

## ADDRESSING YOUR EMOTIONAL WELL-BEING IN MS

Emotional well-being is an important part of overall wellness. Our emotional health impacts how we feel about ourselves and the world around us. It can also impact our physical health and how we take care of ourselves.



Emotional changes are common in multiple sclerosis (MS). It's important to be aware of how MS can affect emotional well-being, as well as strategies to recognize and address these mood changes.

### IMPACT

Emotional changes can have significant impact on daily life, relationships, communication, and quality of life for people living with MS. They can result in loss of interest in activities, change in appetite or sleep patterns, and changes in energy levels. Common mood shifts that can occur include:

#### DEPRESSION

- One of the most common and most treatable symptoms of MS<sup>1,2</sup>
- Caused by changes in the brain and the immune system, as well as the challenges of life with MS<sup>2</sup>
- Characterized by low mood, loss of interest in things you once enjoyed, irritability, changes in appetite and sleep patterns, and other changes<sup>2</sup>
- Worsens other MS symptoms, such as cognitive problems, pain, and fatigue<sup>2</sup>

#### ANXIETY

- At least as common as depression<sup>1</sup>
- Can interfere with daily functioning, sleep, thinking, and memory<sup>3,4</sup>
- Can be treated<sup>3</sup>

#### IRRITABILITY OR MOODINESS

- May be caused by depression or may occur independently as a result of changes in the brain and immune system<sup>1</sup>
- Can be treated<sup>1</sup>

#### STRESS

- Life stress is common and unavoidable<sup>5</sup>
- Goal is to learn how to manage stress rather than eliminate it from your life<sup>5</sup>

*\*Support partners experience their own depression, anxiety, irritability, and stress related to life with MS*



*Routine mental health screening is recommended for people living with MS in order to detect mood changes such as depression.<sup>6</sup>*

## CARE TECHNIQUES

**1.** Report mood changes to a health care provider. Mood changes are very common in MS and nothing to be embarrassed about. Treatment may include talk therapy, medication if needed, and exercise.<sup>1,7</sup>



**2.** Explore exercise options – exercise tailored to a person’s abilities and limitations has been shown to improve mood and quality of life.<sup>7</sup> A good place to start is by contacting a physical therapist who specializes in MS and can help you implement exercise and physical activity into your daily life (your neurologist may be able to help provide a referral). Set realistic and measurable goals for daily or weekly exercise.



**3.** In conjunction with talk therapy and treatment, mindfulness, meditation, journaling, and participation in self-help groups can help improve emotional wellness.<sup>7</sup>



**REFERENCES:** 1. Emotional Changes. National Multiple Sclerosis Society. <https://www.nationalmssociety.org/Symptoms-Diagnosis/MS-Symptoms/Emotional-Changes>. Accessed September 23, 2019. 2. Depression. National Multiple Sclerosis Society. <https://www.nationalmssociety.org/Symptoms-Diagnosis/MS-Symptoms/Depression>. Accessed September 23, 2019. 3. Anxiety Disorders. National Institute of Mental Health. <https://www.nimh.nih.gov/health/topics/anxiety-disorders/index.shtml>. Accessed September 23, 2019. 4. Whitehouse CE, Fisk JD, Bernstein CN, et al. Comorbid anxiety, depression, and cognition in MS and other immune-mediated disorders. *Neurology*. 2019. doi: 10.1212/WNL.0000000000006854. 5. Emotional Well-Being. National Multiple Sclerosis Society. <https://www.nationalmssociety.org/Living-Well-With-MS/Emotional-Well-Being>. Accessed September 23, 2019. 6. Shadday A. Understanding and Treating Depression in Multiple Sclerosis. MSAA; 2007. Accessed September 23, 2019. 7. Minden S., Turner A., Kalb R., Burke D., Emotional Disorders in Multiple Sclerosis. *Clinical Bulletin*, National Multiple Sclerosis Society, 2014. <http://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Clinical-Bulletin-Emotional-Disorders-5-5-14.pdf>.

## RECOGNIZE & RESPOND TO EMOTIONAL SHIFTS

Read the scenarios below illustrating challenges that you and your support partner may be experiencing and explore ways to discuss them with your healthcare provider



1

"I don't feel like myself anymore. I'm irritable and down all the time – no wonder people don't seem to want to spend time with me."

### CONVERSATION STARTERS:

- "Can MS impact how I'm feeling? I've been so down lately. I cry all the time."
- "I've been so moody recently – I don't know whether it's MS, menopause, or just life."
- "I don't feel like myself anymore; I'm sad over all the changes in my life and feel hopeless about the future. I would like to be screened for depression to see whether I might need to talk with a mental health professional."



