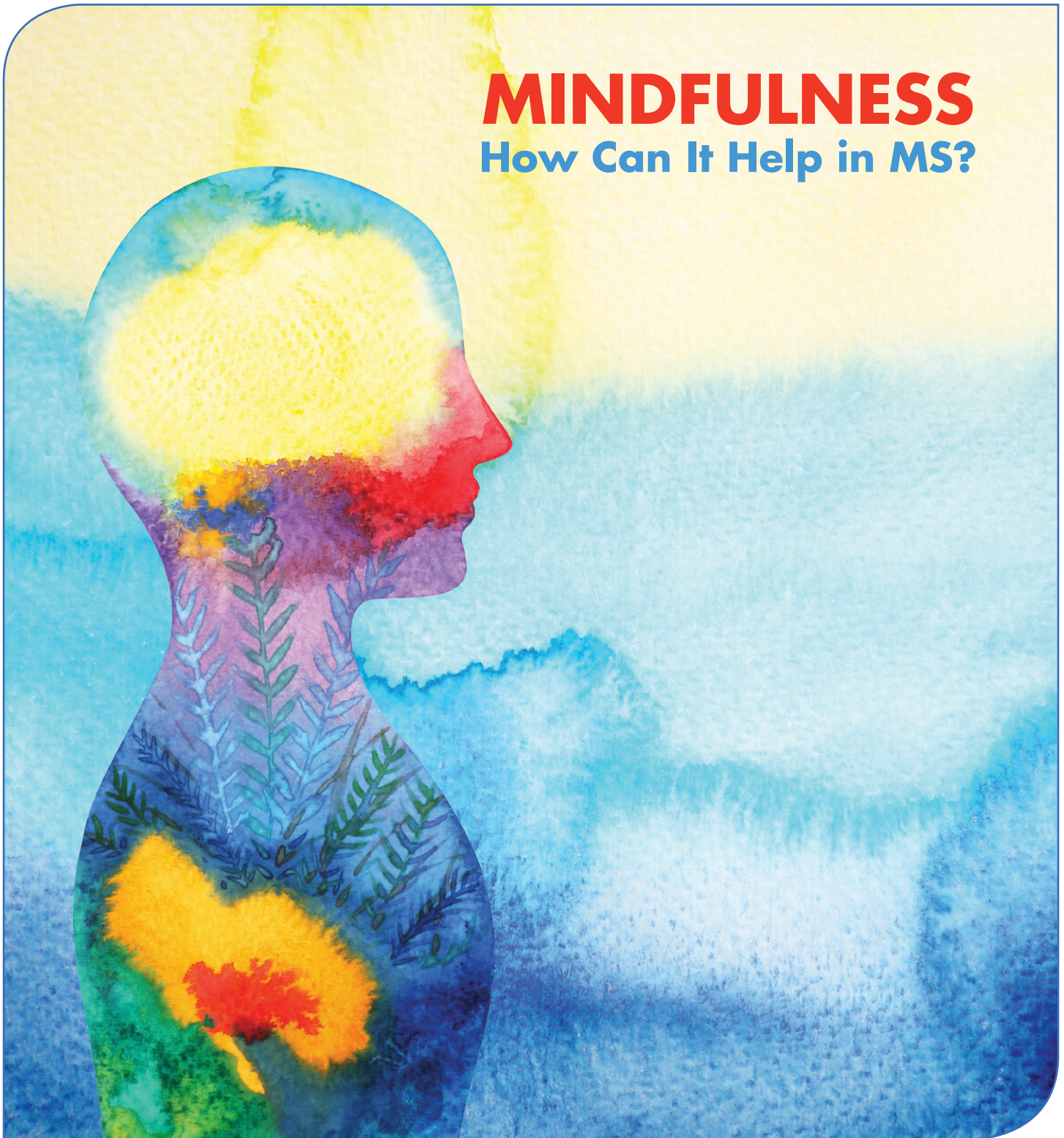


NARCOMS NOW

www.narcoms.org

Vol. 7, Issue 4, 2018



A Publication of the North American Research Committee on Multiple Sclerosis

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INFOCORNER



What is NARCOMS?

NARCOMS is a registry for people who have multiple sclerosis (MS). Registry participants complete two surveys each year to provide information about themselves and their experience of having MS. Data from these surveys are used in research studies and to help further our understanding of MS. Participation in the registry is voluntary, and responders' identity and privacy are carefully secured.



What is the Goal of NARCOMS?

The NARCOMS Global MS Patient Registry helps to facilitate research about multiple sclerosis in North America and around the world. Collaboration between MS centers of excellence throughout the world helps to increase knowledge, improve clinical care, and enhance the quality of life for persons with MS.



How Private Is My Information?

We will keep the information that you provide us confidential by storing your data in a secure database. All information will be used for research purposes only and will be kept private and confidential.



Not Yet a NARCOMS Participant?

Please contact us at www.NARCOMS.ORG to enroll online or call toll free at 1-800-253-7884



Tell Us Your Thoughts!

Have an idea? We would love to hear from you!
Send us your questions, comments and suggestions.

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Robert Fox, MD

Managing Director

Ruth Ann Marrie, MD, PhD

Scientific Director

Amber Salter, PhD

Coordinating Center Director

Gary R. Cutter, PhD

Scientific Advisor

Michele Curran

NARCOMS Project

Manager

Katherine Wandersee

Medical Writer

James Ticchio

Creative Director

Joseph J. D'Onofrio

Frank Marino

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DIRECTOR'S LETTER

Dear NARCOMS Now Readers:

This issue of *NARCOMS Now* highlights some important trends happening in multiple sclerosis (MS) research. One trend reflects the growing focus on patient-centered outcomes. This means planning and interpreting our research with goals that matter most to the people who have the disease. Patient-centered outcomes shown to be important to people with MS are quality of life and the impact of MS symptoms on daily life.



Robert Fox, MD

These trends really reflect the importance of programs like NARCOMS. NARCOMS allows us to learn from large numbers of individuals who can share a wealth of different experiences and insights. We recognize that you are extremely generous with your time and opinions, and we value input. We have learned a great deal and will continue to do more in an effort to serve the MS community.

