

IOMSN^{News}

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A Publication For – and By – IOMSN Members

Professional Growth in MS Nursing



Brenda Brelje,
RN, MSCN

- **Sharpening Your Communication Skills**
- **Use of the Arts in MS**
- **Art Therapy & the MS Nurse**
- **Managing the Suicidal Patient**
- **Enough of the Fear**
- **2019 Southwest Regional Liaison**



IOMSN
International Organization
of Multiple Sclerosis Nurses

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UPCOMING CMSC/IOMSN MEETINGS

2020

34th CMSC ANNUAL CONFERENCE

May 27-30, 2020

Orlando World Center

Marriott

8701 World Center Drive

Orlando, FL 32821

Housing registration will
open in December 2019.

Submit an abstract to
present at the meeting through this link: [https://cmsc.confex.com/
cmsc/2020/cfp.cgi](https://cmsc.confex.com/cmsc/2020/cfp.cgi)

For more information, visit <https://cmssc-scholar.org/annual-meeting/>



2021

35th CMSC ANNUAL CONFERENCE

June 2-5, 2021

San Diego Convention Center

San Diego, California



2022

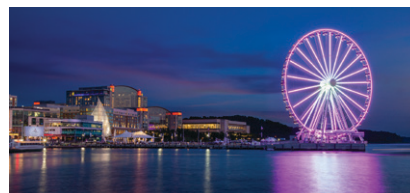
36th CMSC ANNUAL CONFERENCE

June 1-4, 2022

Gaylord National Resort &

Convention Center

National Harbor, Maryland



DID YOU KNOW?

There is a guide to disease-modifying therapies written by Sara Schaefer, NP-BC, CNRN, MSCN, of University of Colorado Health, available on the IOMSN website?

Visit <http://iomsn.org/dmt-information> to read it.

Letter FROM THE Editor

CLOSING OUT THE YEAR

As we put a wrap on our third year of publication, I would like to thank Genentech, Inc. for their support of our quarterly magazine. It's such a pleasure to be able to showcase and share the work we are all doing as multiple sclerosis (MS) nurses with one another, and it's another way our membership in the International Organization of MS Nurses (IOMSN) brings us closer to our colleagues and to cutting-edge research and clinical news. We are very grateful to Genentech for helping us to make this happen.

In this issue of *IOMSN*ews, we continue where we left off the last issue with some highlights of presentations from the 2019 Consortium of MS Centers (CMSC) Annual Meeting in Seattle. These include:

- A Q&A with Marie Namey, APRN, MSCN, based on a session about sharpening your communication skills;
- A review of the evidence for the benefits of therapeutic arts in the management of MS from a symposium moderated by Francois Bethoux, MD; and
- An article about a presentation by Rosalind Kalb, PhD, on managing the suicidal patient.

But there's more! Other articles include:

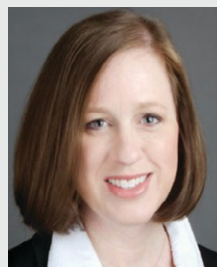
- Professional growth in MS nursing with Brenda Brelje, RN, MSCN;
- Art therapy and the MS nurse with Carrie Lyn Sammarco, DrNP, FNP-C, MSCN; and
- An interview with IOMSN member Mandy Winkler, RN, BSN, MSCN, about the new consumer book *Enough of the Fear*, which she wrote with her colleagues.

We also introduce you to our 2019 Southwest Regional Liaison, Crystal Wright, RN, AGNP-BC, MSN, MSCN. And on pages 21-22, we provide a list of all of our liaisons (I happen to be the International Liaison for IOMSN). Liaisons serve as point persons for nurses looking to better understand the many resources offered by IOMSN. They are happy to provide information on anything from studying for the MS Certified Nurse exam to becoming better connected with the organization. They are eager to address the concerns of the membership, so we urge you to take advantage of their free services.

We hope you find the issue to be helpful to you in your practice as an MS nurse and we wish you the happiest of holiday seasons.

Sincerely,

Marie



Marie Moore,
MSN, FNP-C, MSCN
Editor, *IOMSN*ews



PROFESSIONAL GROWTH IN MS NURSING

Brenda Brelje, RN, MSCN, is the Clinical Patient Staff Supervisor at the Schapiro Center for Multiple Sclerosis (MS) at the Minneapolis Clinic of Neurology, where she has practiced for 39 years.

“Things have changed so much in MS since I started working in the field in the 1980s,” she says. “Because we had no medications to treat the disease, nursing was largely centered on learning about and understanding the effects of the disorder and counseling patients. To help manage relapses and other disease manifestations, we used symptomatic medications and rehabilitative strategies with the goal of stabilizing function for as long as possible so that patients could maintain a better quality of life.”

MS nursing is very different today. The role has become more demanding, and there is a huge learning curve related to understanding all of the disease-modifying therapies (DMTs) and their complex pre-treatment assessments, modes of action, administration and monitoring requirements, and side effects and risks.

The focus of MS nursing has largely shifted to managing drug therapies, supporting adherence to treatment and necessary monitoring, and assessing the patient’s response. “As a result, I think our focus has been diverted away from the ability to concentrate on symptom management, despite its continued importance,” she says. “While new

MS nurses today are knowledgeable about current DMT treatments, they are not as skilled with managing older, injectable agents, and even less experienced in symptom management.”

To effectively address the current needs of patients with MS and their families, Ms. Brelje encourages nurses to seek out educational resources and opportunities to improve their disease knowledge and symptom management skills. “I tell the nurses I hire that they landed the job because they have excellent clinical nursing skills, but my goal is to help them grow professionally and obtain expertise in MS. Our staff’s ability to understand the complexities of the disease and address patient concerns is what differentiates our clinic from others,” she says. “Patients sit in the infusion clinic for hours to receive drug treatment, and questions frequently arise around the disease and its symptoms, so it is very important that nurses are equipped with the ability to effectively educate and counsel patients.”

Currently, Ms. Brelje supervises four nurses at her clinic, all at different stages in their careers. “At our center, we are very committed to providing education to our staff and are interested and invested in their professional growth. We offer a number of individualized opportunities for each of our nurses to help them enhance their knowledge about MS so that they can provide patients with scientifically accurate information. For example, our nurses have the opportunity to learn more about MS through real-life patient situations that occur at the clinic on a daily basis, when a co-worker or provider takes time to discuss the clinical situation and provide education. We also promote education from a variety of other resources, including journal articles, books, webi-



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“IOMSN is a great resource that helps nurses develop on both a professional and personal level. Through the website and regional programs, it offers many educational opportunities.”