2

"I've been feeling irritable and disengaged recently. I have no interest in activities I used to enjoy. My husband says it's impacting the time we spend together, and the time I spend with my kids."

### CONVERSATION STARTERS:

- "Ever since my last relapse, I've been very irritable. I never used to feel this way. Even my husband has noticed."
- "Lately, I don't feel like doing anything anymore. Could this be related to my MS?"
- "I no longer find joy in activities I used to love – and my husband says I've been disengaged from our family recently. Could MS have something to do with how I'm feeling?"



3

"I know we are both consumed with worries about what's going to happen with the MS and what we're going to be dealing with down the road – but it's hard to talk about because we don't want to upset one another. I think we need to ask our neurologist some direct questions about what to expect."

### CONVERSATION STARTERS:

- "We feel nervous about our future with MS. How will living with this disease impact us long term?"
- "Everything just feels hopeless right now – especially looking to the future. How can I know what to expect?"
- "Who can best help us plan financially for our unpredictable future – a financial planner or maybe an elder care attorney?"

Talk to your doctor if you think you may be experiencing emotional shifts related to your MS

## ADDRESSING COGNITIVE CHANGES IN MS

Cognition refers to the higher level brain functions. The human brain receives information, processes it, stores it, and produces output based on that information.



*Multiple Sclerosis (MS) affects cognition in up to **65%** of people living with the condition<sup>1</sup>*

### IMPACT

Cognitive changes can occur at any point during the course of MS. These may affect the speed of processing information, memory, attention, language, and executive functions such as planning, prioritizing, and decision-making.

Challenges with cognition can have significant impact on other aspects of overall health and wellness, as well as day-to-day life.<sup>1</sup>

This can include:<sup>1</sup>



self-care



communication  
& relationships



carrying out  
responsibilities at  
home or at work



managing  
treatment

### CARE TEAM

Members of your healthcare team who can help you identify cognitive challenges and recommend strategies to address them:



#### PSYCHOLOGIST

Completes full neuropsychological evaluation to identify and assess cognitive strengths and deficits; essential for Social Security disability applications



#### OCCUPATIONAL THERAPIST

Performs cognitive screening and recommends compensatory strategies to optimize activities at home and work



#### SPEECH-LANGUAGE PATHOLOGIST (SLP)

Performs cognitive screening and recommends compensatory strategies to enhance communication and daily activities



*Cognitive screening is recommended at the time of diagnosis and yearly thereafter to identify any problems that may be occurring.<sup>1</sup>*



## TECHNIQUES FOR ADDRESSING COGNITIVE CHANGES

### CHALLENGE:

### IMPROVEMENT STRATEGY:

1

#### Unable to process information as quickly as you were once able to

- Easily overwhelmed by too much information; slow to make decisions or respond in conversation
- Difficulty comprehending information the first time reading or hearing it

- Slow down, reduce distractions, and give yourself more time to think and respond
- Re-read information or ask the person to repeat the question or statement

2

#### Reduced attention and concentration

- Easily distracted
- Unable to multi-task
- Reduced cognitive flexibility

- Reduce environmental distractions. Turn off the TV, radio, limit social media use, etc.
- When engaging in conversations, repeat back what you are hearing; ask questions to better understand
- Talk yourself through steps out loud (e.g., "I just turned off the stove")

3

#### Memory

- Difficulty remembering recent conversations
- Forgetting appointments, meetings, instructions, or directions

- Repeat out loud and verify what you hear
- Build associations – when meeting someone new, associate his/her name with a friend with the same name, or with a place, color, event, etc.
- Combine modes of learning - to help ensure you remember a piece of information, read it, say it, hear it, write it, do it

4

#### Executive functioning (e.g., the ability to plan, organize, and complete a task)

- Difficulty executing or performing an activity involving multiple steps
- Challenges with time management, planning, prioritization, organization, etc.

- To improve time management, think about how long it now takes you to complete a task and create a schedule that allows you sufficient time
- Use calendars and/or to-do lists
- Break big tasks into smaller, manageable tasks
- Write out a list of steps, similar to a recipe, so that you are tracking what comes next

5

#### Language

- Unable to recall specific words
- Difficulty keeping up with pace of conversation

- Explain your challenges to the other person
- Stop struggling for the word - it will come to you
- Use other words or phrases to capture the word you can't produce

## RECOGNIZE & RESPOND TO COGNITIVE CHALLENGES

Read the scenarios below illustrating challenges that you and your support partner may be experiencing and explore ways to discuss them with your healthcare provider



1

"My thinking and memory are just not working the way they used to. I'm losing confidence in myself, and I'm worried that others don't see me as capable anymore."