In this issue of *NARCOMS Now* the Feature Focus discusses mindfulness in MS. This topic was selected in response to requests from many readers for more articles on stress and coping strategies. We enjoy hearing from you about the magazine and will continue to respond to your input.

If you are not yet a part of NARCOMS, I encourage you to consider enrolling. We would greatly value your contribution to our growing understanding about MS. Enroll at www.NARCOMS.org.

Sincerely,

A handwritten signature in black ink that reads "Robert Fox". The signature is fluid and cursive, with the first name being more prominent.

Robert Fox, MD

Managing Director, NARCOMS



Using Mindfulness as Part of MS Management

Imagine being able to experience life as it comes, without constantly judging yourself and your experiences. What if breaking certain long-standing mental habits could help to reduce some of the pain, stress, anxiety, depression, and fatigue that comes with multiple sclerosis (MS)? The practice of “mindfulness” is gaining recognition as a way to reduce stress and its negative effects. Practices such as meditation and mindfulness are being studied in people with cancer, chronic diseases, high-stress lifestyles, and other situations where stress can affect health.

Impact of Stress in MS

Many people with MS report having high stress levels. Living with MS is inherently stressful, and this is compounded by the usual stressors of daily life. Prolonged periods of high stress may even worsen MS for some people. For example, severe stress is associated with an increased risk of relapse. Stress is not easy to turn off, especially for people coping with a difficult health condition. A health professional might say, “Try to reduce your stress levels,” but this may add to a sense of being overwhelmed or blamed for one’s condition.

Maryanna Klatt, PhD, studies the impact of emotional stress in people with chronic illness, high-pressure jobs, and other stressful circumstances. Dr. Klatt



Maryanna Klatt, PhD

is Professor of Clinical Family Medicine and an Adjunct Professor of Nursing at Ohio State University. As a certified yoga instructor, she decided to use these skills to create a stress-reduction program, *Mindfulness in Motion*. The program combines mindfulness, gentle movement, and group discussion with a background of relaxing music.

Dr. Klatt initially tested the *Mindfulness in Motion* program with nurses who work in a busy surgical intensive care unit (ICU). After the 8-week program, nurses who participated had lower levels of *salivary amylase*, an enzyme in the saliva associated with prolonged stress. Along with lower levels of these stress chemicals, the nurses had increased job satisfaction and less “emotional exhaustion.” The ICU nurses encouraged Dr. Klatt to teach the skills to patients and families in the ICU, where stress levels run high as they cope with a

serious illness. She has also studied mindfulness for relieving pain in people with certain types of cancers.

Last year, Dr. Klatt and Rachel Gilbertson, MEd, from the University of Minnesota taught *Mindfulness in Motion* to a group of 22 people with MS. They measured the effects of the program on anxiety, depression, fatigue, and quality of life. The group consisted of 6 men and 16 women with either relapsing or progressive MS and an average disease duration of 19 years. They met for 1 hour, once a week, for 8 weeks. With a backdrop of relaxing piano music, the group learned and

discussed a new mindfulness skill each week. Themes included mindful sleep, supporting the breath, and mindful eating. Each class concluded with gentle stretching, meditation, and chair yoga exercises. Participants also agreed to engage in daily 20-minute mindfulness practice at home (**Figure 1**).

After the 8-week program, the participants had improved scores in several MS-specific measures, including anxiety, depression, cognitive function, and fatigue, Dr. Klatt explained. “Interventions such as yoga and mindfulness-based interventions can help people with MS to break the patterns of

