with this strategic priority, the Society has convened meetings to explore the needs around difficult and complex symptoms. The meetings involve multiple stakeholders, including people with MS, care partners, healthcare professionals and researchers.

One of the most challenging symptoms people affected by MS (including those who have the disease and their family members) have identified is depression. They want to know how to recognize, understand and manage the [mood changes](#) that are so common with this disease. Addressing mood changes, along with using diet and exercise to help manage their MS, are the areas that people consistently identify as being high priorities in their efforts to achieve [personal wellness](#) while living with this disease.

However, individuals who experience severe mood changes, particularly significant or major [depression](#), may be unable to engage actively or effectively in any self-care strategies, including MS management, emotional wellness strategies, physical exercise or healthy eating practices. Therefore, effective depression management is necessary not only to help people feel better and improve their quality of life, but also to make it possible for them to embrace self-care and lifestyle changes to enhance their overall health and well-being.

In June, 2015, the National MS Society convened a [group](#) that included people with MS and support partners, healthcare professionals in the fields of neurology and mental health, researchers and Society staff, to address the following depression-related issues:

- High prevalence of significant depression among people living with MS and their support partners, compared to the general population
- High rate of suicide in MS compared to the general population
- Complex, probably inter-related causes of depression in MS (changes in the immune system and in the brain, as well as psychosocial stressors)
- Inadequate recognition, diagnosis and treatment of MS-related depression
- Lack of information about which types of treatment for depression work best for which individuals
- Impact of depression on: quality of life; self-care; ability to participate actively in MS treatment decisions and adhere to treatment plans; MS symptoms such as cognition, pain, fatigue
- Impact of MS-related depression on families
- Possible role of depression and other mood changes in central nervous system inflammation and the MS disease process

- Lack of well-designed studies to:
  - Identify the cause(s) of depression in MS
  - Help individualize treatment plans
- Insufficient numbers of mental health professional who are knowledgeable about MS to provide diagnosis and treatment
- Potential role of wellness behaviors, including exercise, stress management, mindfulness and other self-care strategies in managing depression in people with MS

## Key Priorities in the Identification and Treatment of Depression in MS

Participants identified three areas of focus for reducing the impact of depression on people with MS and their family members: education and awareness, access to treatment options, and partnerships and collaborations:

- **Education and awareness**

- Reduce the stigma of mental health issues and promote early and ongoing conversations about depression between people with MS and their healthcare professionals and family members
- Foster among people affected by MS and healthcare professionals a recognition, acceptance and understanding of depression as a common symptom of MS, and a common experience of support partners
- Provide support partners with the education and support that they need to recognize and deal with depression in their loved one

**“If I had known that depression was a common symptom of MS, I would not have been so reluctant to talk about it and seek help.”**

– person with MS

**“How do I recognize the symptoms of depression and know when and how to step in?”**

– support partner

- **Access to appropriate and affordable treatment options**

- Identify points in the disease course when depression screening and treatment are most effective, including diagnosis, during an exacerbation, and other crisis or transition points
- Identify the most effective treatment options (including counseling or “talk therapy,” medication, exercise, stress management, mindfulness and other self-care strategies) and delivery systems (including face-to-face, by telephone or computer) to meet individual needs

- Explore ways to increase the workforce of mental health professionals who are knowledgeable about MS and able and willing to provide treatment
- Advocate with third party payers for greater access to effective treatment and adequate coverage for mental health services
- Reduce the high rate of suicide

**“Some doctors are reluctant to ask patients about their mood if they have no resources or referrals to offer a depressed patient.”**  
 – neurologist

**“One in three people with MS have suicidal thoughts.”**  
 – mental health researcher

- **Partnerships and collaborations**

- Partner with treatment, policy and research experts in mood disorders and other medical conditions in order to capitalize on their expertise and avoid duplication of effort
- Partner with other MS organizations to broaden outreach, coordinate advocacy efforts and increase impact