— BRENDA BRELJE,
RN, MSCN

nars, various industry-sponsored activities, as well as programs sponsored by the International Organization of MS Nurses (IOMSN) and community educational activities. In addition, we support nurse attendance at the Consortium of Multiple Sclerosis Centers (CMSC) Annual Meeting. We also ensure that nurses have exposure to our physical therapy (PT) and occupational therapy (OT) partners in rehabilitation services so that they can gain insight on how to manage certain MS symptoms, such as fatigue, cognition difficulties, and gait abnormalities, from a nonpharmacological standpoint,” she says.

“As a supervisor, I think that it is important to identify each nurse’s individual educational needs and desires, because everybody has different preferences. For example, while one nurse might aspire to go back to school to become an advanced practice nurse (APRN) or a nurse practitioner

(NP), other individuals may prefer to gain knowledge through on-the-job experience and by learning more about MS at their own pace through books, journals, or continuing education activities. I want all of our nurses to feel supported, so I try to provide them with activities that interest them and fit with their lifestyles.”

Her Personal Professional Growth Journey

Ms. Brelje says that her own professional growth evolved over the years, but she attributes much of the vast knowledge she has acquired in MS to the guidance of the neurologists she has worked under at the Schapiro Center for MS, Drs. Randall Schapiro and Jonathan Calkwood. “At the beginning of my career in MS, Dr. Schapiro was my mentor. To develop a solid foundation in neurology, I attended his general neurology course for

(Continued on page 6)



family practice medical students at the University of Minnesota. His love of teaching entered into our daily clinical activities, where he continued to share his knowledge and help me develop my expertise in MS. Our practice focus was general neurology, with an interest in MS, for the first 5 years that I worked at the center. However, as our specialty grew, we began focusing only on MS and expanding the program with a team approach to managing the disease,” she says. “Dr. Schapiro is now retired, so today, with the management of the disease ever changing, I continue to benefit from the MS and neuro-ophthalmology expertise Dr. Calkwood shares with his staff.”

A Strong Desire to Learn

In order for nurses to gain expertise in MS and grow professionally, Ms. Brelje explains that they must have a strong desire to learn. “A solid commitment to learning is essential. Additionally, nurses should know the resources that are available to them and should seek out programs, meetings, online activities, and publications that provide comprehensive information on MS. IOMSN is a great resource that helps nurses develop on both a professional and personal level. Through the website and regional programs, it offers many educational opportunities,” she says. “The IOMSN Google Group is especially helpful because it opens up access to other nurses in the

field who are facing common clinical challenges in MS. You can throw out a question on a subject that may have you stumped, and you will receive responses from nurses across the country. This connection is so important because many MS nurses are the only nurse in their practice. The IOMSN network really fosters communication with others in the field to ensure that no one feels alone and isolated when caring for patients with MS,” she says.

Additionally, Ms. Brelje encourages all nurses working in MS to become certified by taking the Multiple Sclerosis Certified Nursing (MSCN) examination. “Becoming certified is a significant professional achievement and shows a commitment to MS nursing. Certification is also important to patients because they know that the nurse has worked hard to specialize in MS, and this gives them an extra level of trust and confidence in their clinical care,” she says.

“Undoubtedly,” she adds, “the role of the MS nurse will continue to evolve and become more complex. As nursing professionals we must continually educate ourselves and be equipped with the most up-to-date disease and treatment knowledge in order to provide the highest quality of care to our patients so that they can cope with the disease and enjoy an enhanced quality of life.” 🌐

Get 3 Learning Hour Credits Toward MS Certification

Here is your chance to get 3 learning hours toward your next certification.

Develop **5 Referenced Multiple Choice Questions** for the item bank to be used for a future MS Certification Exam.

We particularly need questions on advocacy and research along with clinical care and education questions. Please indicate the correct answer along with your reference.

This is a very simple example as a reminder:

Multiple sclerosis is a disease of:

- a. The central nervous system
- b. Muscles and nerves
- c. Vision and coordination
- d. Peripheral nerves

Reference: Smith, John. Multiple Sclerosis. Published by xyz press. 2018.

Submit your 5 Referenced Multiple Choice Questions to Elizabeth Porco at eporco@mscare.org.



Q&A WITH MARIE NAMEY, APRN, MSCN: SHARPENING YOUR COMMUNICATION SKILLS

Marie Namey, APRN, MSCN, is one of the founding members of the International Organization of MS Nurses (IOMSN) and a nurse practitioner at the Cleveland Clinic Mellen Center for MS Treatment and Research in Cleveland, Ohio. She is known for her special expertise in bladder and bowel issues related to MS. She chaired a session on communication skills at the 2019 Consortium of Multiple Sclerosis Centers Annual Meeting, and IOMSNNews interviewed her for insights from that session for nurses.

Q: Why are good communication skills so important in MS nursing?

A: Open, honest, and effective communication is the foundation of strong clinician-patient relationships. Building solid lines of communication with patients helps them to feel comfortable with their providers and establishes trust so that they feel at ease when expressing their hopes, fears, questions, and concerns. Over time, effective communication approaches also help to facilitate a

“I encourage all of my patients to have a companion attend appointments with them. In many instances, a family member or friend can bolster the patient’s confidence, help him or her to remember to ask questions, and reinforce counseling points after the appointment.”

— MARIE NAMEY,
APRN, MSCN

their patients. Treatment with disease-modifying therapies (DMTs) has become very complex over the last decade, so nurses need to be able to clearly convey the therapeutic benefits, risks, and

favorable patient experience, improve adherence to drug therapy and rehabilitation strategies, and contribute to a successful individualized care outcome for each person with MS. While good communication skills are essential for every nurse to master regardless of specialty, they are especially important for MS nurses to possess when educating and counseling

goals of the different agents in order to help patients make informed care decisions and establish and maintain realistic expectations.

Q: What are some of the challenges that MS nurses face when communicating and building relationships with patients?

A: The number one challenge is the most obvious: time. All clinicians are limited in the amount of time that they can spend with patients. Because it is impossible to cover everything in one appointment, we need to remember to be realistic and thoughtful about the breadth of information that a patient can absorb in a single session. For this reason, it is a good idea for nurses to verbally prioritize and summarize the top two or three aspects of care discussed during the visit that are the most important for the patient to remember. Additionally, providing patients with clearly written treatment instructions as well as printed take-home patient education materials also helps to reinforce key learning objectives.