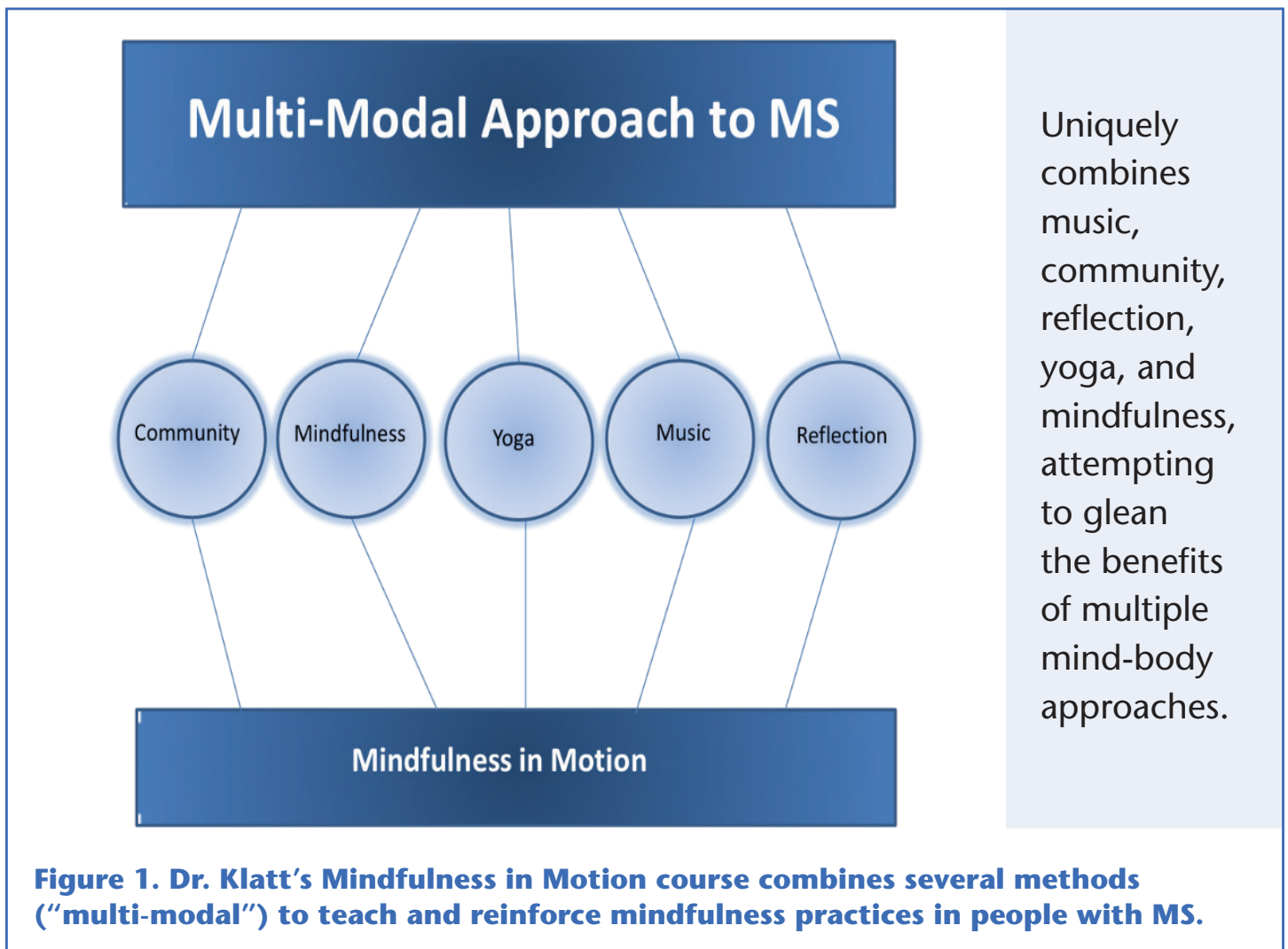


Figure 1. Dr. Klatt’s Mindfulness in Motion course combines several methods (“multi-modal”) to teach and reinforce mindfulness practices in people with MS.

excessive worrying and stress that are linked to depression and anxiety,” she said.

Benefits of Mindfulness in MS

Mindfulness has been described as “paying attention in a particular way: on purpose, in the present moment, and non-judgmentally.”

Mindfulness practice involves:

- Observing without judgement, including one’s experience of pain or stress
- Letting go of defenses, resistance, or protection against the pain or stressful situation
- Moving toward acceptance

Meditation, mindfulness, and Eastern exercises like yoga and qi gong (pronounced “chi gong”) are stress-control methods with some overlapping concepts. These practices can help a person to:

- Stay in the present
- Tune out runaway thoughts
- Regulate emotions
- Stop worrying about what happened in the past or might happen in the future
- Open the mind to new possibilities

Many people think of the mind and the physical body as existing separately. But research shows that the health benefits of mindfulness and meditation practices are not just imagined or temporary. The research suggests that these practices help contribute to *neuroplasticity*, or the brain’s ability to adapt and form new connections. Mindfulness and meditation have been linked to physical changes in key areas of the brain connected to mood, learning, and memory.

In a study of 116 people with MS, meditation helped them improve coping strategies, lower perceived stress, increase resilience, and improve quality of life (**Table 1**).

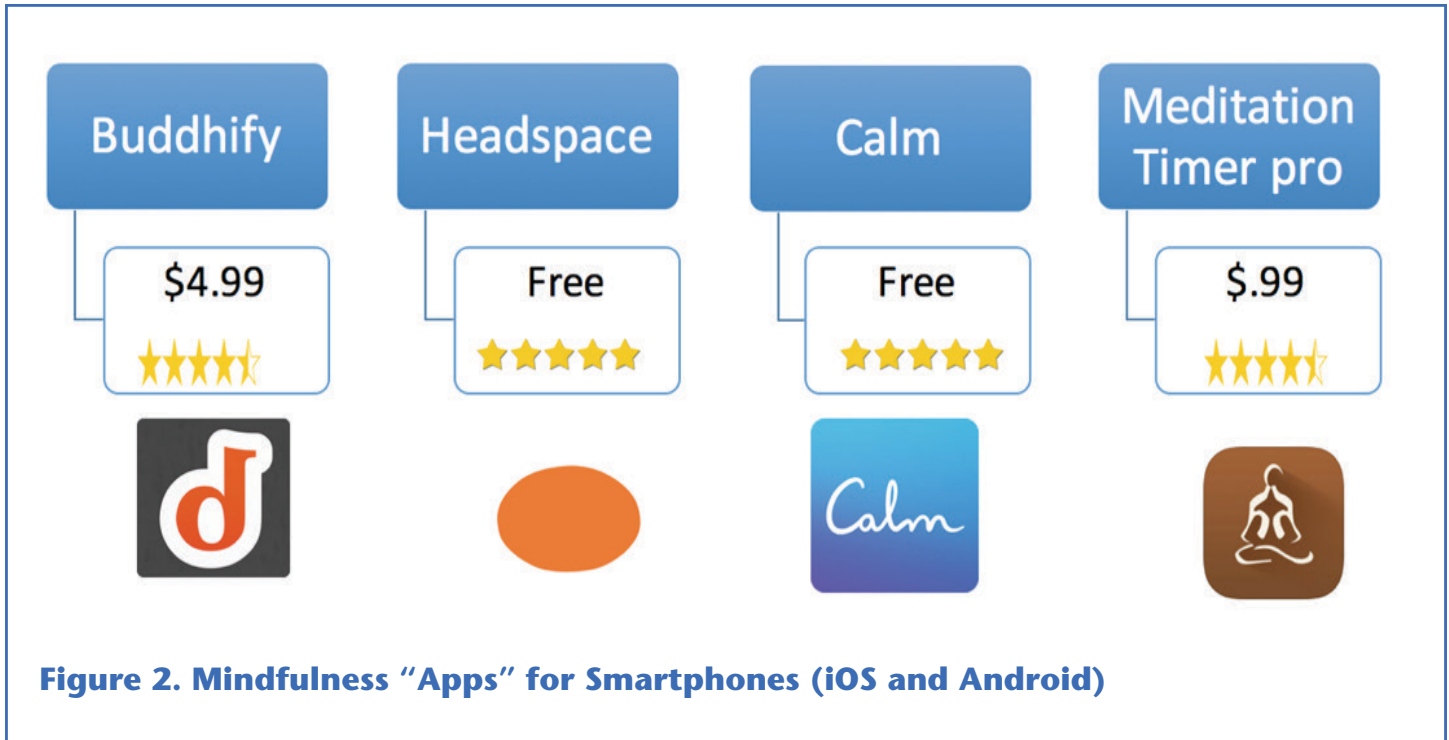
How to Incorporate a Mindfulness Practice Into Daily Life

Mindfulness can be “easy to learn but hard to do,” Dr. Klatt explained. You can get the techniques from a book or video, she says, but making them a regular habit to see noticeable benefits is much more difficult. The *Mindfulness in Motion* course is not available online, she says, because the group dynamic aspect is so important. “Part of the power is in the energy and support of other people,” she said. Sharing experiences and ideas with others helps to reinforce the practice.