### CONVERSATION STARTERS:

- "I don't know what's going on – I can't think like I used to – is it my age, my MS, menopause, stress?"
- "Since my last relapse, I just don't seem to be able to keep up or multi-task the way I used to. What strategies or accommodations would help me stay productive at my job?"
- "I would like us to post a family calendar in the kitchen so we can all be reminded of upcoming activities. How can I explain this to my family?"



2

"My husband says I haven't been remembering our conversations recently. I can tell he's getting a little frustrated and wondering whether I'm not listening or just don't care about what he's saying."

### CONVERSATION STARTERS:

- "Can MS have an impact on memory? Lately, I can't remember anything anymore and it's affecting my relationship with my spouse."
- "My spouse is getting really impatient with me – he says I'm late for everything. Could this be related to my MS?"
- "I get confused and distracted when there's a lot going on – whether I'm talking with another person or trying to drive to the grocery store. Is there anything I can do about that?"



3

"We've had to make some real changes in our household and our partnership, which has been difficult and very emotional. I used to manage all our finances and now I just can't do it. My spouse has taken that on as well as doing most of the driving now because I'm easily distracted and prone to getting lost."

### CONVERSATION STARTERS:

- "I am not sure if this is related to my MS, but I've been getting lost a lot lately."
- "I've been having a hard time with day-to-day tasks that my family used to rely on me for. I think my MS may have something to do with it."
- "Could a cognition specialist provide strategies to help me regain my ability to contribute to household activities?"

Talk to your doctor if you think you may be experiencing cognitive challenges related to your MS.

# UNDERSTANDING YOUR HEALTHCARE TEAM

Multiple sclerosis (MS) is an unpredictable disease that affects a person's daily life in many ways. A 2015 survey of 1,075 people living with RMS, conducted as part of the vs.MS initiative\* by Sanofi Genzyme, revealed:



## COGNITIVE

Nearly 50% feel they now have trouble making decisions  
More than 50% often have difficulties concentrating and remembering things



## HOME AND WORK

More than 30% feel urinary problems associated with relapsing MS (RMS) are a factor in planning to leave the house  
50% feel their ability to progress in their career has changed for the worse since their diagnosis, and 40% are concerned about being able to keep their jobs



## EMOTIONAL

Nearly 50% feel limited by their depression or anxiety  
More than 50% of respondents feel lonely or isolated because of their RMS



## PHYSICAL

More than 50% feel that their physical functioning has worsened since diagnosis  
More than 40% feel bowel challenges caused by RMS are limiting their daily activities



## RELATIONSHIPS

More than 50% of single respondents worry RMS will impact their ability to find a partner  
50% of those in a relationship with someone living with RMS report RMS has impacted their sex life  
More than 25% of respondents fear their partner may leave them

\*To inform the vs.MS initiative, more than 1,500 people living with relapsing MS (RMS) and RMS care partners were surveyed across the globe.

# THE COMPASS TO CARE

Partner with doctors and healthcare providers who have expertise on a wide range of MS experiences



Visit [www.MSPath2Care.com](http://www.MSPath2Care.com)

for more information on how you can be proactive in your MS care.

**CAN DO**  
MULTIPLE SCLEROSIS



# NAVIGATING HEALTHCARE RESOURCES

Understanding the available healthcare resources\* is an important part of proactive multiple sclerosis (MS) management. Check out the information below for finding and leveraging resources for different aspects of life with MS.



## FINANCIAL RESOURCES

There are many programs available to help you manage the costs of care.