**“We cannot and should not tackle the issues of depression in MS without engaging the expertise of others.”**

– psychiatrist

## What We Can Do Now

Based on the recommendations of the meeting participants, the Society has taken immediate steps to address some of these priorities:

- To help reduce the stigma associated with depression and highlight the importance of early recognition, diagnosis and treatment, depression is described on our website as “one of the most common symptoms of MS,” which deserves the same thorough assessment and careful treatment as any other symptom of the disease. Similar changes will be made in all of our publications as they go through updating and reprinting.
- To provide information and support for people with MS and their family members, the Society offers the following resources:
  - Print and online information about emotional wellness, depression and other mood changes
  - MS Navigators in the Information Resource Center (IRC) who provide information, emotional support and referrals to mental health professionals for evaluation and treatment
  - Opportunities to connect with others in the MS community through self-help groups, peer-support programs and online communities
- To identify individuals in distress, promote early diagnosis and treatment and help reduce the risk of suicide among people with MS:
  - Newly-diagnosed callers to the Society’s Information Resource Center are now routinely asked two questions about their mood, regardless of the reason for their call. Those whose responses suggest that they may be experiencing depression will be asked additional questions and given information about

depression and other mood issues in MS, as well as a referral to a local mental health professional, as needed. For other callers to the IRC, the need for the two questions will be determined on an individual basis.

- MS Navigators also monitor the Society's social media sites and respond to posts from individuals who are struggling with depression or suicidal ideation.
- To facilitate access to crisis interventions for those who are severely depressed and/or experiencing suicidal feelings or thoughts, the after-hours phone message for the IRC now includes the National Crisis Hotline contact information in English and in Spanish. The crisis hotline number has also been added in several places on the Society's website.
- To increase awareness and reduce suicide risk in people with MS, the Society has begun conversations with the National Institutes of Mental Health, the American Society for Suicide Prevention and the Grant Gordon Foundation to identify collaborative opportunities for screening, programming and research projects.
- To promote awareness of depression in MS, the Society is highlighting depression-related content and resources across a wide range of media channels, including the Society's website and social media sites, during National Suicide Prevention Week (September 2015) and National Depression Awareness Month (October 2015), and will continue this practice in the future.

### Recommended Next Steps

Other steps that will be implemented over the coming months include:

- Explore collaborative strategies with other MS organizations in the [Multiple Sclerosis Coalition](#) and with other disease groups (e.g., Parkinson's disease, rheumatoid arthritis, inflammatory bowel disease) for promoting awareness of depression in chronic illness
- Engage healthcare professionals who focus on MS care (including [Society-designated Partners in MS Care](#)) to help raise awareness and provide education to people affected by MS and other healthcare professionals
- Develop and disseminate a toolkit to promote early and ongoing conversations about mood between people with MS, family members and their healthcare providers
- Evaluate potential strategies for increasing the mental health workforce
  - Providing more in-person and online training for mental health professionals who want to learn more about MS
  - Promoting the idea of treating people with MS to mental health providers who currently do not see patients with chronic illness or disability in their practices
  - Funding fellowships for mental health professionals who want additional training in MS
  - Providing shared-learning opportunities for mental health professionals who treat people with MS

- Providing incentives (e.g., debt forgiveness) for mental health professionals to provide treatment in underserved areas
- Partnering with community mental health centers to enhance care for people with MS-related depression
- Connecting with organizations and individuals who are using technology (telehealth, for example) to provide services remotely and explore ways to use technology to enhance screening and treatment
- Engaging and training peer volunteers to provide early screening and support
- Engaging the Society's Partners in MS Care, Healthcare Advisory Committees and National Medical Advisory Committee to help: 1) promote early diagnosis and treatment of depression; 2) increase the workforce of mental health professionals who are knowledgeable about MS; 3) advocate for adequate coverage for mental health services.

## Key Research Priorities to Better Understand and Treat Depression in MS

Meeting participants identified a large number of questions about depression in MS for which we do not yet have adequate answers.