Table 1. Studies Showing Benefits of Mindfulness and Meditation in People With MS

Studies using mindfulness practices or yoga for people with MS have found improvements in many areas that affect people with MS:

- Higher quality of life (QOL)
- Improved coping skills and increased resilience
- Increased attention when performing tasks
- Improved physical mobility and balance
- Improved overall physical and mental health
- Reduced depression, anxiety, and perceived stress
- Reduced symptoms of fatigue and pain

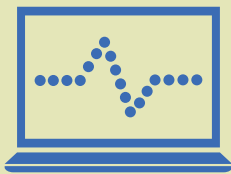


In the same way, taking a regular yoga or meditation class is a good way to stick with the practice. However, there are many ways to reinforce the practice at home. Several smartphone apps are offered as guides or reminders (see **Figure 2**).

For people with MS who participated in Dr. Klatt’s classes, some of the benefits were “game changing.” “Mindfulness helped them begin to let go of the frustration that they can’t control [the disease],” she said. “That’s the benefit of mindfulness for anyone with a chronic disease. Fighting it is going to add to your suffering.” Dropping the resistance enables people to disengage from the negative thought patterns that reinforced pain, sadness, and isolation, Dr. Klatt explained. “It may not change the progression of MS, but adding to your stress certainly isn’t going to make the disease any easier to deal with.”

Sources Cited in This Article

- Gilbertson RM, Klatt MD. Mindfulness in motion for people with multiple sclerosis: a feasibility study. *Int J MS Care*. 2017;19:225-231.
- Steinberg BA, Klatt M, Duchemin A. Feasibility of a mindfulness-based intervention for surgical intensive care unit personnel. *Am J Crit Care*. 2017;26:10-18.
- Senders A, Borgatti A, Hanes D, et al. Association between pain and mindfulness in multiple sclerosis. *Int J MS Care*. 2018;20:28-34.
- Davidson RJ, Lutz A. Buddha’s brain: neuroplasticity and meditation. *IEEE Signal Process Mag*. 2008;25:176-174.
- Lazar SW, Kerr CE, Wasserman RH, et al. Meditation experience is associated with increased cortical thickness. *Neuroreport*. 2005;16:1893-1897.
- Vestergaard-Poulsen P, van Beek M, Skewes J, et al. Long-term meditation is associated with increased gray matter density in the brain stem. *Neuroreport*. 2009;20:170-174.



NARCOMS Study Evaluates Resilience in Persons with Multiple Sclerosis

Recent research is exploring how a quality called “resilience” affects the way a person copes with a major health event or a chronic disease like multiple sclerosis (MS). While resilience has been increasingly studied in MS, a measure of resilience specific to the unique psychosocial and physical issues that affect people with MS has been lacking.

What is Resilience?

When people are faced with a difficult situation with potentially traumatic effects, there are several ways they can respond. The person’s level of resilience is one factor that determines his or her ability to cope, or “bounce back.” People who have a high level of resilience may experience stress in these situations, but are able to maintain their psychological, social, and physical well-being.

Several factors are thought to be related to resiliency among people with chronic health conditions. Being optimistic, having support (both socially and spiritually), and using effective coping strategies are some of these factors. Individuals with fewer of these protective factors and more vulnerabilities (such as greater MS-related disability) may be more likely to become distressed.

Creating a New Resiliency Scale for Persons with MS

The MS Resiliency Scale (MSRS) was designed for use by healthcare providers to identify coping strategies and resources among people with MS, and to reveal areas where they may need additional help. An early draft of the MSRS was tested by persons with MS who were recruited primarily through NARCOMS. A total of 3,000 persons with MS were invited to participate in the online study. In addition to completing the MSRS, participants provided information regarding:

- Age and gender
- Degree of disability, measured using Patient Determined Disease Steps (PDDS)
- Global resilience scores using another Resiliency Scale not specific to MS
- Anxiety and depression symptoms based on the Hospital Anxiety and Depression Scale (HADS)

Results

The final analysis included 932 participants, most of whom were women (82.2%) with relapsing MS (61.9%). Higher MSRS scores were associated with higher global resiliency

scores while lower scores were associated with greater symptoms of anxiety and depression. The items in the MSRS were divided into 5 different subscales:

- 1) Emotional and Cognitive Strategies (e.g., “I can deal with the stress related to my MS”)
- 2) Physical Activity and Diet (e.g., “Exercising helps reduce my stress”)
- 3) MS Peer Support (e.g., “I have learned to reach out to others with MS”)
- 4) Support from Family and Friends (e.g., “I have maintained friendships since being diagnosed with MS”)
- 5) Spirituality (e.g., “Having a belief in a higher power helps me deal with my MS”)

Results of the gender breakdown are shown in **Figure 1**. Women had significantly higher scores on the *Support from Family and Friends* and *Spirituality* subscales compared to men,