- National MS Society: [www.nationalmssociety.org](http://www.nationalmssociety.org)
  - MS Navigator™ Program can help identify financial resources available in your area: 1(800) 344-4867
  - Provides insurance and financial information
  - Guidance on financial planning for life with MS
- Multiple Sclerosis Association of America: [www.mymsaa.org](http://www.mymsaa.org)
  - Provides prescription assistance and MRI assistance
- The Assistance Fund: [www.tafoares.org](http://www.tafoares.org)
- HealthWell Foundation: [www.healthwellfoundation.org](http://www.healthwellfoundation.org)
- Good Days: [www.pnp.cdfund.org](http://www.pnp.cdfund.org)
- National Organization for Rare Disorders (NORD): [www.rarediseases.org](http://www.rarediseases.org)
- Patient Access Network Foundation (PANF): [www.panfoundation.org](http://www.panfoundation.org)
- Patient Advocate Foundation (PAF): [www.patientadvocate.org](http://www.patientadvocate.org)
- For additional resources: [needymeds.org](http://needymeds.org)



### TIPS

- Patient advocacy organizations are resources for information, referrals, support and financial assistance.
- The manufacturer of your treatment may also have support services or a patient assistance program to help navigate insurance and/or treatment costs.
- Speak with a member of your healthcare team, such as a social worker, about your insurance coverage.
- Regularly check for updates to your insurance plan or assistance program(s). Many insurance plans update at the end of each year.



## WORK ASSISTANCE PROGRAMS & RESOURCES

It's important to know the resources and rights available to you as an employee living with MS.

- Can Do MS: [www.CanDo-MS.org](http://www.CanDo-MS.org)
  - Provides programming and webinars on work assistance
    - Navigating Career Change / Working with MS is Possible
    - Enhance Your Job Search with Online Resources
    - Discrimination on the Job
    - Knowing How to Navigate Leaving the Workforce
- National MS Society: [www.nationalmssociety.org/Employment](http://www.nationalmssociety.org/Employment)
  - Provides education on disclosure and accommodation strategies
  - Offers information for employers
- Multiple Sclerosis Association of America: [www.mymsaa.org](http://www.mymsaa.org)
  - Facilitates networking program



### TIPS

- Know your rights under the Americans with Disabilities Act (ADA) and the Family and Medical Leave Act (FMLA), as well as your local human rights laws.
- Familiarize yourself with your company's human resources department, including the time and leave policies, as well as short- or long-term disability plan requirements.
- If you are unsure about your options, many patient organizations will help you find local employment resources or refer you to an employment law attorney.



## SUPPORT PROGRAMS & RESOURCES

Connecting with others who have MS can be a useful lifeline as you navigate life with the disease.

- Can Do MS: [www.CanDo-MS.org](http://www.CanDo-MS.org)
- National MS Society: [www.nationalmssociety.org/Resources-Support](http://www.nationalmssociety.org/Resources-Support)
  - Connection Programs: [www.msconnection.org](http://www.msconnection.org)
  - MS Friends
  - Local self-help groups
  - Peer-to-Peer Connection Program
- Multiple Sclerosis Association of America: [www.mymsaa.org](http://www.mymsaa.org)
- MS World: [www.msworld.org/community](http://www.msworld.org/community)
- MS Foundation: [www.msfocus.org](http://www.msfocus.org)



### TIPS

- Online forums can be a great way to stay in touch with the MS community remotely.
- Keep an eye out for educational and awareness events in your area to gain in-person connections with the MS community.



## ONLINE RESOURCES

- Can Do MS: [www.CanDo-MS.org](http://www.CanDo-MS.org)
- National MS Society: [www.nationalmssociety.org](http://www.nationalmssociety.org)
- Multiple Sclerosis Association of America: [www.mymsaa.org](http://www.mymsaa.org)
- iConquer MS: [www.iconquerms.org](http://www.iconquerms.org)
- MS Foundation: [www.msfocus.org](http://www.msfocus.org)
- MS World: [www.msworld.org](http://www.msworld.org)
- Consortium of MS Centers: [www.mscares.org](http://www.mscares.org)
- MS Views & News: [www.msviews.org](http://www.msviews.org)
- MS One to One: [www.msonetoone.com](http://www.msonetoone.com)
- Above MS: [www.abovems.com](http://www.abovems.com)
- MS Lifelines: [www.mslifelines.com](http://www.mslifelines.com)
- United Spinal Association: [www.unitedspinal.com](http://www.unitedspinal.com)



### TIPS

- National and local patient organizations' websites may be helpful places to look for information about MS.
- Contact the company that makes your MS treatment for additional educational resources.
- MS is not one size fits all – you should share whatever you learn online with your healthcare team, so they can help you make an informed decision about the information.
- MS can affect many dimensions of your life, so understanding your rights and where to go for information can help you manage expectations.

Visit [www.MSPath2Care.com](http://www.MSPath2Care.com) for more information on how you can be proactive in your MS care.

*\*This infographic is not an exhaustive list of all available resources or organizations.*

# PARTNERING WITH YOUR HEALTHCARE TEAM

It is important that you have a long-term, trusting relationship with your healthcare team.