The group then refined the list of questions to arrive at the key priority areas listed here:

**“Why are people with MS at such high risk for depression?”**  
– mental health provider

- What are the causes of depression in MS (relationship to genetics, inflammatory processes, immune regulation, neurodegeneration, microbiome, etc.)
- What are the risk factors for depression in MS?
- What are the best screening measures for depression in MS?
- How can we determine which treatments work best for which individuals?
- How can we best prevent MS-related suicide?
- How can we provide access to mental health care for underserved populations?
- What are the current barriers to accessing mental health services among people with MS?

**“We need to know how to identify people at risk of depression and offer individualized treatment options.”**  
– mental health researcher

## Next Steps

The Society will develop a draft research agenda to address depression and MS. This will be considered by the Society's senior scientific advisors (the Research Programs Advisory Committee) as part of its annual prioritization process. Although it is still too early to specify what that plan will look like, potential strategies could include:

- Soliciting proposals from the research community for studies of one or more specific research ideas related to depression and MS
- Funding a scientific workshop to further refine ideas concerning research on depression and MS
- Exploring joint funding of research in depression with the National Institutes of Health or other funding partners
- Funding fellowships focused on depression research

## How People Can Access the Care and Support They Need Today

Any person affected by MS, including those with the disease and family members who care about them, may need help and support to deal with depression at one time or another. Talking with one's healthcare provider about any changes in mood is an important first step in getting the correct diagnosis and effective treatment. More information about depression is available on the Society's [website](#). [MS Navigators](#) in the Society's Information Resource Center (1-800-344-4867; [contactusnmss@nmss.org](mailto:contactusnmss@nmss.org)) offer information and support and provide referrals to mental health professionals. The Society also offers opportunities for people to connect with others in the MS community at [MSconnection.org](http://MSconnection.org).

The National Crisis Hotline is available 24 hours a day (call 800-273-8255 or text "ANSWER" to 839863) to help any person who is having thoughts of self-harm or of harming someone else. Depression is not something that anyone has to deal with alone.

## Closing Thoughts

People with MS have identified depression as a painful and complex symptom that impacts their quality of life, relationships and ability to function. Finding solutions to complex symptoms is a key priority in the National MS Society's drive to increase access to comprehensive, high-quality healthcare that is supported by research outcomes and delivered by healthcare professionals who are knowledgeable about MS. The Society has made the commitment in its strategic planning to ensure that people have effective

treatments and solutions to the challenges of living with MS and that they are able to connect to the individuals, information and resources they need to move their lives forward. These goals were echoed throughout our recent meeting on depression in comments made by people with MS, support partners, and healthcare providers. This meeting of key stakeholders was a critical first step toward enhancing our understanding of depression in MS and finding solutions for all those who are affected by its challenges.

## Meeting Participants

**Ann Borsellino** – person living with MS

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**Cathy Carlson** – Associate Vice President, Research Information

**Beth Clark** – Senior Manager, Communications

**Tim Coetzee, PhD** – Chief Advocacy, Services and Research Officer

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**Coleen Friedman** – Greater Illinois Chapter Vice President, Programs and Services

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**Karen Lyda, DNP, MSW, LCSW** – psychiatric nurse practitioner and social worker, private practice

**Ruth Ann Marrie, MD, PhD** – neurologist, University of Manitoba

**Robert McBurney, PhD** – CEO, Accelerated Cure Project for Multiple Sclerosis

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**Karen Peterson** – support partner

**David Rintell, EdD** – psychologist, Brigham and Women's Hospital

**Nancy Sicotte, MD** – neurologist, Cedars-Sinai Medical Center

**Angela Taylor, MSCIR, MSSMC** – Senior Manager, Information Resource Center

**Jane Welzant** – person living with MS

**William Welzant** – support partner

**Laura Williams** – sister of a person living with MS

**Roberta Winter, LCSW** – social worker, Rehabilitation Institute of Chicago

**Lisa Wren** – support partner

**Cyndi Zagieboylo** – President and CEO, National MS Society