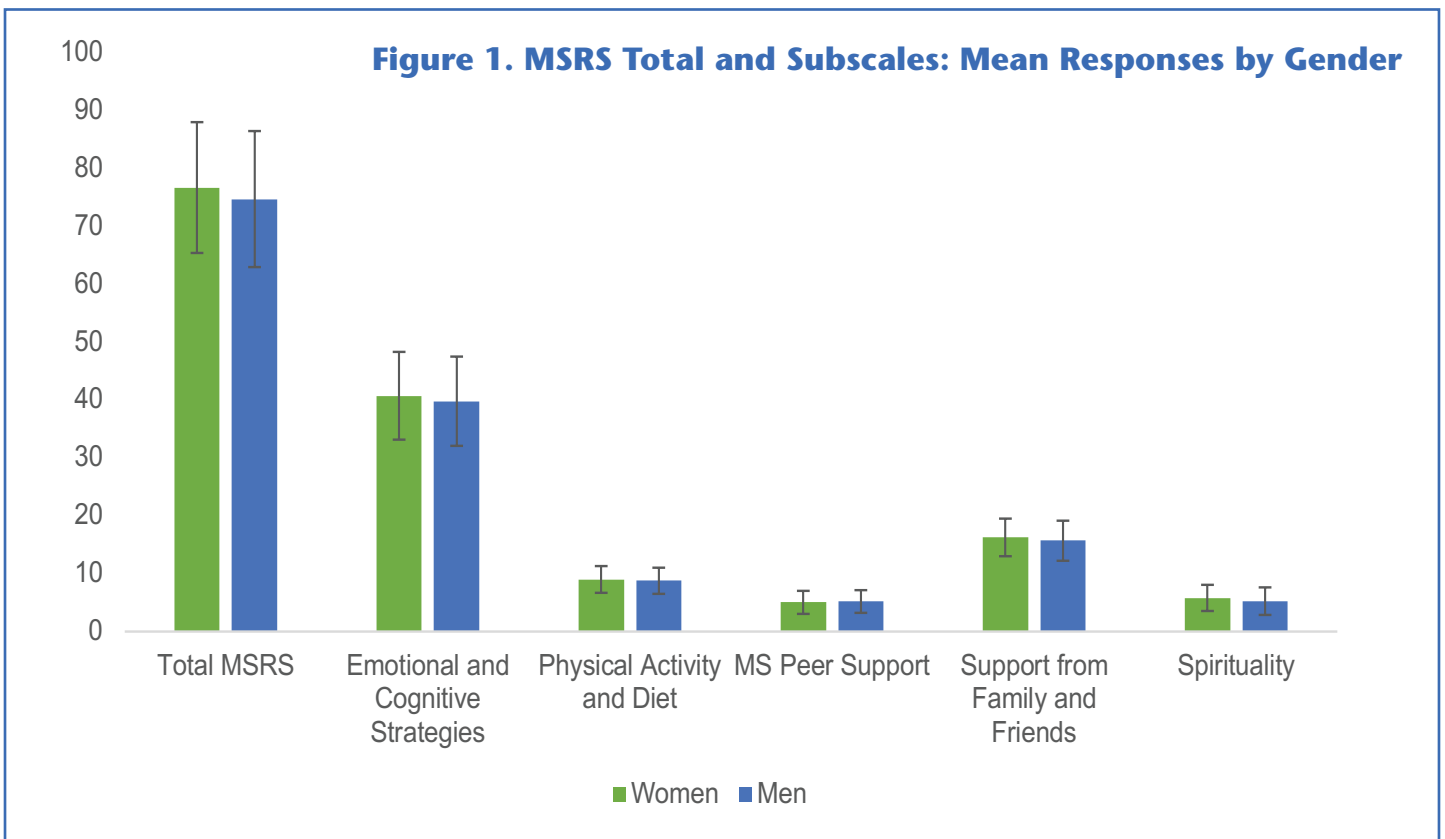
suggesting that these areas are more important components of resiliency for women.

How Will the MSRS Be Used?

This study, which would not have been possible without input from NARCOMS participants, resulted in the first MS-specific measure of resiliency. Other studies using the MSRS include another NARCOMS-supported project looking at perceptions of pain among people with MS and its effects on daily activities. It is hoped that the MSRS will be used in clinical practice to help identify individuals who may need additional support.

— **Elizabeth S. Gromisch, PhD**
 Mandell Center for Multiple Sclerosis
 Mount Sinai Rehabilitation Hospital
 Trinity Health of New England, Hartford, CT

Reference: Gromisch ES, Sloan J, Zemon V, et al. Development of the Multiple Sclerosis Resiliency Scale (MSRS). *Rehabil Psychol.* 2018;63:357-364.





SNAPSHOT

HOW WE'RE USING YOUR NARCOMS FEEDBACK

Health-Related Quality of Life Findings From Spring 2018

NARCOMS Survey

What is “quality of life,” or QoL? This concept can mean very different things to different people. To assess health-related QoL in people with multiple sclerosis (MS), NARCOMS has used the 12-question Rand Health Survey for more than 20 years. This tool has been shown to work well in studying MS and other types of chronic diseases. It can also be used to compare these findings with the general population. The 12 questions in the Rand Health Survey focus on how well responders are able to accomplish

a variety of everyday activities, and how they feel about their health status. When comparing groups, a score over 50 reflects a health-related QoL score that is higher than that of the general (non-MS) population. A score below 50 reflects lower than average health-related QoL. The answers to the 12 questions were grouped to create two summary scores: **physical component score (PCS)** and **mental component score (MCS)**.

Over 7,000 registry participants responded to the NARCOMS semi-annual update survey