It is imperative for nurses to be mindful that many people with MS feel anxious during visits, which can detract from their ability to learn and recall information. This is why I encourage all of my patients to have a companion attend appointments with them. In many instances, a family member or friend can bolster the patient’s confidence, help him or her to remember to ask questions, and reinforce counseling points after the appointment. I also suggest the use of memory



Marie Namey,
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Mellen Center for
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Cleveland Clinic
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tools (eg, taking handwritten notes or recording the conversation on a mobile phone or other recording device) to help patients review and retain counseling information after the clinic visit.

Another communication challenge nurses face is patients' lack of health literacy skills. For example, some individuals with MS may not be savvy about medical terminology or the way in which the healthcare system operates in general. Nurses should think of themselves as "interpreters" in the healthcare arena and identify when patients need to have medical terms broken down and explained on a more simplified level.

Finally, nurses should recognize that each patient's unique emotional status during any particular clinic visit may affect the way he or she processes disease state and treatment information. If the individual with MS is distraught over a new symptom, or has recently had a death in the family, for example, he or she may not be listening closely to the information that the nurse is sharing. Therefore, it is a good idea to find out what else is happening in patients' lives, because they may not disclose personal, family, or professional stress if they are not asked. Even a simple open-ended question, such as "Is there

anything that has happened recently in your personal life that may be affecting your stress level and mood?," can show patients that you care and help them to feel more comfortable about opening up and sharing sensitive personal experiences.

Q: What other suggestions do you have to help nurses build relationships with patients?

A: I recommend asking patients how they learn best. Because everyone learns differently and at a different pace, we cannot adopt a cookie-cutter approach to our counseling sessions. With this in mind, it is helpful for nurses to ask their patients, "Do you learn best by reading, by being educated verbally in person, by listening to instructions on an audio device, or through a combination of all three ways?"

Nurses should also be cognizant of concomitant illnesses individuals with MS may have because some comorbid conditions (eg, uncontrolled diabetes or heart disease) can cause increased disability that can worsen MS symptoms. Frequently, when symptoms of coexisting diseases are addressed and treated appropriately, the symptom load from MS is lightened. Likewise, we know that people with MS tend to have more depression and anxiety than those in the general population, and many times the physical

(Continued on page 23)

Foundations for Communicating Effectively and Enhancing Relationships with Patients

Educate Patients and Their Care Partners

- Provide clear verbal and written information about benefits and risks of treatment options
- State disease management and treatment instructions simply and confirm that the patient understands
- Suggest the use of memory tools (eg, taking handwritten notes or recording the conversation on a mobile phone or other recording device, encouraging a companion to accompany the patient to clinic visits) to help patients retain information after the clinic visit
- Reinforce treatment counseling points verbally and by providing written instructions and patient education materials

Establish and Clarify Realistic Expectations

- Employ a hopeful approach and avoid minimizing patients' concerns
- Emphasize that treatments for MS are preventative and not curative
- Suggest coping strategies, such as relaxation techniques, exercise, mental health counseling, etc.
- Consider the impact that concomitant illness may have on the patient

Enhance Support Networks

- Facilitate access to comprehensive healthcare in the clinic and at home, and refer patients to other healthcare providers (eg, rehabilitative clinicians, psychosocial counselors) when necessary
- Provide access to community resources, such as support groups and peer support





5 Reasons to Join the IOMSN Today

1 Professional Development

Each year, the IOMSN provides dozens of webinars, live programs, and print resources that convey the latest evidence-based information on the assessment, diagnosis, and treatment of MS.

2 Collaboration

The IOMSN is dedicated to fostering working relationships between nursing professionals. One of many means of doing this is the IOMSN Forum—commonly referred to as the IOMSN Google Group—an online resource for members to exchange ideas, ask questions, and share their knowledge.

3 Connections

Participating in IOMSN activities is a great way to network, stay up to date on important trends and career opportunities, and forge enduring professional relationships and personal friendships.

4 Support

The IOMSN offers a limited number of scholarships for members preparing to take the MSCN examination. It also provides financial support when possible for members' research endeavors, and provides a host of resources that enhance nursing professionals' ability to advocate for themselves and their patients.

5 Recognition

In conjunction with the Multiple Sclerosis Nurses International Certification Board (MSNICB), the IOMSN has developed an examination for registered nurses that leads to designation as an MS Certified Nurse, or MSCN. Additionally, each year the IOMSN recognizes outstanding individual contributions to MS nursing through its annual awards program.

When you consider the benefits of joining the IOMSN, it all adds up—and we want to count you among our numbers!

For more information:

- Visit our website at <http://iomsn.org/>
- Call us at 201-487-1050
- Email us at info@iomsn.org



USE OF THE ARTS IN THE MANAGEMENT OF MS

The use of the arts as a path to wellness has a long history dating back to ancient Greece, when Plato wrote, “Man’s music is seen as a means of restoring the soul, as well as confused and discordant bodily afflictions, to the harmonic proportions that it shares with the world soul of the cosmos.”

For patients with multiple sclerosis (MS), research demonstrates that participating in leisure activities and socializing with others has a positive effect on both mental and physical health. Yet therapeutic arts are rarely integrated into the management of MS, partly because of issues related to funding and reimbursement for the therapy, and partly because of lack of awareness about their potential benefits, reports Francois Bethoux, MD, medical director of the Arts & Medicine Institute and Director of Rehabilitation Services at the Mellen Center for Multiple Sclerosis Treatment and Research, both at the Cleveland Clinic Foundation (CCF). Dr. Bethoux chaired a symposium at the 2019 Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC) in Seattle that highlighted research on the benefits of therapeutic arts for people with MS, as well as CCF’s innovative Health, Resilience and Well-Being through the Arts (HeRe We Arts™) project, an evidence-based program that introduces patients with chronic illnesses to various opportunities for art participation, including music, visual arts, journaling, and movement activities.