Below are a few tips on being proactive and collaborative.



## IT'S YOUR STORY

99% of your life is spent outside the exam room. Keep track of experiences that might be important for determining your MS treatment plan through a journal or mobile app to help your healthcare team create an individualized care plan for you.



## SHARE ALL THE PUZZLE PIECES

Be empowered to set your priorities and goals with your healthcare team by asking questions or expressing concerns. No concern or question is too minor.



## SHARE YOUR GOALS

Share your priorities and goals with your healthcare team and ask any questions you want them to address. If you have a particular way you like to communicate or learn, just let your healthcare team know.



## BREAK IT DOWN

Medical jargon can be difficult to follow. With MS terms like demyelination, ataxia, and more, it is no surprise if you're struggling to understand. Don't hesitate to ask for an explanation in simpler terms.



## KNOW YOUR OPTIONS

Work with your healthcare team to determine the best MS treatment options for you, as well as the short- and long-term risks associated with each option.



## ASK FOR THE DATA

Having a copy of your medical records can help you better coordinate with the different members of your healthcare team, as well as help you gain a better understanding of your MS.



## KEEP IN TOUCH

Your partnership with your healthcare team doesn't end when your appointment ends. Ask your healthcare team the best way to reach out with any questions or concerns you may have between appointments.



Your Life  
Expertise



Healthcare  
Provider's  
Medical Expertise



Partnership  
in Care

Visit [www.MSPath2Care.com](http://www.MSPath2Care.com)  
for more information on how you can be proactive in your MS care.

# STRENGTHENING YOUR SUPPORT PARTNERSHIP

A support partner helps a person living with MS cope with the physical, cognitive, and emotional challenges of her or his disease. A support partnership is built on mutual caring and respect – with each partner contributing to the well-being of the relationship.

Rosalind Kalb, PhD, Clinical Psychologist,  
shares her thoughts on MS support partner teams



What **type of support**  
do people living  
with MS need?

- *MS is a very complex, unpredictable disease that can affect physical, emotional and cognitive well-being.*
- *People living with MS may experience many emotional changes over the course of their MS journey – some of these are reactions to the stresses of living with a chronic, unpredictable illness, while others can be symptoms of MS itself.*
- *Open communication with a support partner can help a person living with MS by providing her or him with an outlet to let off steam and/or evaluate life options such as treatment, finances, work, etc.*



How can I  
**cope emotionally**  
when dealing with MS?

- *Support partners may also experience feelings of grief, anxiety and depression in response to the challenges and changes caused by MS.*
- *Self-care is the first step to caring for others. As the flight attendant reminds us on every flight – put on your own oxygen mask before assisting another person.*



How do we not let MS  
get in the way of our  
**intimate relationship?**

- *When your support partner is also a romantic partner, it can impact the emotional and physical intimacy of your relationship.*
- *Concerns about disappointing, upsetting or angering one's partner can create communication barriers.*
- *The visible and invisible symptoms of MS can alter sexual feelings and responses in ways that are easily misinterpreted as disinterest or loss of affection.*
- *Open communication, effective symptom management, creativity and a sense of humor can go a long way toward strengthening or renewing intimacy.*



How do we **plan**  
**for a future** with MS?

- *If you have MS, or are helping support someone living with MS, it's important to plan, but don't rush into any big decisions. Take your time evaluating the situation so you can feel confident in the choices you make.*
- *Start by asking yourself how MS could impact your daily life, at home or at work – and put a plan in place to help you deal with the potential challenges. You'll be able to focus on putting the plan into action rather than your fear of the future.*

## Resources and Information:



What type of  
**resources** are  
available for  
support partner teams?

### **Can Do MS ([www.CanDo-MS.org](http://www.CanDo-MS.org))**

- Webinars
- Online resources
- In-person programs

### **National MS Society ([www.nationalmssociety.org](http://www.nationalmssociety.org))**

- MS Navigators (1-800-344-4867) are available to provide information, support, and referrals to local resources.
- Information about Social Security Disability applications
- Publications for caregivers

### **Caregiver Action Network (National Family Caregivers Association) ([www.caregiversaction.org](http://www.caregiversaction.org))**

### **Family Caregiver Alliance ([www.caregiver.org](http://www.caregiver.org))**

### **Well Spouse foundation ([www.wellspouse.org](http://www.wellspouse.org))**

**Kalb R (ed.). *Multiple Sclerosis: A Guide for Families* (3rd ed.), New York: Demos Medical Publishing, 2006**