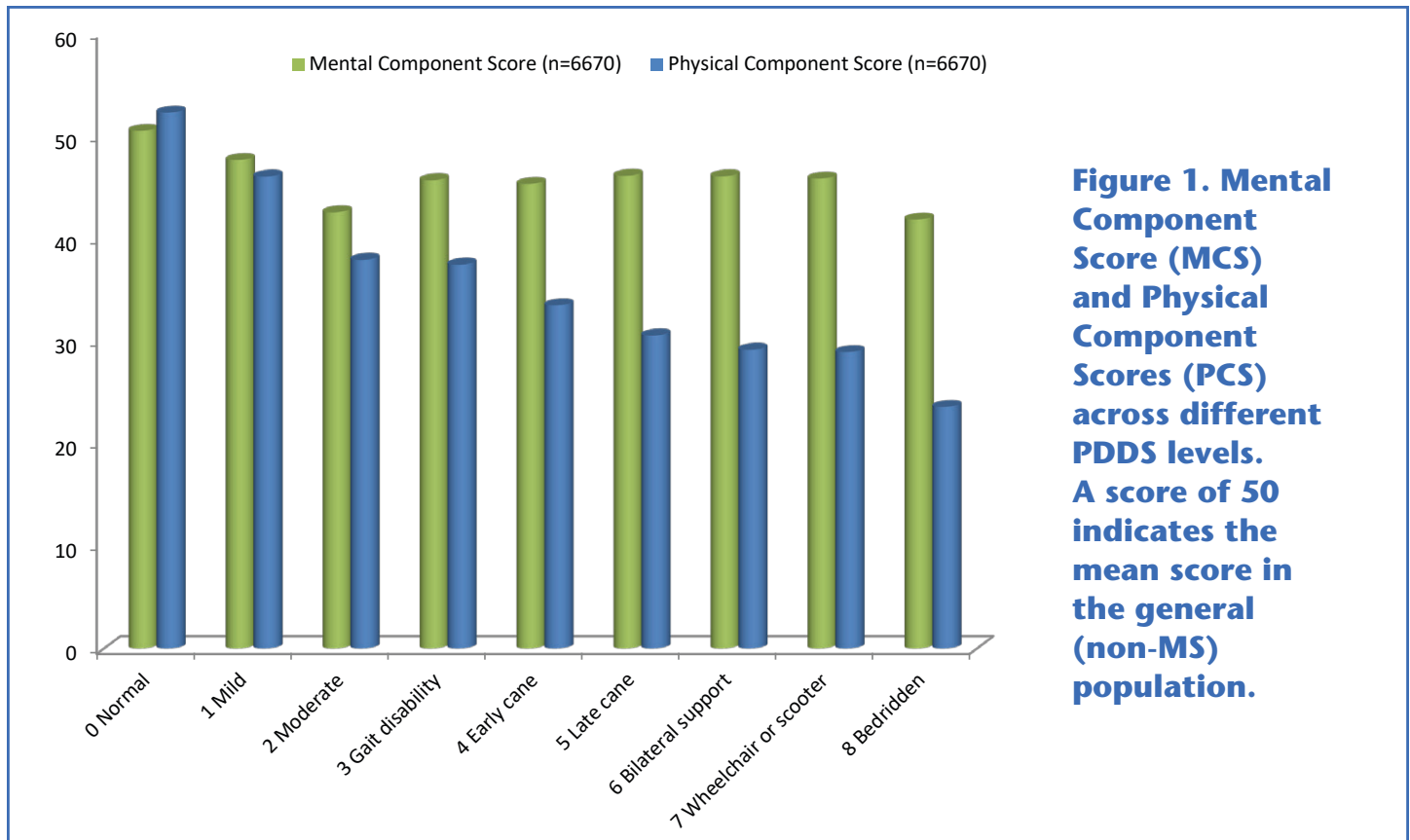


Figure 1. Mental Component Score (MCS) and Physical Component Scores (PCS) across different PDDS levels. A score of 50 indicates the mean score in the general (non-MS) population.

in Spring 2018. This analysis is based on the responses of the 6,670 participants who answered all 12 questions in the Rand Health Survey.

For responders with a Patient Determined Disability Steps (PDDS) level of 0, both the physical and mental quality of life scores were close to 50, thus similar to the average for the general (non-MS) population (**Figure 1**). At other PDDS levels, average PCS and MCS scores were lower than that of the general population. However, it is worth noting that while physical component scores decreased steadily as disability levels went up, the mental component scores did not. After an initial dip in the mental scores, it appears that responders may have found ways to cope with the emotional demands of MS even while facing increasing physical challenges.

These higher mental QoL scores may reflect a shift in response indicating the capacity to cope with challenging situations. A person’s

age, gender, and life events can all play a role in their response, along with several other factors. Some of these factors are modifiable, meaning that a person can change them. An example of a potentially modifiable lifestyle factor is engagement in leisure time exercise or physical activity. **Figure 2** illustrates the average mental component score for physically active and physically inactive responders at different disability (PDDS) levels. On average, people at PDDS levels 0 to 7 who said they engage in leisure time physical activity had higher mental scores than those who reported being inactive. This analysis does not allow us to conclude whether physical activity improves QoL or whether it’s the other way around—a person with improved QoL is more likely to exercise. However, the general health benefits of physical activity are well documented. As always, remember to discuss any major changes in your physical activity with a healthcare professional who is familiar with your situation.