Therapeutic Arts Evidence Base

Patients with MS often express an interest in complementary and alternative therapies, which can include therapeutic arts. While the data for use of therapeutic arts in persons with MS are limited, with a majority of studies being small and uncontrolled, there is growing evidence for its value, Dr. Bethoux says. He cites a literature review he co-authored with CCF music therapist and research program manager Lisa M. Gallagher, MA, MT-BC. This study (Gallagher LM, Bethoux F. Therapeutic use of the arts for patients with multiple sclerosis. *US Neurology*, 2017;13;82) reviewed five art therapy, 12 music

therapy, and two dance/movement studies enrolling patients with MS. Although the programs studied were diverse in terms of content, execution, stage of disease, and setting, they jointly suggested that therapeutic arts interventions are useful for patients with MS in decreasing pain, anxiety, and stress, he says. They can also improve coping skills and promote relaxation. Other benefits included a boost in self-efficacy, emotional well-being, and motor control.

One pilot study included in the literature review, authored by Cira Fraser and IOMSN member Michelle Keating, RN, OCN, MSCN, introduced 14 women living in St. Louis to creative arts such as beading and knitting over the course of 2-hour weekly sessions for 4 weeks. The results showed that the art intervention had a positive impact on the subjects’ perception of self-efficacy, self-esteem, and hope, with the potential to improve their quality of life.

Among six randomized, controlled trials (RCTs) of music therapy in patients with MS, Dr. Bethoux and lead author Ms. Gallagher found statistically significant improvements in two studies in terms of hand function and gait. While there was some indication of benefit with music therapy in the remaining four RCTs, the differences between the control and music therapy groups did not reach statistical significance.

In addition to the literature review, Dr. Bethoux has also conducted his own trials of music therapy. In one investigation involving rhythmic auditory stimulation (RAS) for gait in MS (Bethoux et al, *Int J MS Care*, 2012;14[suppl 2]:10), music therapy was used as an entrainment tool to provide cues to improve gait. Patients with gait disturbances were given recorded music with a strong rhythm at a tempo slightly above



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“I invite all MS caregivers and researchers to champion arts in medicine initiatives in their place of work and in their community.”

— FRANCOIS BETHOUX, MD

persisted for at least 2 weeks after the study ended,” he says. In a subsequent 8-week RCT with 10 participants (Bethoux et al, *Int J MS Care*, 2014;16[suppl 3]:76), Dr. Bethoux and his colleagues found that RAS at a tempo exceeding subjects’ spontaneous walking cadence was effective in producing an immediate increase in their cadence. The researchers also measured cortical activation patterns with functional magnetic resonance imaging (fMRI) in this trial, and found decreased brain activation when patients were performing mental imagery of walking while listening to rhythmic music versus without music, suggesting that walking with rhythmic music may require less brain activation because of an entrainment phenomenon.

HeRe We Arts™ Course Syllabus

Building on the research conducted within the Arts & Medicine Institute, including 25 studies over the past decade, Ms. Gallagher has spearheaded the HeRe We Arts™ program for patients with chronic illnesses including MS. The 8-week course introduces participants to music therapy, movement and

their comfortable walking cadence, and were told to do walking exercise for 20 minutes a day at home for 3 weeks. “At the end of the study, it was found that music therapy had significantly improved walking velocity, stride length, and cadence, improvements that

physical activity, art, theater, journaling, and art appreciation with an emphasis on promoting participation in these activities and showing how they can be modified to an individual’s physical and cognitive abilities. Patients are given art homework to practice during the week in between classes so they can determine if they enjoy and benefit from a particular activity. The final session summarizes the previous seven modules and advises people on how to integrate the arts into their daily lives. “By exposing patients to different art activities every week, we hope that some of the spaghetti will stick on the wall and they will find at least one activity they will continue to benefit from after the program is over,” Dr. Bethoux says.

In a quest to develop a more robust evidence base for use of the therapeutic arts, Ms. Gallagher and colleagues performed an uncontrolled study of the HeRe We Arts™ program, enrolling

(Continued on page 23)



The *International Journal of MS Care*, in collaboration with the MS Association of America’s Art Showcases initiative, has been featuring art from persons with MS on its covers since January 2019. Dr. Bethoux serves as medical editor for this official journal of the IOMSN and the CMSC. <https://ijmsc.org/>

ART THERAPY AND THE MS NURSE

Art therapy can be used by MS nurses as well as patients with MS to improve their quality of life, and can be easy to do in spare moments. For instance, journaling, expressive writing, and drawing have been shown to have significant psychological benefits, serving as tools for self-discovery. There has also been a groundswell of research into the benefits of a gratitude practice on physical and mental health, bringing to popularity the concept of gratitude journaling. The idea that we should focus on wanting and being grateful for what we have rather than on what we don't have encourages a powerful mind shift from a perspective of scarcity and dissatisfaction to one of abundance and contentment.

Carrie Lyn Sammarco, DrNP, FNP-C, MSCN, of the Multiple Sclerosis (MS) Comprehensive Care Center at NYU Langone Medical Center in New York City, advocates for starting a gratitude journal as a way to cope with stress. "I keep a gratitude journal where I write down three things I am grateful for that day before I go to bed," she reports. "I try not to overthink the entries—the list can include simple things like the cup of espresso I had with a friend, the fact that it was sunny today, or that I had a good interaction with a patient."

The physical act of writing the list has been shown in research studies to be particularly beneficial. "In addition, you can go back to these entries at a later date," she notes. "Reading the little things

that I've written down helps me to reflect on joyous, gracious moments in my life that I may have forgotten about."

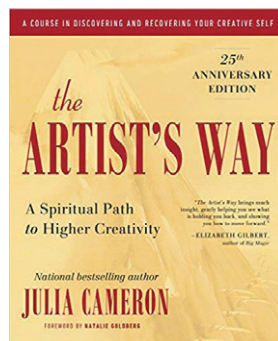
Beyond Gratitude Journaling

Your journaling practice doesn't have to be restricted to a gratitude list, however: Julia Cameron, author of *The Artist's Way: A Spiritual Path to Higher Creativity*, suggests a daily practice of three pages worth of "Morning Pages," an outpouring of all that is on your mind in a disorganized, stream-of-consciousness style. The point is not to make an intelligible journal entry, but simply to relieve your mind of its burdens and



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clear it for whatever is important to you. Cameron writes that "When people ask, 'Why do we write morning pages?' I joke, 'To get to the other side.' They think I am kidding, but I'm not. Morning pages do get us to the other side: the other side of our fear, of our negativity, of our



moods." Other ways of journaling include doodling and painting in a sketchbook, drawing pictures, and collaging photos together.

If writing isn't your style, Cameron suggests making regular dates with yourself to nurture your creative side. The date, which is only with

you and should be solitary in nature, might consist of going to a museum or gallery, to the beach at sunrise or sunset, or out to listen to music at a local club. 🎧



MANAGING THE SUICIDAL PATIENT

Whether you work in a multiple sclerosis (MS) clinic or a private neurology practice, MS nurses and other clinicians need to be knowledgeable about the higher (doubled) rate of suicide among this patient population compared to the general population, as well as prepared to identify suicidal patients and manage their care appropriately, advises Rosalind Kalb, PhD, a psychologist affiliated with the National Multiple Sclerosis Society (NMSS) and Can Do MS. Dr. Kalb moderated a session on managing the suicidal patient at the recent Consortium of Multiple Sclerosis Centers (CMSC) Annual Meeting in Seattle, and the panel published an article on the topic (Kalb R, et al. Depression and suicidality in multiple sclerosis: Red flags, management strategies, and ethical considerations. *Curr Neurol Neurosci Rep.* 2019;19:77).

The statistics on suicide in people with MS are compelling: A study of 140 consecutive MS clinic patients published by Dr. Anthony Feinstein in *Neurology* in 2002, for instance, found a lifetime suicidal intent of 28.6%, which was associated with lifetime diagnoses of major depression, anxiety disorder, comorbid depression-anxiety disorder, alcohol abuse, a family history of mental illness, and living alone. One-third of these patients had not received psychological help and 2/3 of those with major depression who were suicidal were not receiving therapy. Other research indicates that 29.4% of MS patients have had transient thoughts of ending their lives over a 2-week period while 10.8% have had persistent thoughts. In addition, 77% of patients with MS who died

by suicide have had contact with a physician within a year of their death and 40% within a week. The risk for suicide is greatest within the first 1 to 3 years of diagnosis, and among males with onset before age 30, those who are socially isolated, and those who abuse alcohol.



Rosalind Kalb,
PhD
National MS
Society and
Can Do MS
New York, NY

Responding to Concerning Statements

“During clinical visits, patients may share feelings of hopelessness and helplessness,” says Dr. Kalb. She emphasizes that patients may not present with crying and other stereotypical signs of suicidal intent. Instead, they may say subtle things that indicate they have lost the wherewithal to cope, such as:

- I’m a burden to my family.
- I’m not interested in what I used to be interested in.
- I’ve got so much stress that I don’t know how to handle it anymore.
- My financial burdens are too much for me to handle.

“These are important clues to the potential for suicide, and nurses need to be prepared to listen for these clues and to have thought in advance about how they will respond to statements such as these, and have a list of mental health professionals they can refer patients to.” She adds

NON-VALUE-LADEN, APPROPRIATE TERMINOLOGY TO USE

Words matter. Dr. Kalb says that it is important to use nonjudgmental language when talking with patients about suicide because it will lead people to be more open with you about their feelings and intentions. Therefore:

Avoid

- “Commit suicide” or “successful suicide attempt”
- “Completed suicide” or “successful suicide”
- “Unsuccessful suicide attempt” or “failed suicide attempt”

Instead, use

- “Death by suicide” or “suicide”
- “Died by suicide”
- “Non-fatal suicidal behavior”

Source: Kalb R, et al. Depression and suicidality in multiple sclerosis: Red flags, management strategies, and ethical considerations. *Curr Neurol Neurosci Rep.* 2019;19:77.

(Continued on page 16)

that there is no evidence that asking patients if they are thinking of suicide increases the risk of suicide.

If you are unprepared for the topic to come up, she says, you may miss the signs, change the subject, dismiss the distress, or provide reassurance without following up, which can lead to tragic consequences. Instead, she says, in the face of these kinds of statements MS nurses and other clinicians need to stop and say, “You sound like you are having a hard time,” and ask follow-up questions, such as:

- Have you talked to someone about these feelings?
- Do you have a mental health provider?
- Can I encourage you to call the National MS Society and talk to an MS Navigator, who can refer you to a mental health provider?
- Can I encourage you to mention these feelings to your neurologist?

If the patient appears to be in imminent danger, your practice or center should have a proto-

Dying with Dignity

Dr. Kalb suggests that MS nurses assess their feelings about physician-assisted suicide—which is legal in Montana, Oregon, Vermont, and several other states—and how they will handle patient inquiries about the topic.

Patients who are severely disabled and in extreme discomfort or pain due to MS may feel that their quality of life (QOL) is no longer good enough to go on living, and that death with dignity is a reasonable and rational choice. “These patients may not be depressed,” Dr. Kalb says, “but they may have simply made the decision to end their lives. Depending on the state you live in, physician-assisted suicide may be legal, and you can talk to a patient about dying with dignity and refer them to a mental health professional for a psychological assessment and to ensure that there are no underlying conditions that could be playing a part in their decision.”

In states where assisted suicide is not an option, she suggests pursuing palliative care to improve QOL or discussion of ending treatment.

col in place for how to manage the patient, she advises. For instance, a protocol might direct you to say, “I am really worried about you and I’m not sure it’s safe for you to leave the office now. Let me get you some help.”

Factors Associated with Suicide in Patients with MS

Depression is both one of the most common comorbid conditions in MS and one that increases the risk of suicidal ideation and death by suicide because it has a significant impact on quality of life. Statistics suggest that approximately one in two people with MS will experience major depression in their lifetime. Anxiety, bipolar affective disorder, and psychosis also occur at a higher rate than in the general population.

Other factors associated with suicidal intent and completion include poverty, homelessness, increased MS symptoms and progression, and difficulty managing activities of daily living. Specific warning signs of patients in danger include:

- A positive score on a depression screen (which ideally might be performed at every visit at intervals of 3 to 6 months)
- Abrupt changes in health and/or behavior
- Intense bereavement
- Statements of hopelessness
- Social isolation
- Substance abuse
- Worry about being a burden
- An inadequate support system
- Family members who express concern about the patient’s mental state

Assessing your patients’ safety and environment, scheduling more frequent visits, limiting refills on medications that could be used in suicide attempts, and referring patients to mental health professionals are proactive responses to concerns about such patients, she says. She concludes that, “Nurses play a central role in MS comprehensive care. Patients may share more thoughts, feelings, and concerns during their time with a nurse than with a neurologist. Being confident in your ability to recognize and address depressed feelings and suicidal ideation will facilitate difficult conversations, and help you improve your patients’ safety and quality of life.” 🌐

ENOUGH OF THE FEAR

New Book for Consumers Written by MS Experts Now Available

Mandy Winkler, RN, BSN, MSCN, is a registered nurse at the University of Texas Southwestern Medical Center Clinical Center for Multiple Sclerosis in Dallas, Texas. She has been working in MS for 6 years and is an IOMSN member. She recently passed her Multiple Sclerosis Certified Nurse (MSCN) exam. In 2019, she along with Katy Wright, PA-C, and Darin T. Okuda, MD, published Enough of the Fear: An Insider's Guide to Understanding, Managing, and Living Well with Multiple Sclerosis, a comprehensive book for people with MS and their caregivers that is available through Amazon.com and Apple Books. IOMSNNews interviewed Ms. Winkler about the release of the book.