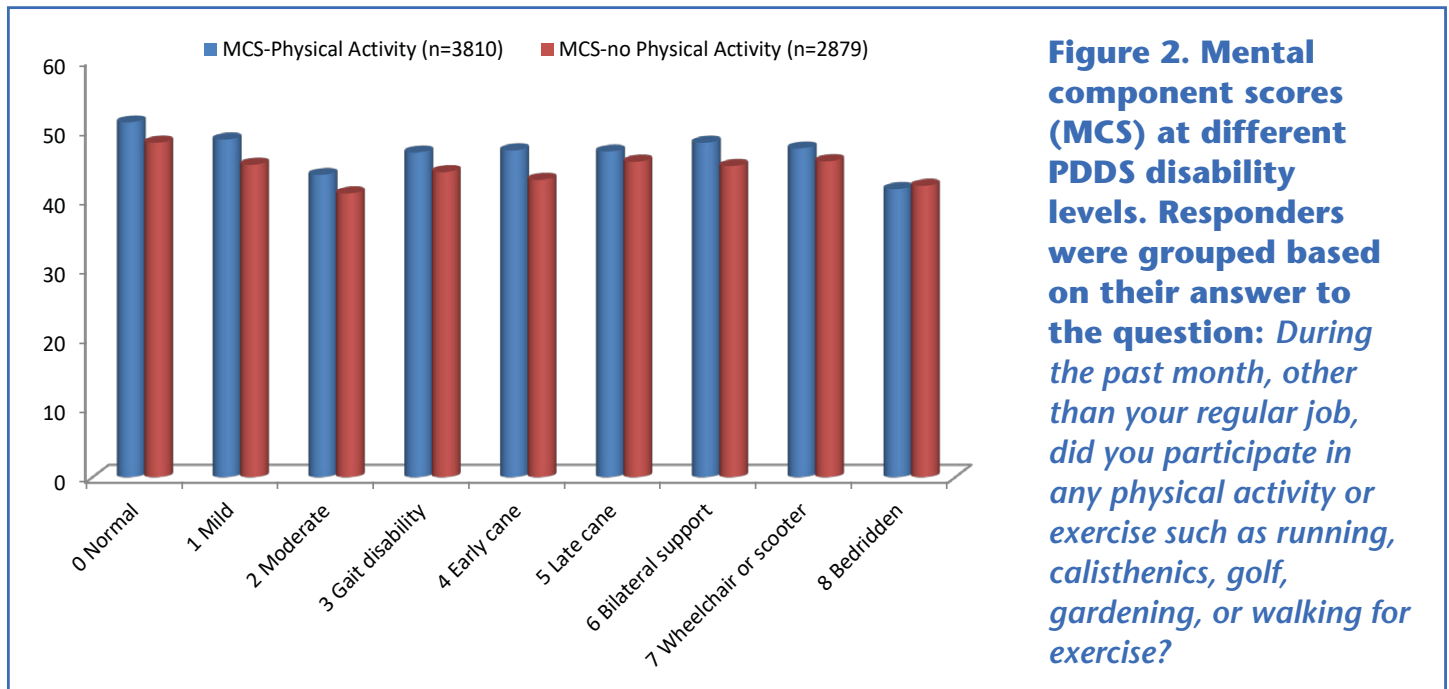


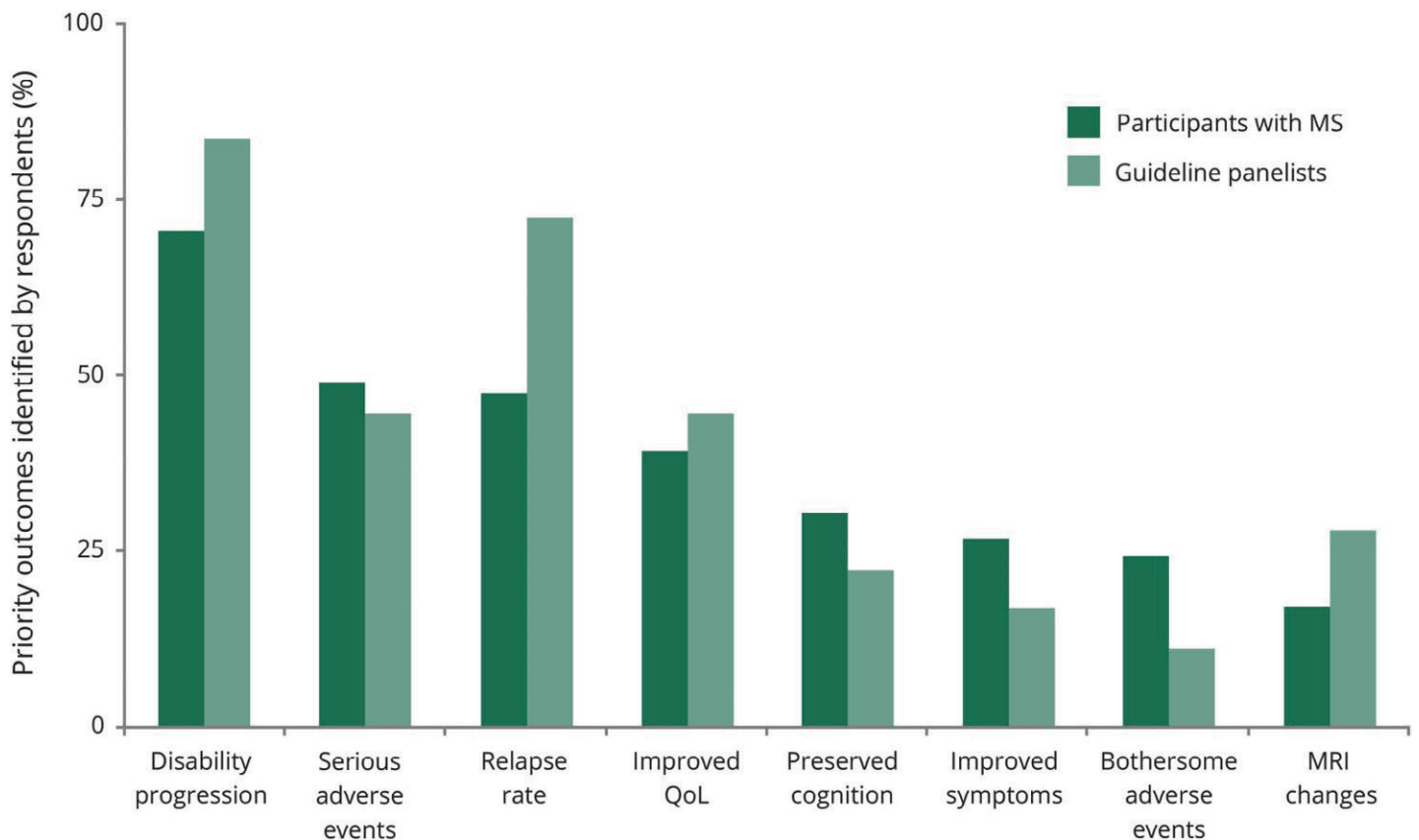
Figure 2. Mental component scores (MCS) at different PDDS disability levels. Responders were grouped based on their answer to the question: *During the past month, other than your regular job, did you participate in any physical activity or exercise such as running, calisthenics, golf, gardening, or walking for exercise?*



NARCOMS Study Reflects Treatment Priorities of People With MS

Newer research trends highlight the importance of being a NARCOMS participant. Traditional scientific studies use measures like MRI and blood tests to determine how well a drug or therapy is working. But an increasing number of studies are focusing on “patient-centered outcomes” to learn about managing disease, from the perspective of the people who are living with that condition.