Q: What led you to write this book?

A: Dr. Okuda, Katy Wright, and I have been working together for 6 years as a team, and all three of us are big believers in the value of patient education. Dr. Okuda has developed several educational apps for smartphones on how magnetic resonance imaging (MRI) scans are read, fatigue in MS, and treatments. Katy has also developed an app about plant-based eating. In keeping with that, we wanted to create a comprehensive hand-out for patients of all the things we tell them, and especially for new patients, to help decrease their fear of what's ahead. We know that it's hard to think about which medications to use and an appropriate diet and exercise program until you get over the fear of the disease and can accept the diagnosis of MS. When the fear subsides, patients can take an active role as a partner in stopping the disease from progressing.

Q: So is the book intended just for newly diagnosed patients?

A: No, it's for anyone with MS as well as their family members. A lot of patients that we see in

our clinic are coming in for a second opinion, to confirm a diagnosis or to correct a misdiagnosis, or they have seen a local neurologist and are on an older injectable but their disease is progressing. These patients need education just as much as newly diagnosed people, especially since treatments are rapidly advancing and expanding and we are learning more each day about what causes MS.

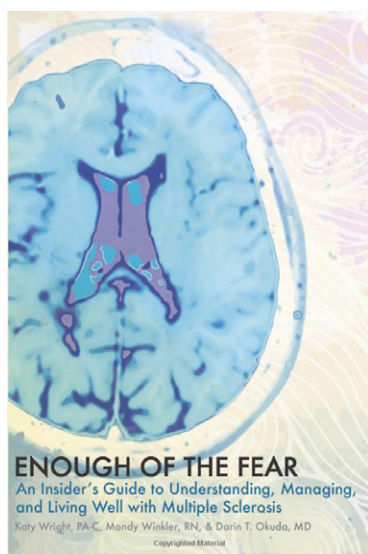
Q: Why did you focus on the fear aspect in the title of the book?

A: People with MS have a lot of depression, both because of the emotional and financial impact of the diagnosis and the physical changes caused by MS. When patients are newly diagnosed, they go through a grieving process of what their life would have been if they hadn't been diagnosed with MS. Their world is being turned upside down and it's a very emotional time. We want newly diagnosed people to know that MS is not a death sentence, and, in fact, if they had to get the diagnosis, this is the best time to get it because there are so many disease-modifying therapies available to treat it. Before 1993, we could only manage symptoms and not prevent progression.

There's a different emotional component for people with progressive disease, who have typically had MS for a long time and have continued to worsen despite treatment. There is still a great deal of fear and grieving about the life they



Mandy Winkler,
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dreamed of having. Even if they've come to terms with their diagnosis, people with progressive disease are seeking cutting-edge or adjunctive symptomatic treatments, which we describe in the book.

Q: How is the book different from other MS books out there?

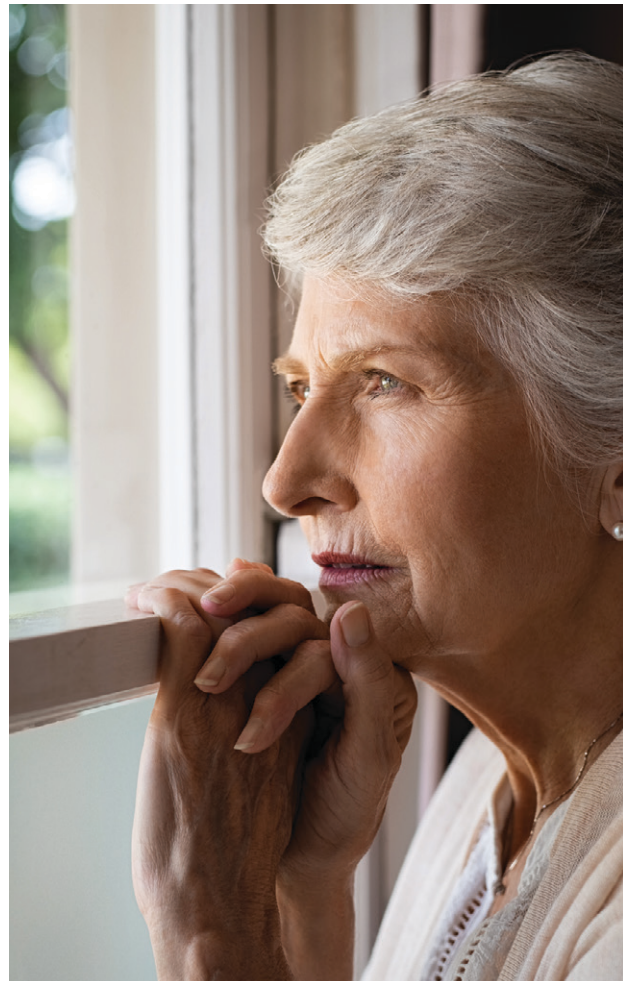
A: There have been books written by a doctor, or a doctor and a physician assistant, or a nurse, but we wanted our book to be from all three viewpoints, since we see things slightly differently and serve different functions. For instance, like many MS nurses, I am the main point of contact for patients at our center and they talk to me more often than the other providers. In addition,

“There have been books written by a doctor, or a doctor and a physician assistant, or a nurse, but we wanted our book to be from all three viewpoints, since we see things slightly differently and serve different functions.”

— MANDY WINKLER,
RN, BSN, MSCN

that is changing all the time. We feel the future is so promising for the management of MS as a chronic disease and we want patients to view it like hypertension and type 2 diabetes. Ultimately, we hope the book will help patients better understand what we've told them in the office, and that it will help them come up with questions to ask us at their next visit.

we tried to make our book very contemporary, comprehensive, and practical. We end each chapter with helpful hints and we've included content patients might not find in other conventional MS books—the real nitty-gritty details of living with MS that comes from interacting with thousands of patients over the years. Of course, we also include the latest on MS medications, although



Q: The digital version of the book actually has some advantages over a printed copy. What are these benefits?