A goal of NARCOMS is to make sure that people with multiple sclerosis (MS) have their voices heard. In collaboration with the American Academy of Neurology, researchers invited 9,126 NARCOMS registry participants to rank the factors they consider to be most important when selecting a disease-modifying therapy (DMT) for MS. A total of 2,056 NARCOMS participants responded to the survey. The researchers also surveyed a group of 18 people—mainly healthcare professionals—who develop MS guideline



Reprinted with permission from Rae-Grant A, et al. *Neurology*. 2018;90:777-788.

statements. Their answers were compared with the answers from the NARCOMS respondents.

As shown in the Figure, the priorities of guideline developers and group with MS were generally in agreement. Guideline developers ranked relapse rate reduction as a higher priority than did people with MS. Both groups ranked improved quality of life as a high priority. However, as the authors of the paper pointed out, this outcome is less-studied in MS clinical trials despite its importance to people with MS.

“In MS shared decision-making is a growing practice, and increasingly recognized as key to the delivery of high-quality health care,” the study’s authors wrote.

“Incorporating patient preferences in drug development is key to informing development of clinical practice guidelines and advancing [shared decision making] in the clinic environment.”

“Incorporating patient preferences in drug development is key to informing development of clinical practice guidelines and advancing shared decision making.”

Reference: Day GS, Rae-Grant A, Armstrong MJ, et al. Identifying priority outcomes that influence selection of disease-modifying therapies in MS. *Neurol Clin Pract.* 2018;8:1-7.

What is Myelocortical MS?

A newly discovered subtype of multiple sclerosis (MS) seems to cause damage to certain gray matter cells in the brain, but not to the myelin layer covering the nerve fibers. Demyelination, or breakdown of the myelin, is considered a hallmark of MS. White matter makes up about half of the human brain, and is usually seen as a main target of the immune system damage in MS.

Researchers from Cleveland Clinic studied tissue from 100 people with MS who had donated their brains upon their death. In 12 of the 100 brains, the characteristic white matter demyelination was not seen at all. Instead, the researchers found lesions in the spinal cord and in an outer layer of the brain composed of gray matter. These people may have had a form of MS not previously identified, which the researchers called “myelocortical MS.”

Standard MRI is not sensitive enough to distinguish the difference between regular MS and myelocortical MS. But more advanced imaging techniques may show the different pattern of damage. One of the lead investigators, Bruce

Trapp, PhD, said, “This study opens up a new arena in MS research. It is the first to provide pathological evidence that neuronal degeneration can occur without white matter loss in the brains of patients with [MS].”

The research findings suggest a need for use of more sensitive imaging to detect different MS subtypes, Dr. Trapp noted. They also may point to a need for more personalized therapies. Treating myelocortical MS may require a combination of approaches.

The study was supported by the National Multiple Sclerosis Society and the National Institutes of Neurological Disorders and Stroke.

Reference: Trapp BD, Vignose M, Dudman J, et al. Cortical neuronal densities and cerebral white matter demyelination in multiple sclerosis: a retrospective study. *Lancet Neurol.* Oct 1 2018;17:870-884.

Understanding Cannabis and its Applications in MS

People with multiple sclerosis (MS) are clamoring for scientifically accurate information on *Cannabis sativa*, or the marijuana plant. Part of the confusion comes from the huge variety of forms of the plant and its many uses, explained MS expert Allen Bowling, MD, PhD. Marijuana contains over 80 chemicals. The psychoactive component—or part that makes a person feel “high”—is tetrahydrocannabinol (THC). However, these effects are not necessarily the main benefit. Cannabidiol (CBD), a substance extracted from the plant’s flowers and buds, has applications in many diseases. CBD has been used to treat pain, spasticity, and other symptoms in people with MS. For people with severe forms of epilepsy, the Food and Drug Administration recently approved a purified form of CBD in capsule form, which completely removes the psychoactive components.

“Cannabis contains over 80 chemicals. The FDA recently approved a purified form of CBD [for seizure disorders] which completely removes the psychoactive components.”

Medical marijuana is legal in most states for management of MS. At the Annual Meeting of the Consortium of Multiple Sclerosis Centers earlier this year, Dr. Bowling noted that many MS healthcare professionals are unprepared to answer patients’ questions about topic. In addition, most medical marijuana dispensary staff have no medical or scientific training, he said. Oils containing CBD are available in 30 states where medical marijuana is legal, but these agents are highly unregulated and have varying amounts of any active substance.

Many studies have examined the safety and effectiveness of inhaled or edible marijuana in managing MS. But these findings don’t always apply to the specific cannabis products sold in dispensaries, Dr. Bowling said. He urges healthcare professionals and people with MS to learn more about marijuana in general and the substances available locally. People with MS should understand the benefits and drawbacks of using cannabis in their treatment and to talk to their MS care provider about what is most suitable for them.

Report from “An MS Health Professional’s Guide to Marijuana” chaired by Allen Bowling, MD, PhD, at the CMSC 2018 Annual Meeting, Nashville, TN.



Play **WORDSEARCH**

Find the following hidden words relating to mindfulness.

MINDFULNESS

MEDITATION

CALM

ENERGY

STRESS

RESILIENCE

BREATHING

CONCENTRATION

YOGA

BIOFEEDBACK

GROUP

NEUROPLASTICITY

CLASSES

SLEEP

BRAIN

COPING

C	J	E	G	N	S	P	M	F	C	J	G	S	R	H
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STATUS OF AMBASSADOR PROGRAM

The pilot phase of the NARCOMS Ambassador Program is starting to take shape. This program enables a group of NARCOMS participants to help promote the registry in their own area. The current group of volunteers will help plan how to best reach out to the MS community in their areas. We will keep *NARCOMS Now* readers posted on any new opportunities for joining the Ambassador Program later on.

SHARE YOUR IDEAS!

Do you have any new or innovative ideas that may help us inform others about the NARCOMS registry? If so, please share them with us by phone, email, mail or twitter. You can find our contact information in the NARCOMS Info Corner on page 2 of this issue. We would love to receive your input!

Thank you very much for all you do to help expedite research on MS.



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