A: Many people like to have a physical copy, but MRI photos are in black and white in the softcover book. In the digital version, you get a slightly better experience because it has color MRI photos and even videos. Whichever way nurses and patients choose to view the book, our feeling is that the more resources you can provide to patients, the better. Different clinicians have different takes on the disease, which is so specific to each patient with MS. And if other nurses have a different perspective after reading our book, I encourage them to write a book or article, too. If you're in an MS clinic with just one nurse, having an article or book that educates you about how others are practicing makes you feel less alone and more plugged into the MS community. Thankfully, I have other wonderful nurses and providers that are a great resource for me. 🌐

MEET YOUR 2019 SOUTHWEST REGIONAL LIAISON

Crystal Wright, RN, AGNP-BC, MSN, MSCN
Multiple Sclerosis Clinic
University of Texas Southwestern
Medical Center
Dallas, TX

Crystal Wright, RN, AGNP-BC, MSN, MSCN, began caring for patients with multiple sclerosis (MS) in 2009 at the Texas Multiple Sclerosis Center, a part of Neurology Associates of Arlington. “This was a general neurology practice where one of the partnering neurologists decided to specialize in MS and open an MS center within the practice. I was the only nurse and, later, the only nurse practitioner (NP) that specialized in MS. It was there that I developed a passion for treating patients with the disease,” she says. “However, in 2015, the neurologist that founded the MS clinic passed away unexpectedly. I did not know where I would end up, but I was sure that I wanted to keep treating patients with MS and not move into a different specialty.” Shortly thereafter, Ms. Wright found employment as an NP at the University of Texas (UT) Southwestern Multiple Sclerosis Clinic.

“I love working with MS patients and their families,” she says. “I have always been impressed with the MS community and the support that is shown among those living with the disease and by their friends and families. For example, in our area, we have a physical training program that offers yoga, Pilates, and strength-training classes for patients that is sponsored through the National MS Society. Several of my patients attend these classes and they really band together and support and encourage each other. Additionally, this past year, I participated in an MS bike ride and it was amazing to see friends and family members come out and show their support by riding beside, or in honor of, the patients. It was an incredibly touching experience.”

Establishing a Disability Clinic

In addition to her clinical responsibilities, Ms. Wright initiated a disability clinic within her practice to help individuals work through the process of determining if they qualify for disability benefits or need particular accommodations in the workplace due to MS-related symptoms. “I found that we were receiving requests from employers and insurance companies inquiring about our patients’ degree of disability,” she says. “When I began looking through the charts to find the answers to these questions, I discovered that these topics were not being addressed during routine visits. I came up with the idea of bringing the patients in to discuss any specific on-the-job struggles they were experiencing due to their MS. I felt that I could help develop a plan to potentially keep some patients in the workforce longer, as well as educate individuals about long- and short-term disability rules and requirements so that they could make more informed decisions.”

Ms. Wright says that when she sees patients in disability clinic sessions, she inquires about the unique types of issues that may be impeding their performance on the job, and also does a thorough physical exam to help assess each person’s ability to work. “Since I started the clinic, I have discovered that difficulties in the workplace may often be under-reported and that many of my patients have some degree of MS-related impairment, such as fatigue, cognitive difficulties, or bowel and bladder problems, which may be impacting their job performance,” she says. “If someone complains of cognitive difficulties at work, I will often recommend formal neurocognitive testing to help determine the areas in which they may be having difficulties, as well as identify their



Crystal Wright,
RN, AGNP-BC, MSN,
MSCN

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strengths. Then, if appropriate, we may be able to request accommodations from employers to help the patient function better on the job. Furthermore, if the testing shows that the individual has significant cognitive decline, we may start the process of discussing how to apply for disability. Either way, these formal tests and visits appear to help ensure that the legal documentation is charted to help assist patients in getting what they need, whether it is work environment accommodations, job retraining, or disability benefits."

She notes that many of the accommodations

she requests for her patients with MS are quite simple for employers to implement, such as allowing the person to work from home a couple of days a week, or having the employee's office desk moved closer to a restroom. "Other examples of modifications we have requested include permitting the patient to have 'rest breaks' throughout the day, or allowing the individual to park his or her vehicle closer to the building entrance to shorten walking distance," she says.

IOMSN Membership Committee Southwest Regional Liaison


In addition to her work responsibilities at the UT MS clinic, Ms. Wright is currently serving her second year as the Southwest Regional Liaison for the Membership Committee of the Inter-

 *Nurses and NPs should remember that Regional Liaisons are MS experts who are available to help and advise. We can be especially helpful to new MS nurses who may feel overwhelmed and a little intimidated by the amount of information they have to learn about the disease when they are first starting out in the field."*

— CRYSTAL WRIGHT,
RN, AGNP-BC, MSN, MSCN

national Organization of MS Nurses (IOMSN). "As an IOMSN Regional Liaison, I support MS nurses and NPs who live in my region," she says. "I can help nursing professionals in numerous ways, such as by answering any questions on MS-related clinical care concerns, best practices, or the MS disease process and treatments," she says. "Additionally, I am happy to discuss the benefits of IOMSN membership, assist in finding continuing education opportunities, and provide direction on how to study for the Multiple Sclerosis Certified Nursing (MSCN) examination."

Ms. Wright says that while she enjoys serving as an IOMSN Regional Liaison, she feels that it is an underutilized position. "Even though I can be a valuable resource for other nurses, very few have reached out to me, so I am hoping that this article might bring more exposure to the role. Nurses and NPs should remember that Regional Liaisons are MS experts who are available to help and advise," she explains. "We can be especially helpful to new MS nurses who may feel overwhelmed and a little intimidated by the amount of information they have to learn about the disease when they are first starting out in the field."

In addition to contacting IOMSN Regional Liaisons (see next page), Ms. Wright also encourages MS nurses to participate in as many educational opportunities as possible. "For example, I highly recommend attending the Consortium of Multiple Sclerosis Centers (CMSC) Annual Meeting to take advantage of all the courses offered. If you are new to MS, taking the Fundamentals of MS Care track can really accelerate your knowledge. Three months after I started in MS, I went to my first CMSC meeting and learned so much over the course of 3 days," she says. "If you are not able to attend the CMSC meeting, definitely look online for educational resources offered by the CMSC, National MS Society, and IOMSN. Even the patient education handouts on the National MS Society website are wonderful resources for new MS nurses to help them get their feet wet and become more knowledgeable about the disease and its symptoms." 



IOMSN LIAISONS

IOMSN is committed to making the organization as accessible as possible. Regional Liaisons are knowledgeable, experienced nurses who live and work in communities across the country and the world. They are available to assist you in accessing the information that you need.

Here are a few ways your Regional Liaison can serve you:

- Increase awareness of IOMSN-related educational opportunities
- Connect you to the IOMSN Google Group
- Serve as a resource for MS care-related concerns

- Provide information about the organization to new or potential members
- Collect recommendations for how IOMSN can better serve you

We hope that you will take advantage of the opportunity to reach out to your Regional Liaison for any of your MS nursing needs. Please use the maps below to identify your Regional Liaison based on your region.

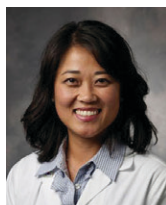
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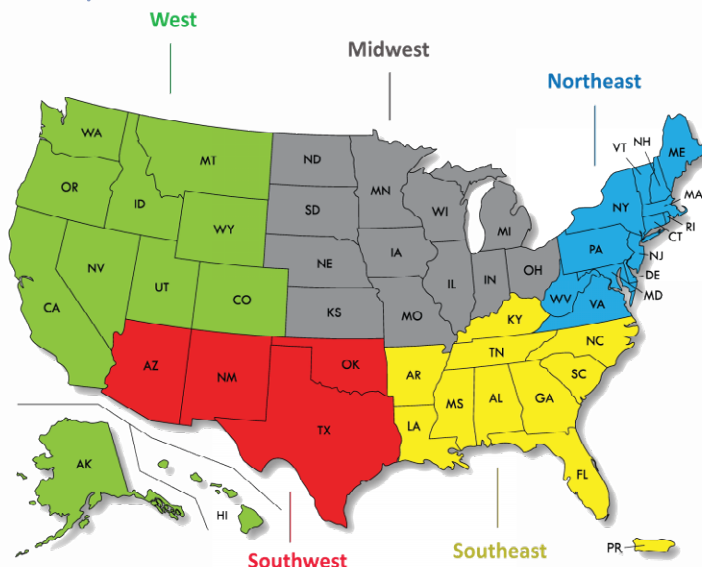
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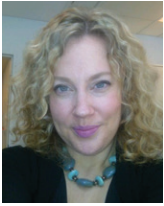


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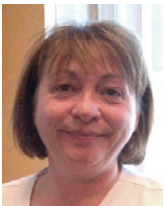
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LiveWiseMS

IOMSN PARTNERING WITH YOU

Encourage Your Patients to Visit [LiveWiseMS.org](https://www.livewisems.org)

Information is power, and the right information is empowering.

LiveWiseMS.org is a premier MS resource that seeks to empower patients with MS, their care partners, and healthcare professionals by providing trustworthy, evidence-based information about the disease and its treatment.

Patients can find answers to frequently asked questions on the site, as well as general and cutting-edge information on MS, well-being, and symptom management. All of the information on the website is sourced from trusted medical experts and reviewed and approved by the IOMSN. Patients can also engage with a community of people with MS through the LiveWiseMS forum.

Q&A with Marie Namey (Continued from page 8)

symptoms of the disease are driven and exacerbated by emotional disturbances. For this reason, patients should be asked about their mood at every visit and referred to mental health services, if necessary.

Additionally, MS nurses need to be the experts that patients come to when they have questions or seek suggestions on support services and wellness and self-care resources. I suggest that nurses compile a list of local and online support groups, peer support resources, and community wellness programs to have on hand to print out and discuss with patients.

Finally, as MS nurses we take pride in our excellent teaching and counseling abilities; however, we should never be so satisfied with ourselves that we think the way we communicate with patients is perfect, because everyone has room for improvement. Look for opportunities to enhance and sharpen your communication skills by reading journal articles and books on clinical relationship-building, taking continuing education courses, and seeking out advice from other clinicians and colleagues about how they approach communicating with their patients. Furthermore, if your clinic provides patients with surveys to rate their clinical care and patient experience, review the survey responses, take them to heart, and learn from them.

Q: What are the three top things nurses can do immediately to improve communication with their patients?

A: First, practice active listening without interrupting. Listening to and understanding the patient's concerns and fears helps to estab-

lish trust and lets the person know that you are interested and invested in his or her health-care and well-being. It should be noted that the ability to actively listen to another person does not come naturally to most of us, so like other interpersonal communication and relationship-building skills, it must be learned, practiced, and acuminated.

Second, remember to have a hopeful approach when counseling people with MS and be careful not to minimize patients' symptoms and concerns. For example, avoid statements that begin with "At least..." Rarely, if ever, does an empathic response begin with "At least..." Similarly, one of my former colleagues, the late Dr. Lael Stone, also suggested that instead of recommending that patients have a positive attitude, or complimenting them when they do, we should consider asking, "What are you doing to take care of yourself and how can I assist you in those efforts?" Other suggestions for facilitating open communication, acknowledging patient concerns, and showing compassion include statements such as:

- "I see. Let me summarize: What you're thinking is..."
- "That sounds frustrating."
- "What are your thoughts about what we just talked about? Does it make sense to you?"
- "What can I do for you? How can I help you along your journey with MS?"

Finally, never be judgmental or confrontational with patients, and always respect an individual for who he or she is as a person. 🌍

The Arts in MS (Continued from page 11)

36 people with chronic illnesses, 20% of whom had MS. The results showed that subjects reported modest improvements in well-being, happiness, leisure time, and resilience/coping measures over the course of the 8 weeks. "The changes were small, but provided enough of a signal to continue the program," says Dr. Bethoux, adding that Ms. Gallagher has received a grant from the National Endowment for the Arts to perform an 8-week RCT comparing the HeRe We Arts™ program to a health education program without an arts component in 40 people with MS and other chronic health issues.

"While the ongoing push to control healthcare expenses and to promote value-based care can raise concerns regarding our continued ability to provide comprehensive care to patients with MS, these changes represent an opportunity to highlight the relatively low cost, easy scalability and adaptability, and potential benefits of therapeutic arts activities. I invite all MS caregivers and researchers to champion arts in medicine initiatives in their place of work and in their community," says Dr. Bethoux. 🌍